



How do GPs approach person-centred care when considering insulin initiation in T2DM?

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Figure 1 person-centred versus patient centred care (PCC v PtCC)

Abstract

The increasing need to manage individuals with a cluster of diseases, such as T2DM in the primary care setting (Witty, 2020), places primary care as a key service provider for person-centred care. Escalation of therapy in T2DM, including insulin initiation is an example of a decision requiring a person-centred approach and was identified amongst the empirical literature. This study aimed to explore the experiences and views of general practitioners (GPs) to understand insulin initiation in the primary care setting.

Within a critical realist ontology and constructionist episteme, semi-structured interviews with a 'travelling' approach (Kvale, 2007) were co-produced with a purposive sample of 16 General Practitioners (GPs), recruited using a snowballing technique, from South Yorkshire, UK. GPs related their experiences about managing T2DM patients and considering insulin initiation. A two-stage analysis was used: an initial reflexive thematic analysis, including identification of tensions followed by narrative structural analysis.

Reflexive thematic analysis constructed GPs in positive and negative stances towards patients, in person-centred (PC) or doctor-centred (DC) approaches to patients, staff, resources and delivering a chronic disease management service. Insulin initiation was infrequent across the GPs and an instrumentality attitude indicated GP expected adequate resources to deliver it. Thematically generated findings confirmed the literature with doctor-centred (DC) attitudes to adherence/engagement to self-care, such as insulin as failure and blame toward patients, and the distal GP.

Narrative structural analysis provided an alternative lens to explore thematically derived tensions. GPs were constructed to hold PC or DC attitudinal stances, towards patients, staff or even service delivery, that may indicate an instrumentality when GPs believed a disease-centred objectives. They would shift from DC or PC stances or vice versa stances or mindsets driven by often unresolved tensions.

Reflective practitioners may consider the using the concept of PC or DC to understand their own person-centredness, being aware of the biomedical bias of healthcare and aiming to place the patient at the centre person-centred care in the primary care setting.

Table 1 of Abbreviations

| | |
|------|---|
| PCC | Person-centred care |
| DCC | Doctor-centred (note the literature may see the acronym of disease centred care as DCC; which is not the same and in this thesis is equivalent to biomedical approaches). |
| PtCC | Patient-centred care |
| SED | socio-economic demographic |
| CDM | Chronic disease management |
| CVD | Cardiovascular disease |
| DC | Doctor-centred |
| PC | Person-centred |
| SDM | Shared decision making |
| GP | General practitioner |
| FP | Family practitioner |
| HCP | Healthcare professional |
| EBP | evidence-based practice |
| QOF | Quality Outcomes Framework |
| RCT | Randomised controlled trial |
| WPC | Whole person care |

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Chapter One

1.1 Introduction

This thesis aims to contribute to the knowledge of the person-centredness of GPs in the primary care management of chronic disease using the example of type 2 diabetes mellitus (T2DM). Person-centredness has been defined as the organised care of people to meet the individual's requirements, and healthcare professionals (HCPs) respect and collaborate with patients to ensure the patient's preferences, needs and values are incorporated in decisions (Health Foundation (Great Britain), 2016). Person-centred care (PCC) is a valued component of healthcare management among patients and leading healthcare authorities, yet it remains an unmet area of practice and procedure (Institute of Medicine Committee on Quality of Health Care in America, 2001; Little *et al.*, 2001; Wiley *et al.*, 2014; Health Foundation (Great Britain), 2016; Ekman, Ebrahimi and Olaya Contreras, 2021; NIHR Public Health Collection, 2021).

Clinical therapeutic inertia, on the other hand, is the delay in escalation of treatment when patients' biomedical goals are not met. In the field of chronic illness management, GPs' growing involvement in the treatment of patients with one or more chronic diseases has resulted in an increased role in therapy escalation, as well as the necessity to offer person-centred care for individual patients. Type 2 diabetes mellitus is an example of such a disease and there remains a lack of knowledge of how GPs manage T2DM both in terms of person-centred care and the achievement of biomedical goals within the primary care setting. More specifically, insulin is an example of a treatment that may require initiating in T2DM therapy, and GPs have been identified as one of the healthcare professional groups contributing to the problem of clinical therapeutic inertia (Khunti *et al.*, 2013; A Zafar *et al.*, 2015; Seidu *et al.*, 2018).

Consequently, the aim of this thesis is to understand the GP perspective of T2DM management in the primary care setting with focus on insulin initiation as an exemplar of person-centred care in chronic disease management.

This introductory chapter provides the contextual background of primary care T2DM treatment and its increasing importance as the burden of T2DM increases across nations. The biomedical representation of T2DM and the problem of inertia in insulin initiation in T2DM as an example of chronic disease, is then followed by several key approaches to person-centred care that represent prior concepts for this thesis. Thus, this conceptual framework attempts to describe the essential components, constructions, or variables and assumed connections between them (Miles and Huberman, 1994). The wider current literature on the person-centredness of GPs in primary care chronic disease management will be later explored in Chapter 2.

1.2 Primary care management of chronic disease

Chronic conditions can be defined as health conditions that require regular healthcare and/or monitoring, and this often takes place in primary care rather than specialist secondary care clinics (Barnett *et al.*, 2012; Sidorkiewicz *et al.*, 2019). Chronic disease management in primary care includes many different biomedical diseases and long-term conditions, and includes cardiovascular, metabolic conditions such as diabetes, musculoskeletal and rheumatological conditions, neurological and mental health, as well as conditions that involve the frailty, and health decline related to aging. In primary care this has meant a service that aims to deliver care through case management that entails community teams of HCPs coordinating care with GPs, a structured chronic disease management for patients within National Service Frameworks (NSF) and General Medical Services (GMS), and encouraging patient self-management (Blakeman *et al.*, 2006a) The burden of chronic conditions is increasing, and primary care roles in chronic disease management are increasing, often due to delegation and collaboration with specialist services (Dennis *et al.*, 2008).

In comparison, 'multimorbidity' refers to the circumstance in which people have two or more conditions at the same time (Whitty *et al.*, 2020). The increased prevalence of chronic conditions and multimorbidity, has been identified to be the result of aging populations and improved health care, particularly in high-income countries (Barnett *et al.*, 2012; Whitty *et al.*, 2020). According to European population data, multimorbidity may exist among the young and, more crucially, in less advantaged socioeconomic populations, and deprivation is thought

to accelerate the development of chronic illnesses and multiple health conditions - which may coexist from childhood onwards (Schiotz et al., 2017).

Moreover, healthcare delivery, research and medical education has been dominated by a single disease approach, but multimorbidity requires different more person-centred approaches compared to the fragmented approach when managing single diseases (Barnett *et al.*, 2012). Managing patients with the intention of treating each chronic disease in isolation is suspected to lead to poorer outcomes and increase interactions in healthcare (Whitty *et al.*, 2020). Specialists may treat single illnesses, however by virtue of the population types that may present, some specialities, such as primary care and geriatrics, may be argued to encounter patients with multimorbidity more frequently and with rising prevalence (Schjøtz *et al.*, 2017; Whitty *et al.*, 2020)

Another way to frame numerous illnesses in the same individual is to consider the biomedical problems as "**clusters of disease**" that might occur in the same person due to similar genetic, behavioural, or environmental disease pathways (Whitty *et al.*, 2020). Diabetes is one such cluster that affects tissues of the heart, kidneys, nerves, skin, eyes, and peripheral arteries. Although diabetologists may manage the multimorbidity associated with a cluster and have generalist skill sets to manage the cluster of disease that present together when people present with type 2 diabetes mellitus (T2DM), diabetes is managed as part of chronic disease management in general practice (see section 1.3 below).

As a result, generalist skills mean the requirement is to manage individual patients rather than the separate diseases and it is suggested that specialists who lack generalist skills will face challenges to manage their patients (Whitty *et al.*, 2020). Clustering of disease can include both physical and mental health problems and there is growing need to respond to increasing demand for management of people experiencing them (Schjøtz *et al.*, 2017). The consideration of the individual person with multimorbid conditions as a professional approach has been called essential to the medical workforce (Whitty *et al.*, 2020) and is a defining core construct for generalism. Generalism, to the individual practitioner, is the delivery of care for multiple conditions to individual patients.

It is also claimed that sustaining generalism is critical within projects to educate the workforce of the future (Whitty *et al.*, 2020). Consequently, improving the delivery to individuals with chronic disease and multimorbid conditions has become of increasing relevance to primary health care and research.

One part of improving this care is to understand the generalist approach to managing the care of people with chronic disease and multimorbid conditions, or what could be termed as people with a cluster of diseases. This thesis uses the example for T2DM management to qualitatively investigate the person-centredness of GP decisions in primary care. The next subsection explains T2DM as an example of a chronic disease.

1.3 Type 2 Diabetes Mellitus: an example of a chronic disease

T2DM is part of a group of metabolic disorders that manifest as hyperglycaemia when they are untreated (World Health Organization, 2019). In England, 4 million people have diabetes, and approximately 90% of people with diabetes have T2DM (Diabetes UK, 2019). This common and chronic condition is also an increasing burden worldwide and is increasingly perceived as a condition to be managed in primary care. This chapter explains the importance of T2DM, how it is managed, the aetio-pathology, treatment and management guidelines, and the context of primary care. Despite the introduction of newer diabetic therapies, insulin remains within the treatment guidelines of T2DM and an essential aspect of diabetic treatment in the community (Baxter *et al.*, 2006; Sharma, Nazareth and Petersen, 2016; Khunti and Millar-Jones, 2017).

1.3.1 The biomedical aetio- pathology

A state of hyperglycaemia (raised blood sugar levels) characterises type 2 diabetes. However, the aetio-pathology of T2DM is due to the pancreatic Beta cells dysfunction to produce insulin and resistance to the action of insulin in peripheral organs and cells – insulin resistance, which can be caused by or aggravated by obesity. Early in the disease, hyperglycaemia may not be severe enough to manifest noticeable patient symptoms or require treatment and consequently may pass undiagnosed for years (UK Prospective Diabetes Study (UKPDS) Group, 1995;

Adler *et al.*, 2002). However, patients remain at risk of microvascular and macrovascular complications (Leiter *et al.*, 2019; World Health Organization, 2019). The association between T2DM, obesity, and lifestyle can mean hyperglycemia may improve in response to diet and exercise lifestyle changes (Adler *et al.*, 2002) However, the long-term sequelae of T2DM include retinopathy, nephropathy, neuropathy. Also, T2DM patients are at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease, obesity, cataracts, erectile dysfunction and non-alcoholic fatty liver disease (NAFL)(World Health Organization, 2019).

1.3.2 Type 2 diabetes management in primary care

In the UK, T2DM has persisted in being a significant and burdensome public health problem. The prevalence rates in 2013 have been estimated to affect 6% of the UK population (prevalence rates of 6% in England and 6.7% in Wales) (National Department of Health, 2022). In 2017, NHS Digital reported that management of T2DM medications accounted for approximately 11% of the entire United Kingdom NHS budget (NHS Digital, 2017)(NHS Digital, 2017)In 2016, Public Health England produced a prevalence model of diabetes based on Health Surveys for England (HSE) in 2012, 2013 and 2014 and estimated that by 2035, the prevalence of diabetes in England will be 4.9 million people (Public Health England, 2016). Finally, the cost of diabetes is claimed to be 10% of the England and Wales NHS budget and an estimated twelve billion pounds is spent on treating T2DM and its complications every year (Kanavos, Aardweg and Schurer, 2012; Diabetes.co.uk, 2019). These statistics emphasise the importance of T2DM in research, particularly in primary care, because it is central to diabetes care in the United Kingdom (Murrells *et al.*, 2015; National Department of Health, 2022).

Primary care in the UK has increasingly managed T2DM care since the 2004 general practice (GP) contract introduced the NHS Quality and Outcomes Framework (QOF). QOF aimed to improve the management of diabetes in primary care through financial incentives (Lester and Campbell, 2010). As a result, primary care research and audit data are used to understand diabetes in the UK (Sharma, Nazareth and Petersen, 2016).

1.3.3 T2DM as a multimorbid condition

T2DM has associations with obesity, inactive lifestyles, raised blood pressure and lipid levels, and a tendency to develop thrombosis. As a result, patients with T2DM are at risk of cardiovascular disease (National Department of Health, 2022). Additional complications are also the result of microvascular and macrovascular complications of T2DM include eye disease (retinopathy), chronic kidney disease (CKD), and neurological problems manifested as peripheral neuropathy- specifically foot disease (McGuire *et al.*, 2016; National Department of Health, 2022). As a result, diabetes management is an example of a condition that can present in the same person as a cluster of diseases (Whitty *et al.*, 2020). As a result, the condition requires additional healthcare management directed at cardiovascular disease prevention and microvascular problems of kidney and eye and foot disease (McGuire *et al.*, 2016). Initially, after diagnosis, T2DM therapy guidelines recommend lifestyle and dietary modification alone or in combination with metformin monotherapy as a first-line oral antidiabetic medication (OAD). This lifestyle medication involves patient self-care, including education and support in lifestyle modification (Rutten, Van Vugt and De Koning, 2020). Following metformin, other alternative antidiabetic medications are considered before insulin therapy is considered (Scottish Intercollegiate Guidelines Network, 2017; National Department of Health, 2022).

1.3.4 Intensive glucose-lowering

Intensive glucose-lowering therapy had been shown to reduce microvascular complications of T2DM (Crofford, Genuth and Baker, 1987; Adler *et al.*, 2002). The ACCORD study (Action to Control Cardiovascular Risk in Diabetes) was a study aimed at investigating intensive diabetic management in order to reduce cardiovascular risks in T2DM (Ismail-Beigi *et al.*, 2010). The outcomes of the ACCORD study showed that intensive glycaemic control (average HbA1c levels of 6.4% compared to 7.5% in the standard arm of the study) made improvements in microvascular complications. However, there was an increased all-cause mortality rate amongst the intensive group, more harmful to older patients and those with known heart disease. As a result, the intensive arm of the study was stopped early (Ismail-Beigi *et al.*, 2010). Rosiglitazone was a drug frequently mentioned by the GPs in this research and is worth explaining in the context of the historical evidence-base. The ACCORD study included a relatively high proportion of patients receiving rosiglitazone in the intensive treatment arm, and rosiglitazone has since been associated with increased cardiovascular events. The implication is that the drug caused patient harm (Nissen and Wolski, 2010).

Similarly, the ADVANCE study (Intensive Blood Glucose Control and Vascular Outcomes in Patients with T2DM) also showed a beneficial effect of intensive blood-glucose control on vascular complications and kidney disease, but sulphonylurea medications were mainly prescribed to the intensive arm of the study (The ACG, 2008; de Galan *et al.*, 2009). The implication was that intensive glycaemic control was valuable to prevent diabetic complications.

1.3.5 Guidelines

NICE guidelines in the UK advises patient-centred care to achieve recommended levels of glycaemic control. They recommend considering the person's individual factors informing the decision: the patient preferences, comorbidities, risks of polypharmacy and intensive glucose control (risk of hypoglycaemia) and the person's ability to reduce the risks of associated vascular complications (National Department of Health, 2022). Pancreatic beta-cell function declines progressively, and patients require intensification of treatment as T2DM progresses over time. Metformin monotherapy is followed by the addition of other oral or injectable therapies, which involves a decision to prescribe an escalation in therapy (American Diabetes Association, 2016; Cosentino *et al.*, 2019; National Department of Health, 2022). The guidelines advise 3 to 6 monthly monitoring after the new medication is commenced, and the European Association for the Study of Diabetes (EASD) advises the need to reassess treatment regularly to avoid 'therapeutic inertia' - the failure to advance therapy by a healthcare provider (Cosentino *et al.*, 2019; Khunti, Khunti and Seidu, 2019).

1.3.6 Goals for diabetic treatment

The 2015 NICE guidelines (updated in June 2022) made recommendations for T2DM management through patient education, blood glucose targets or glycaemic control (measured using HbA1c), drug treatment and management of associated complications (National Department of Health, 2022). Glycaemic control was identified as one dimension of T2DM management, and patient involvement was recommended when deciding their individual HbA1c target (National Department of Health, 2022). Notably, the 2015 NICE guidelines relaxed the target HbA1c levels and aimed at patient-centred individual targets due to historically changing evidence indicating a need to balance the risks and benefits of intensive

glycaemic control since 2009. Previously the guidelines recommended intensive glycaemic control in diabetes because of the vascular benefit of tight glycaemic control (Crofford, Genuth and Baker, 1987; Adler *et al.*, 2002). Since 2010, research evidence has shown that intensive glycaemic control (i.e. HbA1c less than 7.0%), compared to moderate control (HbA1c of 7.0 to 8.5 %), does not show an increased benefit for microvascular (i.e. renal disease, retinopathy and neuropathy), or macrovascular (cardiovascular deaths, non-fatal strokes and all-cause mortality) (Ismail-Beigi *et al.*, 2010; Boussageon *et al.*, 2011; Hemmingsen *et al.*, 2011; Vijan *et al.*, 2014). Significantly, intensive glycaemic control was associated with a two to three-fold increased risk of severe hypoglycaemia, and increased polypharmacy, treatment side effects and costs for patients, especially for the over 75-year-old patients (Hemmingsen *et al.*, 2011; Vijan *et al.*, 2014; Rodriguez-Gutierrez *et al.*, 2019).

Although the clinical practice guidelines continue to recommend glycaemic control, the consensus for USA, UK and European guidelines is to aim for goals of treatment that also control BP, cholesterol and manage (Ali *et al.*, 2016; Cosentino *et al.*, 2020; Davies, Melanie J. Aroda *et al.*, 2022; National Department of Health, 2022) (Ali *et al.*, 2016; Cosentino *et al.*, 2020; Davies, Melanie J. Aroda *et al.*, 2022; National Department of Health, 2022). The rationale for cardiovascular (CVD) risk stratification lies in the evidence that an established past CVD history and CKD are important predictors of future major cardiovascular events (MACE). Moreover, T2DM is in itself a major risk factor for CVD. Consequently, the latest updated European guidelines for diabetes management emphasise the recognised cardiovascular protective effects of specific antidiabetic medications. SGLT-2 inhibitors and encourage the earlier consideration of these medications in the treatment ladder for T2DM with very high CVD risk (empagliflozin, canagliflozin and dapagliflozin) and GLP-1RAs (liraglutinide, semaglutide, albuglutide and dulaglutide) are believed to provide proven cardiovascular protection for patient with T2DM and atherosclerotic cardiovascular disease (ASCVD) (Seidu *et al.*, 2022a).

How GPs use guidelines and evidence-based medicine has been explored in the literature. The literature that claims that GPs rarely access, appraise or use EBP, research evidence and guidelines (Gabbay and May, 2004). Consequently, Gabbay and May offer ‘mindlines’ as an alternative view of how GPs manage and interpret biomedical knowledge in practice that is “*collectively reinforced, internalised tacit guidelines*” (Gabbay and May, 2004). Other researchers have since replicated their findings (Wieringa and Greenhalgh, 2015). Wieringa et

al. have shown in their systematic review that ‘mindlines’ have continued parallel to guidelines but not incorporated into recommendations for practice (Wieringa and Greenhalgh, 2015). Although it is unclear if the GP approach prescribing guidance provides a barrier or problem for consideration in inertia of T2DM, the alternative approach to how GPs may consider patient care in chronic disease management indicates the problem of inertia and GP care for chronic disease management requires further understanding.

1.3.7 Beyond the biomedical management of T2DM

In addition to the biomedical management of T2DM as a chronic disease, the guidelines also recommend a person-centred approach to the diabetic care, including HbA1c target goals and the choice of drug treatment. The latest American Diabetes Guidelines and NICE guidelines re-enforce the message to take this person-centred approach and tailor care to the individual context, including a focus on patient education, diet advice, CVD risk, glucose and long-term risk management (Davies, Melanie J. Aroda *et al.*, 2022; National Department of Health, 2022).

Biomedical targets remain individualised for HbA1c and advise considering relaxed targets for the frail and elderly, whilst hypertension targets are similar to the guidelines for the general population (average blood pressure monitoring (ABPM) below 135/85 for under 80 years and below 145/85 for over 80) (National Institute for Health and Care Excellence, 2022). The personalisation of diabetes management requires patients’ personal preferences for drug, side effects and even costs of treatment to be considered and primary care physicians have been increasingly responsible for the prescribing role of diabetic medication in the UK (A. Zafar *et al.*, 2015; Sharma, Nazareth and Petersen, 2016; Seidu *et al.*, 2018; Davies, Melanie J. Aroda *et al.*, 2022). This increasing involvement in diabetes management has meant participation in decisions about escalation or de-escalation of therapy. GPs are claimed to be associated with the problems for therapeutic inertia in diabetic care (Harris *et al.*, 2010; Zafar *et al.*, 2010; A Zafar *et al.*, 2015; Reach *et al.*, 2017; Seidu *et al.*, 2018). Although multiple factors or barriers are purported to lead to therapeutic inertia, the key barriers have been attributed to care providers, patients, and the healthcare systems (Khunti and Millar-Jones, 2017; Reach *et al.*, 2017; Khunti, Khunti and Seidu, 2019).

An example of research claiming GP involvement in therapeutic inertia is presented by Seidu *et al.* surveyed GPs in the UK with a special interest in diabetes on the delay of intensification of T2DM medications. The GPs reported on 240 patient records. Therapeutic inertia had occurred in 22.1% of these patients (Seidu *et al.*, 2018). The researchers proposed a model of eight variables such as age, sex, number of oral hypoglycaemic agents and HbA1c target, was not statistically significant and so, unable to predict when therapeutic inertia would have taken place. Moreover, patient level characteristics individually were not shown to be predictive of therapeutic inertia. The lack of clarity of the GP role in therapeutic inertia as part of T2DM therapy escalation remains a gap in knowledge that is believed to add to the T2DM disease burden both nationally in the UK and worldwide (Seidu *et al.*, 2017; Khunti, Khunti and Seidu, 2019). The focus disease-centred, or biomedical, in focus and fails to appreciate possible person-centred care related barriers in T2DM care.

Despite this lack of clarity on how to manage a chronic disease within the biomedical guidelines whilst maintaining a person-centred approach, as mentioned above, modern guidelines continue to recommend person-centred care (PCC). PCC is a core principle to guide GPs towards individualised biomedical and psychosocial care for patients, with anticipated biomedical gains such as to overcome therapeutic inertia (Seidu *et al.*, 2018). How to achieve a shared decision with patients to balance quality of life, avoid polypharmacy, and avoid medication side effects are less evident in the guidelines. Making therapy decisions in diabetes in the primary care situation requires balancing the benefits of glycaemic control with the potential harms, multimorbidity, and the patient's preferences and goals for therapy.

Moreover, the barriers individuals may face can be multifactorial and the next section summarises these before a final section on the person-centred approaches available as prior concepts.

1.4 Barriers to T2DM Care

The barriers to care can be viewed from a context of the person and clinician-centred experience. Janes and Titchener reviewed the literature that divides barriers to T2DM care into those of the disease and illness experience, the effect on patient function expectations, and proximal or distal barriers to the individual person (Janes and Titchener, 2014). The division of patient barriers in this way allows a person-centred approach to diabetes, and more widely,

chronic disease management to further explore the empirical literature. Table 1 summarises the barriers to chronic disease care from the patient perspective, and table 2 from the perspective of the clinician and patient, and the clinician only.

Table 2: Barriers to diabetic care from the person-centred perspective (Janes and Titchener, 2014).

| Patient experience | Type of barrier | Subtypes or examples |
|--------------------------------|--|---|
| Disease and illness experience | Fears or feelings as barriers to self-care | Fear and distress: emotional and psychological response to illness e.g., fear of disease, or drug side effects Despair Guilt/self-blame: self-blame for poor diet/lifestyle resulting in poor T2DM control. Shame, embarrassment, or stigma: of diagnosis, or using needles akin to IV drug abuse. Lack of self-confidence |
| | Ideas/beliefs about self-care | Non-scientific health beliefs: poor understanding of biomedical disease to specific beliefs e.g., diabetes is caused by eating sugar; resignation, reliance on symptoms to control diabetes; Culture-specific beliefs (overly positive or negative views of healthcare and drugs), or belief cultures around the world e.g., South Asian or, Māori. |
| Impact on Function | Disease imposed barriers | The routine of diabetic drugs and their side effects, and diet |
| | Disabilities | Disease complications causing functional disability. Diabetes related complications e.g., blindness, neuropathy, amputation, or mental health complications such as depression. Similar chronic disease complications may occur in say multiple sclerosis, or heart disease. |
| Expectations of patient or HCP | Communication barriers | Ineffective communication or lack of sharing of knowledge with the patient. |
| | Time | Short appointment times |
| | Relationships | Patients being passive or too trusting to the other extreme of not trusting the HCP; or clinicians being judgemental and unrealistic of patients. |
| Whole person | Individual | 'External locus of control ' resulting in passivity and low-self efficacy, males may be poor attendees. |
| | Proximal to the patient | Family lack of support; finance; lack of disease related education or health literacy; employment (e.g., specific barriers to insulin: flexibility of breaks, privacy for injections, managing hypoglycaemia in demanding work, or driving for a living); leisure activities (e.g., avoiding exercise due to hypoglycaemia or the inconvenience of planning days out). |
| | Distal to the patient | Cultural beliefs (as above); cross- cultural gaps and language barriers; or lifestyle beliefs such as exercise and sports have no meaning. Healthcare system barriers: access to care (e.g., appointment wait times or travel related), resources related (workforce shortages, lack of education for patients, lack of drugs/tests); wider national resource issues (e.g., low priority for chronic disease management); Local community barriers (e.g., lack of healthy food availability). |

Adherence to medication or lifestyle change remained a significant biomedically framed barrier that persists as a concept in the literature. From the person-centred perspective, compliance to medication is irrelevant if patients' autonomy and active right to participate decisions is accepted, including the right to refuse or disagree with expert advice (Janes *et al.*, 2013). Moreover, in their review and a separate qualitative study from the patient perspective, Janes and Titchener argue that clinicians' lack of understanding of patients views and the biomedical framing of adherence and compliance created an additional barrier to the therapeutic relationship between patient and HCP (Janes *et al.*, 2013). Moreover, other concepts amongst subtype of barriers such as health locus of control, may be argued to be biomedically framed or judgementally positioned in the direction of HCP to patient.

Further to these patient barriers, there were clinician-patient relationship barriers that divided into those related to both patient and clinician, and those related to the clinician or their working environment.

Table 3: clinician/patient and clinician related barriers to T2DM care.

| Persons involved | Type of barrier | subtypes |
|--|--|---|
| Clinician and patient related barriers | Agreement found on problems and priorities | Differing patient and clinician health beliefs. |
| | Agreement found on goals | Goals imposed by clinicians, or not individualised to patients. |
| | Clinician-patient relationship | Communication related (gender differences, cultural barriers, lack of shared decision making (SDM), or use of external motivators e.g., fear of complications; or conflicting clinicians' advice). |
| Clinician related | Compassion, trust, SDM, and power | Clinician attitudes (judgemental or unrealistic clinician expectations of patients, paternalism, or forced responsibility) or health target focused clinician behaviours. |
| | Clinician self-reflection | Clinicians' lack of self-awareness (lack of knowledge, skills or negative attitudes), clinicians' emotional responses (lack of respect, frustration or anger due to patient non-compliance). |
| Systemic barriers related to clinician | Workload related to time | Limited time for appointments |
| | Teamwork | Workforce barriers (shortages of staff) and multidisciplinary team |

| | | |
|--|--|--|
| | | dysfunction (poor collaboration and lack of local support) |
|--|--|--|

The following section explores the person-centred care approach for the management of chronic disease.

1.5 Person-centred care (PCC)

Person-centred (PCC) care can represent an approach to guide an individual HCP's practice or entire systems of care (Stewart, 2005; Health Foundation (Great Britain), 2016). One description of PCC is that it is a collaborative working between HCPs and people receiving health and social care, and involves individualised, compassionate, and respectful care that empowers people to make confident, informed decisions about their own health. Regardless of this apparently common-sense presentation of PCC, person-centred care is claimed to remain outside of standard practice (Health Foundation (Great Britain), 2016).

According to a 2016 Health Foundation report, 70% of health and social care resource funds in the UK are spent on 18 million people with long-term conditions, and services organised with person-centred care in mind will be more affordable while also being ethically valuable (Health Foundation (Great Britain), 2016). The indication is that PCC is important to establish but incorporating it into everyday practice is thought to involve significant changes in how services, particularly health care professionals, interact with patients. Furthermore, how healthcare professionals interpret PCC's ethical values and concepts influences how they interact with patients as individuals and as members of a team. (Entwistle and Watt, 2013b; Elwyn *et al.*, 2014; Håkansson Eklund *et al.*, 2019).

However, there are various representations of PCC in the literature and some of these representations support the simplified approach published by the Healthcare Foundation (Cathy Charles, Gafni and Whelan, 1999; Health Foundation (Great Britain), 2016; Britten *et al.*, 2017). The fact that definitions of person-centred care (PCC) have remained an evolving field without a clear agreed definition is problematic for healthcare delivery purposes and growing understanding of the incorporation of PCC into healthcare practice may be helped by more consensus in practice. According to the literature, PCC is an approach and not a formulaic

or methodological delivery. Before embarking on the literature review in person-centred care in chronic disease management, the following chapter section attempts to outline some of the definitions and intrinsic concepts that may be included to characterise the approaches to PCC.

1.5.1 Definitions of person-centred care

Person-centred care (PCC) developed as response to the limitation of the biomedical tradition of healthcare to manage patient illness and even the biopsychosocial perspective was believed to lack sufficient understanding of the patient experience of illness. The concept has developed in response to healthcare being either disease-centred, and so biomedical in approach, or on the other hand, health organisation or system focused (Entwistle and Watt, 2013b).

The early presentation of patient-centred medicine by Michael and Enid Balint was a result of doctors' struggles to manage psychological patient problems in general practice (Balint, 1969; Balint, Ball and Hare, 1969). More latterly, the concept of person-centred care was introduced as progression from patient-centred care (PtC), based on the philosophy of personalism: framing a 'person' as a subjective, unique, and self-actualising individual (Håkansson Eklund *et al.*, 2019). In healthcare, the concept was meaningfully set a precedent when Kitwood coined the theory of person-centred care within dementia care by "*seeing the person*", and so, recognising their individual psychosocial needs, interests, and autonomy (Kitwood, 1997; Entwistle and Watt, 2013b; Håkansson Eklund *et al.*, 2019).

Eklund *et al.* reviewed the literature on person-centred and patient centred care (PtC) to explain the differences. They found that although there was a significant overlap in terms of empathy, respect, relationship (including trust), communication, shared decision making, individuality and holistic focus, there were important differences between the two concepts. Person-centred care places less focus on the sick role, but more on the illness experience or impairment (Lambert *et al.*, 1997). The 'sick role' concept originates from Parsonian descriptions of doctor and patient rights and obligations. In this paternalistic model, the person is granted the right to the sick role status by the doctor, whilst also having the obligation to improve their health by seeking care and adhering to medical treatment (Gallagher, 1976; Charles, Gafni and Whelan, 1997). The paternalistic model will be discussed further below, but for the time being, referring to the sick role allows comprehension of key differences between PCC and PtCC.

PCC and PtCC also differ significantly in the goals of the two concepts: patient-centred care aims at keeping a functional life, whilst person-centred care aims at a ‘meaningful life’ (Håkansson Eklund *et al.*, 2019). To elaborate, the person-centred concept emphasises function and individuality, which means that HCPs may extend understanding of feelings to empathic appreciation of the patient's life circumstances; and sharing information extends into dialogue beyond decision-making to incorporation of patient values about their life (Håkansson Eklund *et al.*, 2019).

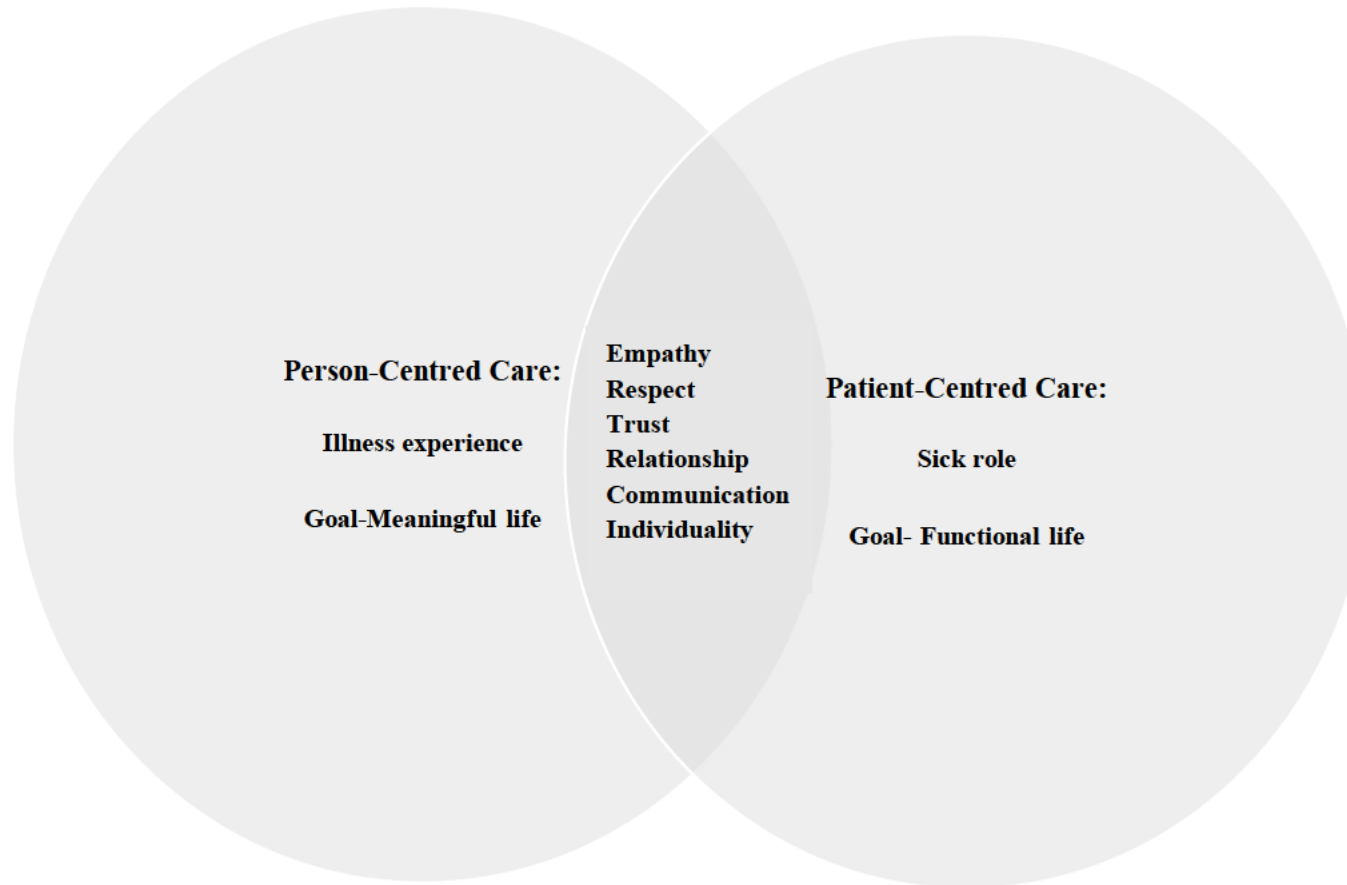


Figure 1 person-centred versus patient centred care (PCC v PtCC): The overlap between the two definitions includes key constructs of how patients are perceived as persons, but there are noticeable differences in how PtCC holds the individual within the construct of patient, with the emphasis on the role as a patient and how the patient functions in their life, rather than the person's experience and what meaning their life holds for them.

So, by treating patients as ‘persons’, healthcare professionals are recognising a potentially ethical approach to healthcare that has ill-defined meaning in the literature. (Entwistle and Watt, 2013b). Different approaches to PCC have been recognised and the next section explores a selection of the different constructions and approaches to PCC that represent the PCC prior sensitising concepts in this thesis. These were identified through literature scoping, guidelines, review articles and the systematic literature review search performed and documented in chapter 2. The approaches are the clinical method, shared-decision making (SDM), the doctor-patient relationship, collaborative deliberation, the capabilities approach, the Gothenburg Centre for Person-Centred care (GPCC) routines of PCC, the health foundation principles of PCC. Table 3 offers an overview of the approaches, whether they were patient- or person-centred, and the accompanying concepts.

Table 4: Approaches to person- and patient-centred care with their related core principles.

| Approach | Concepts | Principles |
|---|-----------------------------|--|
| The clinical method (Stewart, 2001) | Patient-centredness (PtCC). | <ol style="list-style-type: none"> 1. Exploration of the patient’s disease and illness experience. 2- Understanding of the whole person 3- Finding common ground-partnership 4- Incorporation of prevention and health promotion 5- enhancing the doctor-patient relationship 6- Being realistic |
| Shared Decision Making (SDM) (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999) | PtCC | <ol style="list-style-type: none"> 1- Elicit patient preferences 2-Share information bidirectionally between doctor and patient in biomedical and personal terms. 3-Patient and doctor deliberate together 4- patient and doctor jointly agree on a treatment/therapy plan. Patient Decision Aids offer a way of delivering SDM. |
| Doctor-patient relationship (Mead and Bower, 2000, 2002; Mead N, 2000) | PtCC | <ol style="list-style-type: none"> 1- The biopsychosocial perspective of the patient 2-The patient as a person 3- The sharing of power and responsibility 4- Developing a therapeutic alliance 5- The doctor as a person |
| Collaborative deliberation (Elwyn <i>et al.</i> , 2014) | PCC | <ol style="list-style-type: none"> 1- Constructive engagement by all parties 2- Recognise multiple options 3- Comparative learning together 4- Elicit preferences, constructing them together 5- Integrate preferences together into a plan |

| | | |
|---|--|--|
| Capabilities approach (Entwistle and Watt, 2013a, 2013b) | PCC, but authors are accepting of PtCC, relationship, client-C, family-C | 1- Respect and compassion 2- Subjective experiences, unique biographies, identities, and life projects. 3- Supporting persons capabilities to be autonomous |
| The Health Foundation principles (Health Foundation (Great Britain), 2016) | PCC | 1- Treating people with “ <i>dignity, compassion and respect</i> ”. 2- Co-ordinated care and treatment. 3- Personalised care, support, and treatment 4- Enabling: assisting people in recognising and developing their own skills and capabilities to live an independent and fulfilled life. |
| Gothenburg Centre for Person-Centred Care (GPCC) Routines (Britten <i>et al.</i> , 2017; Ekman, Ebrahimi and Olaya Contreras, 2021) | PCC, accept PtCC. | 1- initiate partnership by eliciting personal narratives 2- Integrate- implement partnership through SDM 3- Safeguard partnership by documentation of personal narrative, preferences, and management plan |

1.5.2 The clinical method approach.

The doctor-patient interaction in family medicine has been framed in different conceptual models to include separate components that allow understanding of family practitioner (FP) and patient encounters.

One such model by Moira Stewart (Stewart, 2005) proposes a patient-centred clinical method for family medicine with six components: exploration of the patient disease and illness experience, understanding of the whole person, finding common ground, incorporation of prevention and health promotion, enhancing the doctor-patient relationship, and being realistic (Stewart, 2005). Stewart explains the concept of ‘being realistic’ is a prompt to GPs to acknowledge their limitations, that time and resource challenges for GPs means consideration of the wider practice team to provide patient care. Stewart is careful to highlight the growing clinician-patient connection over time, and hence the clinical method components indicate broad aims to be attained through regular consultations and shared experiences such as hospitalisations or home visits (Stewart, 2005).

A review of the literature on effective communication between physicians and patients endorsed the six-component model by Stewart and the positive impact of patient-centred consultations on health outcomes. Stewart reviewed empirical data that attempted to identify whether improved communication impacted on measurable health outcomes (Stewart, 1995, 2001). Included studies were interventional randomised control trials, observational intervention trials that randomly assigned doctors or patients to interventional changes in communication. The types of study were categorised into history-taking, discussion of management plans and other.

The history-taking group of empirical studies found that physician education positively affected patients' emotional status, whilst patient education improved measurable physical health outcomes such as level of function, blood pressure and blood glucose. Asking patients about their understanding of the problem, concerns, and expectations, and how the problem affected their function led to improved anxiety for patients and impacted symptom resolution. Similarly, showing empathy and support improved psychological distress and symptom resolution, but asking about the patient's feelings alone improved psychological distress only. In contrast, effective doctor-patient discussion of management plans involved: encouraging more patient involvement in the verbal interaction, such as the patient asking more questions; the doctor providing emotional support; the doctor sharing the decision making; and ultimately, patient and doctor agreement on the how to resolve the problem and follow up. Although the other aspects of management discussions led to patient improved anxiety, functional status and symptom resolution, doctor-patient agreement was an identified key factor related to problem and symptom resolution.

In summary, Stewart was able to show that key aspects of patient-centredness and so, effective communication involved (Stewart, 2005):

- The flow of information from patient to doctor during history- taking.
- The flow of information from doctor to patient during discussion management.
- Provision of emotional support in some form during the consultation.
- The redistribution of power and control in the relationship towards the patient – particularly with reference to decision-making.

When the patient was participating in the history taking aspects, such as asking more questions, and feeling supported to participate in the management planning and decision making, they did this in an “*caring, respectful and empowering context*”(Stewart, 2001).

That is, effective communication led to patient empowerment when it was created in a caring and respectful context that allowed the patient to interact more with the clinician. Stewart had highlighted an important aspect of the required shift in the power dynamic between patients and doctors. Rather than the abdication of power from doctor to patient, patients can benefit from an engagement in the process of decision making to an agreed management plan (Stewart, 2001, 2005).

Little et al. presented empirical evidence that supported the conceptual framework put forward by Stewart et al in 1995 and showed that most patients prefer a patient-centred approach (Little *et al.*, 2001). According to the quantitative data, the patient has a stronger desire for three specific aspects of the consultation: communication, partnership, and health promotion. These domains were prioritised over biomedical consultation aspects such as prescription or examination. Interestingly, those who were socioeconomically vulnerable, or who felt ill or anxious, expressed a stronger desire for patient-centeredness. In terms of communication, older patients were less likely and middle-aged patients were more likely to want good communication - that is, listening, showing interest in what the patient wants to know, understanding, friendly and approachable, and clearly explaining management (Little *et al.*, 2001).

In summary, from an interactional perspective, patients want a doctor to act in certain ways (Little *et al.*, 2001; Stewart, 2001, 2005):

- Investigate the patient's issue, concerns, and the level of need for shared information.
- Provide an integrated approach to include the patient's life issues and emotional needs.
- Find common ground, i.e., agree on the problem and the management strategy.
- Incorporate both preventative measures and health promotion.
- Develop and strengthen the ongoing relationship.

Importantly, Stewart explains that patient-centeredness does not imply sharing all information and decisions, but rather considering the patient's desires and responding appropriately.

Additionally, she argues that patient-centredness is not neatly divided into separate parts but conceiving the components in this way can aid teaching in medical training.

1.5.3 Shared Decision-Making approach.

Another way of framing how information is shared between HCPs and patients is the concept of shared decision making (SDM). SDM is a method that has been argued to be a positive way to deliver more informational balance between the doctor and the patient, thereby empowering patients and increasing their autonomy, particularly in terms of decisions about treatment (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999; Murray, Charles and Gafni, 2006). Plausibly, the origins of SDM can be traced back to consumer rights movements, and person-centredness may have evolved from legal rights arguments of informed consent to broader concerns about autonomy, control, and power dynamics between patients and HCPs (Charles, Gafni and Whelan, 1997).

There are many different sorts of decision-making contexts, with examples including cancer therapy, chronic conditions like hypertension and cardiovascular disease, and the more immediate decisions like acute medical emergencies. For chronic illness and long-term condition care, the doctor-patient relationship is longer-term. Three different models of medical decision making were presented by Charles et al., allowing for conceptualization of the patient-doctor dyad within a potentially life-threatening condition that necessitates a decision in the non-emergency situation: the early diagnosis of breast cancer. The problems of how to include patients in decision-making, which are left unresolved by other models of decision-making: paternalism, informed consent, and professional as an agent, were addressed by Charles et al. with the introduction of SDM.

The **paternalistic paradigm**, as a well-established concept, represents the less empowered and negatively portrayed patient position in the medical experience. According to Parsons, paternalism frames the patient in a passive sick role, whereby the expert doctor dominates the medical consultation and recommends therapies to the patient (also discussed in section 1.11.1) (Gallagher, 1976). It excludes the individual from the decision-making process, does not account for patient preferences, and, at best, seeks patient consent for recommended treatments.

It is stated that several presumptions have historically supported the medical profession's authority within the paternalism frame. The result is an expectation among patients and the profession of the doctor's dominating role in treatment decisions (Charles, Gafni and Whelan, 1997; C Charles, Gafni and Whelan, 1999):

- Doctors are biomedically aware about the treatments that are accessible and can make the proper clinical decisions.
- As clinicians, doctors apply their knowledge and medical information to select the available therapies for their patient.
- As experts in their field, doctors were best placed to balance the risks and benefits of the treatments and so, make the treatment decisions.
- The doctor remains invested in every treatment decision because, by virtue of their professional role, they were concerned about the wellbeing of their patients.
- The medical professional codes of conduct legitimise and bound the doctor to act in the best interests of patient.

The paternalistic position has faced challenges, including increased awareness of the patient's legitimate right to choose the best treatment available within the decisional context. There was also concern for the accuracy of doctors' decisions, variation in the quality of healthcare provided across patient populations, and perhaps a lack of training or awareness on the part of clinicians of the best treatments and guidance (Charles, Gafni and Whelan, 1997). Although these challenges may have helped to shape the person-centred paradigm and shifts away from paternalistic attitudes, a key transformation was the developing acceptance of the patient's engagement in decision-making processes and how information was transferred between a doctor and patient (Institute of Medicine Committee on Quality of Health Care in America, 2001).

Consequently, the type and quantity of information exchange and the direction of the flow was central to understanding the models of decision making. **Informed decision making** and the concepts of the professional as an agent recognise the informational imbalance between the patient and doctor: the patient is the expert on his or her own social context, lifestyle, and well-being, whilst the doctor is expert on the biomedical problem (Charles, Gafni and Whelan, 1997). Moreover, the patient may have beliefs, fear, and awareness of alternative sources of knowledge including experiential, lay or non-biomedical sources, that they bring to the medical

encounter. Charles et al argue that this decisional flow in the informed model of decision making remains from doctor to patient, but the quantity and type of information is wide and includes the patient's own information. Accordingly, the doctor is left outside of the final decision on therapy and the patient is empowered with all the information to decide on the treatment of choice (Cathy Charles, Gafni and Whelan, 1999).

However, the premise that information alone is empowering is challenged by the variability of patient preference. Patients may not want the responsibility to make the treatment decision and entrust the decision to the doctor. For a variety of reasons, patients may delegate decisions to doctors, including time restraints, the severity of the illness, and psychological fragility, which may make the patient's choice burdensome rather than free (Charles, Gafni and Whelan, 1997). To improve sharing of information, patient decision aids (PDAs) offer a solution to simplify the exchange and help patients prioritise knowledge, and so, involvement in treatment decisions. However, the central value that patients must be offered the choice of participation has remained a force in the person-centred argument and is central to informed decision making frames.

Finally, **'the professional as an agent'** model contrasts with paternalism and informed decision making in that the doctor assumes knowledge of the patient preferences and makes decisions of care on behalf of the patient. In the ideal formulation of this model, the doctor is acting in the patient's best interests, and the doctor's own preferences or values are not involved. However, the patient sits outside of the decision-making process and ultimately has not delegated the decision to the doctor. The model's problem stems from the doctor's decision-making authority and the possibility that they may, consciously or otherwise, bring value systems and attitudes to the choice, influencing the course of a decision (Charles, Gafni and Whelan, 1997). The notion that HCPs bring their own values to the decision-making interaction with patients applies to all the models of care and it is also argued that doctors may infer patient preferences for information and potentially get them wrong (Strull, Lo and Charles, 1984; Charles, Gafni and Whelan, 1997). As with the other models, the SDM model offers no solution to this potential problem.

However, the SDM model does offer a contrasting model to the former three by eliciting the patient preferences as well as sharing information of the biomedical problem and the doctor's treatment recommendations. The 'shared-decision' equates with the idea of an agreed decision

between patient and doctor that incorporates the patient perspective. Within the interactional approach to patient-centred care, the Stewart model argues for the concept of agreement between the patient and the doctor on the management plan and is key to the decision-making process. The SDM model integrates this idea (Charles, Gafni and Whelan, 1997; Stewart, 2001).

Charles et al. explain a variety of situations in which the patients' preferences may vary, resulting from individuality of patients and the decisional context. As explained earlier, PDAs may allow information sharing and ease the problem of the technical and biomedical knowledge differences between doctor and patient. What is significant in SDM, is that the power to agree on the decisions mutually between patient and doctor also allows the patient to accept the knowledge shared, ignore the recommendations for therapy or treatment and so, make a preferential choice based on the patient's own values and position. For the SDM process to be successful, both parties agree to a decision but that does not mean that both agree that the chosen option is the best available option (Charles, Gafni and Whelan, 1997; Loewe and Freeman, 2000).

Notably, no single route to the SDM process can be formulated to apply to all situations of decision making and therefore, Charles et al argue against the idea of a list of recommendations to represent the SDM process. However, they do offer the fundamental principles of SDM to help doctors as healthcare providers and offer an option where the decisional responsibility may be shared between patient and the doctor.

In summary, Charles et al provide a model of decision making that lies between that of informed DM and paternalism and excludes the position of the professional as an agent. Within paternalism and informed DM models, the flow of information is largely from doctor to patient, and both types of decisions incorporate biomedical decisions only. The quantity of information may be more in informed DM, whereby both patient and doctor deliberate all relevant information, which contrasts with the minimally required information within the paternalistic model. Within the paternalistic model, the treatment choice is decided upon by the doctor, whilst in the informed DM, it is the patient.

However, in the SDM model, information exchange flows bidirectionally between doctor and patient, the type of information shared is both biomedical and personal, the doctor and patient deliberate together and jointly come to a decisional agreement.

1.5.4 The doctor-patient relationship

Mead and Bower proposed another model that focused more on the doctor-patient relationship (Mead N, 2000). Utilising the conceptual and empirical literature, they developed a model composed of:

- The biopsychosocial perspective
- The patient as a person
- The sharing of power and responsibility
- Developing a therapeutic alliance
- The doctor as a person

There is increasing awareness that medical education needs to help HCPs develop person-centred skill sets that allow them to manage patients with a variety of interest, medical literacy (Bayne *et al.*, 2013). Mead and Bower's final concept of the doctor as a person recognised the healthcare professional in the relationship with their own set of values, feelings, and interpretations of health. The suggested model provides a remedy for the issue of possible decisional conflict that may arise when a patient has not transferred decision-making authority to the doctor, and who makes the final decision based on his or her values and preferences. The Mead and Bower model therefore allows opportunity to understand the healthcare issues of patients and their interactions with HCPs, from the additional and self-aware perspective of the professional. It also potentially allows an opportunity for scrutiny of the potentially subjective professional perspective.

The interactional, SDM and the relationship-based model by Mead and Bower indicate more collaborative relationships emerging in the person-centred decision-making processes by virtue of involvement of patients and key component of agreed decisions between doctors and patients. The next subsection presents a model in which collaboration is seen as a key concept for the person-centred process.

1.5.5 Collaborative deliberation

Previous models have focused on the patient-doctor dyad and arguably the over-simplified decisions made at the individual level. The case for patient participation in decision-making is further advanced by the collaborative deliberative model for patient care (Elwyn *et al.*, 2014). The authors provide an approach to person-centredness to demonstrate how patients may be assisted in making decisions to consider difficult or alternative courses of action or possible new decision-making directions. Moreover, the authors propose the model be considered when delivering specific activities in such as motivational interviewing, goal setting, action planning and shared decision-making. The approach aims to support empathic clinical practice (Elwyn *et al.*, 2014). In particular, the doctor has traditionally been the main HCP figure when defining decision-making models in the past. The collaborative deliberation method openly addresses how any HCP could engage with patients and the greater context of healthcare decision-making.

The argument for collaborative deliberation is based on the explicit recognition of the patient's unique agency and their right to participate in decision-making, even though the professional may think the choice was unwise. The collaboration between patients and doctors when expressing goals and preferences, however, is crucial to the conceptual model. The model proposes a five-fold interactional process (Elwyn *et al.*, 2014):

- Constructive engagement- clinicians, patients and carers show curiosity, respect, and empathy.
- Recognition of alternative actions- the recognition of different options for action.
- Comparative learning – Comparing various options available is done by all parties.
- Preference construction and elicitations – think about, create, and elicit preferences about possible courses of action.
- Preference integration- Consider each person's preferences while choosing the next course of action.

Elwyn *et al.* acknowledge that feelings of dread and worry can affect everyone involved in the process, not just patients, and that these feelings might bring to light issues that may require discussion, such as self-blame if results are unsuccessful (Elwyn *et al.*, 2014; Joseph-Williams, Elwyn and Edwards, 2014). The collaborative model appears as another way to frame PCC in an interactional way so clinicians and persons can recognise how to engage with each other to

achieve a common goal, whether that is the treatment decision, improving self-care or planning management.

The commonality across the approaches to PCC discussed so far is the involvement of the patient in information sharing and agreement in decision-making, respect for the persons autonomy and personal preferences (even when the clinician views the patient choice as unwise) and empathic and respect throughout. In the next subsection, Entwistle et al.'s explanation of the capabilities approach to PCC is summarised and shows another framing of a PCC approach.

1.5.6 The Capabilities approach.

So far, certain commonalities across PCC's and strategies have been apparent, with each approach putting a differential emphasis on issues in person centeredness. The emphasis on treating patients as "persons" may be the core and repeated theme. This has its roots in the examples of patient-centeredness theories, developed in response to the negative patient construct (Balint, 1969; Balint, Ball and Hare, 1969; Kitwood, 1997; Lambert *et al.*, 1997), when the idea of depersonalization was a key justification for an alternative to the biological frame of clinical care.

Entwistle also recognise the multiplicity of terms that are similarly used to mean a person-centeredness and accept synonyms of patient-centred care (PtCC), client-, family, relationship-centred care (Entwistle and Watt, 2013b). Accepting these synonyms paves the way for the pragmatic usage of PCC, PtCC, and other synonyms in the next chapters of this thesis.

Additionally, by concentrating on patient preferences or satisfaction, the fundamental value of person-centeredness may be concealed. Understanding the patient's point of view about the information they have access to and considering the patient's wishes both demand a balanced perspective from the HCP. Patients may have been misinformed, have unstable preferences in which they have a weak belief, or the patient has not considered and balanced the choices offered. In that case, HCPs may feel justified in believing that PCC is either unattainable or untenable (Epstein and Peters, 2009; Entwistle and Watt, 2013b).

Entwistle et al. argue that the task of communicating information to the patient alone does not achieve PCC and that the care relationship between the HCP and patient has value to support patients. Those less obvious aspects of the HCP-patient relationships such as continuity of care, are not emphasised in person-centred interventions (Entwistle and Watt, 2013b). Importantly, this social relationship between the HCP and the patient may be recognition of the way human beings are socially situated. Persons are more than simply preferences and choices; they are persons moulded by their social environment, with biographical narratives and capabilities with which they identify in order to make sense of themselves (Entwistle and Watt, 2013b).

Entwistle et al. describe capabilities in two separate ways, at the level of functioning- the way of doing things, such as working, free of disease, literacy; or the level of ability to function which is environmentally or socially defined, such having the resources to be working, access to healthcare, and knowledge or skills of literacy. The authors do provide more detailed examples of what and how capabilities of persons can be understood but are also careful to state they provide illustrative examples only, and that over specification distracts from the guiding principles that make their model an approach rather than a detailed process.

The more in-depth debate for and against capabilities approach are beyond the boundaries of this thesis, but what is relevant is the guiding concepts for how HCPs can use the approach in healthcare. Treating people as persons involve three concepts as guides for HCP to consider in person centred care.

- 1- **Respect and compassion:** The term respect requires HCPs to show patients they are a person to be valued and is akin to the notion of respect identified in other approaches. Compassion is emphasised to acknowledge the way people suffer emotionally and psychologically. Conversely, dismissing patients' concerns, distress, and unfavourable perceptions of patients who do not conform to accepted norms may lead to human suffering and represents the antithesis of person-centeredness.
- 2- **Responding to subjective experiences, unique biographies, identities, and life projects:** The diversity of human experience requires an appreciation of each person's unique perspective. Being responsive to contextual narratives, personal identities and relationships that are important to the individual is similar to other approaches that recognised the individuality of personhood, such as the biopsychosocial (Mead and

Bower) and the holistic approach that acknowledges emotional needs, and life concerns (Stewart et al, 2001).

- 3- **Supporting persons capabilities to be autonomous:** Entwistle et al argue for this construct in three areas. Firstly, supporting people who have limited capabilities to make decisions such as those with mental health problems. For example, in societies where information and choice favours people with abilities to access the information, such as the more health literate. By helping patients with aspects of health literacy, HCPs are supporting autonomy. Secondly, that health support does not undermine patients' own beliefs of what is right for them, nor misaligned with what their capabilities do not allow, such as the lack of inclination or readiness to engage with smoking cessation programmes. Thirdly, the emphasis on supporting the person to be autonomous requires the HCP to actively recognise that the individual choice is justified and help them to identify and pursue their desire improved health. This latter concept shifts the capabilities approach towards the shared decision-making models that help patients' self-care in long-term conditions such as diabetes (Entwistle and Watt, 2013b) .

Although the capabilities approach has been criticised for its usage of the term "capabilities," which risks portraying the approach as denigrating individuals who lack capabilities, it has been added here as an additional PCC approach that shows similarities to others represented earlier in this chapter. The final subsection looks at an approach to PCC that is advocated by an establishment that aims to develop and implement person-centred care.

1.5.7 The Gothenburg Centre for Person-Centred Care (GPCC) Routines of PCC.

In Sweden, the University of Gothenburg Centre for Person-Centred Care (GPCC) was founded in 2010 by a group of clinical and non-clinical academics from several disciplines with the goal of "*initiating, integrating, and safeguarding*" person-centred care into everyday clinical practice. The approach advocated by the founders of the centre encouraged three "*routines*". The routines are clinically oriented tasks for HCPs and everyday objectives for

families and caregivers (Ekman *et al.*, 2015; Britten *et al.*, 2017; Ekman, Ebrahimi and Olaya Contreras, 2021). The routines indicate previously identified themes of PCC approaches of person hood and partnership but place an additional emphasis on the person's biography or narrative.

- 1- Initiation of partnership by eliciting the personal narrative: the sick person's personal story of their sickness, symptoms, and impact on their lives. The construct encompasses the concept of individuality as well as a person's experiences of suffering in the context of their environment.
- 2- Implementation of the partnership through shared decision making: The partnership concept is inclusive of patients, relatives, family or friends and professionals working together to achieve commonly agreed goals.
- 3- Documentation of the patient's narrative to safeguard the partnership: Documentation of preferences and values, as well as the patient's care plan and treatment decision-making.

The GPCC model of person-centred care also emphasises a capabilities approach, comparable to Entwistle *et al.* The roots of the approach are argued to originate in care pathways framework development and has incorporated the philosophical ideals of personhood concepts and beliefs in individuality and autonomy. (Riccœur, 1992; Ekman *et al.*, 2015; Ekman, Ebrahimi and Olaya Contreras, 2021). The GPCC is linked to both hospitals and primary care centres, and patients' treatment objectives, as well as medical information, are documented in care plans produced with patients and caregivers within 24 hours of hospitalisation (Ekman *et al.*, 2015). The approach is healthcare practice based and aims to manifest PCC into both systematic practices of health care establishments such as hospitals, as well as developing the mindset for personalism: ideals or guidelines for person-centeredness for HCPs to aspire towards in every practice.

Britten *et al* explored professionals' perspectives of GPCC model of PCC and the routines through a qualitative study involving 18 clinician-researchers participating diverse GPCC projects (Britten *et al.*, 2017). The interviewees identified HCP perspectives of personalism required a different 'mindset'. From the clinician's perspective, the emphasis was on symptoms rather than signs, and on the individual's objectives rather than the professional's treatment and outcome goals. The time element involved was an issue and associated with establishing the

person's goals. The concept of partnership was dependent on the patient population and the problem or illness. When goals were unrealistic, there was opinion that the goals may be broken into smaller steps, and even a view to skilfully change a person's perspective, which the authors interpreted as a sharing of information and negotiation process to elevate the persons consideration of the issues. However, dangerous goals were identified as objectionable, such as keeping firearms when suffering paranoid mental health symptoms (Britten *et al.*, 2017).

There was opinion that partnership was about agreeing on common goals. The challenge from the clinical perspective may be that the patient narrative takes precedence over the biomedical focus in the dialogue, resulting in a failed attempt at shared decision making and patient care is not met. This tension between the persons desires and the professionals' objectives was also evident when considering the advocate role of the professional. As professionals with duties and obligations to satisfy guideline-led care, and as service providers with limited resources within healthcare systems, their capacity to deliver the GPCC personalism objectives was noted as a limitation:

"You can't be someone's best friend because you're still there to do a job in the context of healthcare." Respondent 18 in (Britten *et al.*, 2017).

The paradox of person-centred care remained an issue for the participants. In the healthcare setting, persons are first identified by their biomedical condition and then personalism is offered in the form of care. However, Britten et al hypothesise that this paradox may not apply if patients experience multimorbidity or long-term conditions (Britten *et al.*, 2017). The implications are that patients in these situations are identified as persons first and foremost and then, that they suffer from health conditions. Ultimately to maintain PCC in practice required modifying professional perceptions and this change was thought to be as helpful as the three GPCC 'routines' (Britten *et al.*, 2017).

1.5.8 The Health Foundation principles of PCC

The Health Foundation was mentioned early in this series of subsection (at 1.11) as a presentation of an apparently simplified vision of person-centred care (Health Foundation (Great Britain), 2016). The guidance offered represents a framework rather than a definition of PCC, as do many of the previous approaches to PCC. Four principles are outlined, emphasising elements that previous approaches have already highlighted.

The principles are (Health Foundation (Great Britain), 2016):

- 1- Treating people with “*dignity, compassion and respect*”.
- 2- Co-ordinated care and treatment.
- 3- Personalised care, support, and treatment
- 4- Enabling: assisting people in recognising and developing their own skills and capabilities to live an independent and fulfilled life.

The enabling concept is akin to the capabilities approaches stated by Entwistle et al and the GPCC framework for routines in PCC. For healthcare to be enabling, HCPs and patients need to work in partnership and the relationship on more equal terms. The relationship involves empowering patients to gain skills, knowledge, and confidence, and so participate in collaboration (Health Foundation (Great Britain), 2016).

Notably, PCC may be viewed by HCPs or healthcare leaders as low priority rather than essential when it is in competition with other factors such as safety, time, or financial resources. Viewing the principles as an attitude or “*mindset*” (Health Foundation (Great Britain), 2016) may afford HCPs benefits that are pragmatic as well as person-centred. For example, by prescribing for patients to meet their needs and wishes, including their daily routine, may improve medication adherence, symptoms, and result in reduced healthcare demand.

1.5.9 Summary of the explored PCC approaches

Table 4 summarises the approaches and allows similarities to be evident across them and extends table 1. The transition of patient-centredness to person-centredness is evident from top to bottom of the list of approaches in the table and correlates with earlier and later approaches indicating development around PCC amongst academics. The second column indicates how over time patient-centeredness has transitioned to person-centeredness.

However, the concepts in the third and fourth columns appear to show alignment across time. The final column shows how the various approaches align to others in the group of approaches. Aspects of PCC is evidentially sustained and re-emerges in similar forms. Narrative or biography that appears later in the GPCC approach, appears to align with exploration of illness experience in the Interactional approach. The biopsychosocial perspective is arguably a narrow healthcare orientated view of the patient illness narrative.

Table 5: The patient- or person-centred approach, the associated principles, and the constructs that the principles align with or are similar to.

| Approach | Concepts | Principles | Aligns with: |
|---|-----------------------------|---|---|
| The clinical method (Stewart, 2001) | Patient-centredness (PtCC). | Exploration of the patient's disease and illness experience | Narrative or biography of patient experience |
| | | Understanding of the whole person | Whole person aligns with individualism (arguably) |
| | | Finding common ground-partnership | Partnership and/or collaboration. |
| | | Incorporation of prevention and health promotion | health promotion and enabling support or capabilities. |
| | | Enhancing the doctor-patient relationship | Partnership, relationship between patient, carers and professionals |
| | | Being realistic | Pragmatism/realism |
| Shared Decision Making (SDM) (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999) | PtCC | 1- Elicit patient preferences 2-Share information bidirectionally between doctor and patient in biomedical and personal terms. 3-Patient and doctor deliberate together 4- patient and doctor jointly agree on a treatment/therapy plan. Patient Decision Aids offer a way of delivering SDM. | 1- Patient preferences/values/choice 2- Informational sharing 3- Deliberation together is arguably, akin to Collaboration 4- Agreement |
| Doctor-patient relationship (Mead and Bower, 2000, 2002; Mead N, 2000) | PtCC | 1- The biopsychosocial perspective of the patient 2-The patient as a person 3- The sharing of power and responsibility 4- Developing a therapeutic alliance | 1-A narrow healthcare conceptualisation of the narrative of the patient experience 2- The whole person or individualism 3- Collaboration |

| | | | |
|---|--|--|--|
| | | 5- The doctor as a person | 4- Agreement 5- The doctor as a person |
| Collaborative deliberation (Elwyn <i>et al.</i> , 2014) | PCC | 1- Constructive engagement by all parties 2- Recognise multiple options 3- Comparative learning together 4- Elicit preferences, constructing them together 5- Integrate preferences together into a plan | 1-Dignity, respect, compassion 2- Not explicit, but options are implied in other approaches 3- Deliberation 4- Collaboration 5- Agreement |
| Capabilities approach (Entwistle and Watt, 2013a, 2013b) | PCC, but authors are accepting of PtCC, relationship, client-C, family-C | 1- Respect and compassion 2- Subjective experiences, unique biographies, identities, and life projects. 3- Supporting persons capabilities to be autonomous | 1-Dignity, respect, compassion 2- Narrative or biography of patient experience 3- capability of persons and autonomy NB- preferences are not a focus |
| The Health Foundation principles (Health Foundation (Great Britain), 2016) | PCC | 1- Treating people with “ <i>dignity, compassion and respect</i> ”. 2- Co-ordinated care and treatment. 3- Personalised care, support, and treatment 4- Enabling: assisting people in recognising and developing their own skills and capabilities to live an independent and fulfilled life. | 1- Dignity, respect, compassion 2- Collaborative care in partnership between patients, carers, and professionals 3- Individualised, personal 4- Capabilities approach |
| Gothenburg Centre for Person-Centred Care (GPCC) Routines (Britten <i>et al.</i> , 2017; Ekman, Ebrahimi and Olaya Contreras, 2021) | PCC, accept PtCC. | 1- initiate partnership by eliciting personal narratives 2- Integrate- implement partnership through SDM 3- Safeguard partnership by documentation of personal narrative, preferences, and management plan | 1-Dignity, respect, compassion through narrative 2- collaboration and SDM 3- Documentation to safeguard and, collaborative agreement |

The consideration of patients as persons, whole persons, individualism are explicit in some approaches (Mead and Bower, 2000, 2002; Mead N, 2000; Stewart, 2001; Entwistle and Watt, 2013b; Health Foundation (Great Britain), 2016), and implied or assumed in others (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999). The concept of the person in the earlier approaches aligns to the philosophical theories of personhood as described by

Ricoeur, and explicitly underpins the Gothenberg PCC approach (Ricoeur, 1992; Health Foundation (Great Britain), 2016; Britten *et al.*, 2017).

A sense of partnership, collaboration, finding common ground or relationship between patients, carers and HCPs is arguably similar and apparent across the approaches. The constructs indicate a shift of power from the biomedical authority of HCPs to personal or individual preference or choice and embeds personal autonomy more significantly than sharing of information alone.

Information sharing appears explicit and foremost in the SDM model (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999), whilst implied in others, namely (Entwistle and Watt, 2013b; Elwyn *et al.*, 2014; Health Foundation (Great Britain), 2016; Britten *et al.*, 2017; Ekman, Ebrahimi and Olaya Contreras, 2021).

Agreement on management or treatment plans is explicit in some approaches (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999; Mead N, 2000; Mead and Bower, 2002) with an interactional or SDM focus, and assumed in other approaches focusing more on collaboration, relationship between HCP and patient, or support for personal autonomy (Elwyn *et al.*, 2014; Health Foundation (Great Britain), 2016; Britten *et al.*, 2017; Ekman, Ebrahimi and Olaya Contreras, 2021).

Significant differences between the approaches are also evident. Entwistle *et al.* are explicit in stating that preferences of patients are less valuable in delivering PCC when a capabilities attitude is taken. The priority is on enabling persons to develop their considered and understood preferences and so, supporting the person to be autonomous (Entwistle and Watt, 2013b).

Another significant difference across the approaches is that of Stewart and Mead, who identify the HCP in the decision making or PCC approach (Mead and Bower, 2000; Mead N, 2000; Stewart, 2001). Stewart explicitly recognises the HCP perspective when delivering health care in limited resources in the form of realism or pragmatism (Stewart, 2001). Mead, however, identifies the HCP, namely the doctor, as a 'person' and explicitly identifies the values, human behaviours, or emotions that HCPs may bring to the interactional process (Mead and Bower, 2000, 2002). This construction of the doctor in the doctor-patient interaction or process of person-centredness is a valuable reminder that HCPs hold personhood positions themselves. This HCP personhood concept is arguably implied in other processes which explain HCP

professionalism, legitimate duties of care and hypothesise on the values of doctors (Entwistle and Watt, 2013a). It is also arguably implicit in the collaborative, relationship or SDM processes where the doctor is involved in the sharing of information and opinion (Charles, Gafni and Whelan, 1997; Cathy Charles, Gafni and Whelan, 1999; Elwyn *et al.*, 2014). Interestingly, the GPCC model appears to not recognise this possible HCP own personhood when attempting to bring PCC into the fore of daily healthcare practice (Britten *et al.*, 2017; Ekman, Ebrahimi and Olaya Contreras, 2021).

What was obvious from the articles presenting the approaches was that PCC was not believed to be adopted as "normal" or "routine" practice in the healthcare arena. Moreover, the existence on the GPCC department and approach was expressed as reactionary and an attempt to aid implementation of PCC into daily healthcare practice (Ekman *et al.*, 2015; Britten *et al.*, 2017). The development of the different approaches were efforts to address how clinicians and patients may manifest PCC into healthcare practice.

This thesis accepts the patient-centred concept and the historical transition to the person-centred domains, but also takes a pragmatic stance to accept Eklund *et al.*'s view that much of the wider literature may underpin person-centredness using patient-centred sub-constructs (Håkansson Eklund *et al.*, 2019). The PCC approaches presented in sections 1.4.2 to 1.4.9 included the concept of the 'whole person care' (WPC), which has also been identified as a "*defining feature of general practice*" (Thomas *et al.*, 2018). The construct of WPC appears similar to PCC and yet when explored separately to PCC and PtCC, WPC has additional characteristics. The next section explains the construct further.

1.5.10 Whole-person care

Whole person care (WPC) has been identified as an objective for primary care to meet the needs of patients living with chronic disease and for those experiencing multimorbidity (Primary Healthcare Advisory Group, 2016). Despite the wide acceptance of WPC as a core skill in primary care, the concept of WPC remains ambiguous in the literature and can be used interchangeably with 'holism' and biopsychosocial care (Thomas *et al.*, 2018). Even general practice leadership organisations may define the terms differently. For example, the European

conception of WPC explains a '*holistic approach*' to physical, psychological and social aspects of patient care which incorporates the "*cultural and existential dimensions*" (Allen *et al.*, 2002). In contrast, the Royal College of General Practitioners (RCGP) has described holism as a core competency that includes care for the whole person in the context of their individual values, family beliefs, as well as the psychosocial and wider cultural aspects of patient beliefs about health, but also associates the concept with safeguarding and health promotion (Walter, 2019).

The construct of the whole person within the previously mentioned literature on PCC approaches centred around the construct of the individual autonomous person in need of care (Mead N, 2000; Stewart, 2001). A systematic review of the literature on whole person, holistic and biopsychosocial care in general practice found WPC was understood to also be an 'approach' that had multiple dimensions. In WPC the person is perceived as a whole with facets of the individual personhood, biological, psychosocial, spiritual, and even ecological (Thomas *et al.*, 2018).

The key themes in WPC presented by Thomas et al were (Thomas *et al.*, 2018):

- A multidimensional integrated approach to the individual, viewing and integrating different facets of the person to comprehend the whole.
- Values the therapeutic relationship, collaborative approach, and continuity of care.
- Acknowledges the humanity of the doctor, self-awareness, and resilience, with potential for growth through patient care.
- Recognises patients' uniqueness as individuals and so, personhood and the illness experience of patients.
- Prevention is key to health, whilst health goes beyond the absence of disease.
- Applies a variety of treatment modalities and may include complementary and alternative medicines (CAM).

Like PCC, the therapeutic value of the doctor-patient relationship remained central within WPC with similar collaborative and supportive characteristics. On the one hand, WPC was presented as a multifaceted approach to patient care that was comparable to PCC techniques in the literature, whilst on the other the WPC term may also be used interchangeably with holism and biopsychosocial terminology.

In the literature, holism was represented by a medical view of whole person care incorporating the personhood, biological, psychosocial and existential individual (McWhinney, 1980; Thomas *et al.*, 2018). In addition, the term holism had also developed strong associations with unorthodox, complementary and alternative medicines (CAM), despite a long and traditional presence within orthodox medicine (McWhinney, 1980). It follows that a prominent claim in the WPC literature was that even CAM treatments used in isolation failed to sustain the word "holism" and was seen as *one* of the possible therapies accessible when treating patients holistically. (Thomas *et al.*, 2018). As a result, whole person and holistic care may surround biopsychosocial care for primary care doctors and HCPs, and holistic complementary and alternative therapies (CAM) may share similar values and constructs but employ a range of therapies that lie outside of orthodox medical practice (Thomas *et al.*, 2018).

Thomas *et al.* also found that there were few papers that consistently distinguished between WPC, holism, and biopsychosocial ideas (Thomas *et al.*, 2018). For example, Wun added the concept of continuity of care to the WPC construct, whilst Pietroni included newly discovered biomedical science such as psychoneuroimmunology. (Pietroni, 1984; Wun YT, 2002). The lack of clarity between the definitions of WPC, holism and biopsychosocial terms highlighted the wide range of concepts used to frame them resulting in confusion for practitioners applying the approaches. The lack of agreement on definitions indicates the need for further research to understand PCC, WPC and integrating them to deliver chronic disease management in the setting of primary healthcare.

In the PCC approach by Stewart *et al.*, there was literature on WPC that also acknowledged the value of the humanity of the doctor and aimed at maintaining self-awareness and self-care. However, the WPC and holism literature also emphasised the role of doctors to maintain their own health, resilience and ability to be objective in the clinical interactions (Thomas *et al.*, 2018). Although these additional ideas add to the notion of the humanity of the doctor, there remained a lack of knowledge amongst the WPC papers of how doctors may manifest this humanity and contribute to the person-centred care.

The thematic analysis of the literature on WPC in primary care by Thomas *et al.* was broad geographically and in its range of literature due the search strategy employed. However, the English language limitations, and the over representation of western countries may reflect the lack of literature across the world on WPC in the English language. Cultural differences in

medical culture, languages, and social culture may result in distinct terminology in other nations with alternative meaning and relevance locally. Additionally, the gatekeeper role of GPs may vary across countries and health systems and so, whilst the construct of WPC may be current and reinforced by professional bodies, it may not represent a term used worldwide. Moreover, the heterogeneity of the papers and thematic approaches presented by Thomas *et al.* may be perceived differently by other researchers.

Consequently, in this thesis, the WPC construct is seen in the wider context of the PtCC and PCC approaches. Acknowledging that the underpinning concepts and terminology used for the PtCC, PCC and WPC approaches may be used interchangeably in the literature allows individual papers to be understood from concepts and principles laid out in this chapter.

In conclusion, like PCC, the WPC construct was an approach to be applied by HCPs in the care of patients. WPC also acknowledges individuality and personhood, but with an emphasis on maintaining the multidimensionality of WPC in terms of biopsychosocial, whole person and holism constructs. The addition of integration of WPC across healthcare providers such as primary and secondary care added the issue of how WPC may be delivered by the design of healthcare systems (Thomas *et al.*, 2018). The challenge of delivering integrated WPC is comparable to delivering PCC across various care providers, and the two constructs may be used interchangeably in the literature.

1.5.11 Summary

Primary care management of chronic disease, and in the example of T2DM and its associated cluster of diseases, requires person-centred approaches to deliver improved population and individual health care according to guidelines and recommendations. Transition away from paternalistic and disease models of clinical care requires a change in how clinicians and patient relate, interact and approach health care decisions. PCC is recommended as a core principle to help clinicians provide individualised biomedical and psychosocial care for patients (Seidu *et al.*, 2022b). Patient involvement in self-care and treatment decisions has been recommended in guidance and has been shown empirically to be what patients want (Little *et al.*, 2001).

Person-centred care (PCC) has been argued to represent a more equal partnership between clinicians and patients, involving patients in bidirectional informational exchange and healthcare decisions. The individual patient exercises autonomy and actualises their preferences in both health and lifestyle. The clinician may support this autonomy through collaborative care involving family and carers, but throughout the person is viewed as an individual with the right to respect dignity and compassion. WPC has similarities to PCC approaches to patient care but incorporates multidimensional views of the patient in terms of biopsychosocial, holism and whole person constructs, whilst also recognising the HPC/doctor as a human.

The preceding introductory account of person-centeredness, whole person care and chronic illness care, including type 2 diabetes treatment, establishes prior sensitising concepts which will be used to inform the thesis. Whilst accepting the lack of clarity in the definitions of the terms used, and how some terms such as WPC and holism may be used interchangeably, there is clarity in the message that there is a growing shift toward delivery of care with a person-centred approach. The constructions of PtCC, PCC, and WPC, as well as their underlying principles, offer supportive *a priori* concepts to move forward to the literature review. The stance taken by this thesis is that of healthcare research seeking to understand the PCC arena in primary care.

The next chapter presents a review of the empirical literature on the person-centredness of GP decisions in primary care chronic disease management.

2 The literature review

2.1 Introduction

This narrative literature review aims to explore the wider and current literature on the person-centredness of GPs in primary care chronic disease management. Following on from the arguments presented in chapter one, the understanding of patient-centred approaches to chronic disease patient care in the primary care setting remains an important and relevant issue. The review examines recent and current literature, search of the literature, quality appraisal, and finally a conceptual thematic analysis, acknowledging previously identified prior concepts (Booth, Sutton and Papaioannou, 2016).

The next section of the chapter will explain the review question, protocol to search and the process leading to the final papers chosen for literature review synthesis.

2.1.1 Review question

The chosen literature review research question that led the primary study identification was:

“What does the literature tell us about the person-centredness of GPs in primary care chronic disease management?”

2.2 Methods

This section will explain the methods and so, steps of the literature synthesis. the consideration of the literature review question in the introduction above, the next section of the chapter will explain the literature review protocol used to identify and search the literature systematically.

The SPIDER (sample, phenomenon of interest, design, evaluation, research type) framework was formulated to aid qualitative literature reviews and evidence synthesis (Cooke, Smith and Booth, 2012; Soilemezi and Linceviciute, 2018). Consequently, the topic of interest was focused using the SPIDER framework for formulating a literature research question and then,

later for planning the review protocol and search strategy. Importantly, the intended contextual nature of the topic guided the decision to employ the SPIDER framework for the search strategy and tabulation of the screening process of the abstracts of papers. The aim was to capture papers in the broader field of the topic area at the earlier phases of the literature search screening.

2.2.1 The sample

The key phenomenon of interest was GPs' person-centeredness. The sample (or population for quantitative research) of interest was GPs, and additionally, empirical research that reported on patients' perspectives of the person-centredness of GPs was also included. Healthcare professionals (HCPs) involved in primary care chronic disease management include nurses, healthcare assistant, pharmacists and practice administration staff. The focus on GPs as part of the topic of interest was acceptance that decisions made by GPs at an individual level in chronic disease management was different to the care delivery performed by other primary care allied HCPs. However, any research that included other healthcare professionals (HCPs) as well as GPs was still included. The research designs included were qualitative, quantitative, and mixed. The types of evaluation or outcomes of empirical work sought were initially left wide and refined in an iterative process, together with discussion with supervisors.

2.2.2 Phenomenon of interest

The chosen phenomenon of interest was person-or patient-centredness within the primary care setting. A tightly focused research question to guide the literature review aids production of manageable and appropriate citations. However, a literature review that is too narrowly cited may not report enough of the breadth of knowledge available to understand the phenomenon (Soilemezi and Linceviciute, 2018). The aim for the primary search strategy was to remain broad and allow inclusion of conceptual phenomenon beyond limiting concepts such as barriers and facilitators. As a result, the following additional phenomenon of interest were included:

- Primary care- the setting within which the phenomenon of interest occurred.
- Person- (PCC) or patient-centredness (PtCC)- the topic of concern within the phenomenon of interest. Specifically, the person-centredness of individual GPs was

chosen to focus the understanding of PCC at the practitioner level, rather than practice systems, or specific methods of delivery such as shared decision-making tools.

- Chronic disease management and long-term conditions within the primary care setting was chosen to leave the phenomenon of interest broad and allow person-centred empirical research in chronic diseases other than diabetes. Asthma for example was added as a term in an initial trial run of the chosen search terms and the outcome results were no different.
- Patient-general practitioner relations was a construct within the phenomenon of interest and the concept of person-centeredness within the context of interactions with GPs was identified in the scoping literature.
- Shared decision making (SDM) was included as a topic of concern within the phenomenon of interest. Although papers that were solely focused on SDM were later excluded (3rd stage of screening), SDM papers had been identified in preliminary searches to include person-centred concepts or sometimes objectives such as, the failure of clinicians to engage in SDM and so, lack person-centredness (Farrell *et al.*, 2017) So, SDM, when added to the primary search terms increased amount of PCC related empirical research that may inform on the GP perspective of PCC.
- In keeping with the construct of person-centred care, the integrated delivery of healthcare was included as an evaluation concept. Although the aim was individual GP delivery of PCC, preliminary searches had identified papers informing on GP person-centredness when investigating the delivery of care across care providers and in integrated care systems. Consequently, the term was included with a Boolean ‘or’ combination.

2.2.3 Design

The research design refers to the overall method adopted to combine the many components of the study in a cohesive and logical manner, assuring that the researchers effectively address the research topic; it serves as the plan for data collecting, measurement, and analysis.

The original search includes a wide range of study designs to allow for multiple designs that have been used to explore PCC, which was confirmed by initial scoping exercises. As a result, design-related search terms were not used to restrict the primary literature search, and the output papers included designs and approaches using a variety of theoretical frameworks and methods. Appraisal of the design and research methods used the Mixed Methods Appraisal Toolkit (MMAT) (Hong *et al.*, 2018) and is described later in section 2.5.3.

2.2.4 Research type

The literature was intended to concentrate on empirical research, or primary research based on experimentation, observation, or simulation. As previously mentioned, the designs of the published research were not restricted and a broad range of design was expected amongst the output papers and so, the research types were also expected to be diverse, i.e., qualitative, quantitative, and mixed methods. This acceptance was based on an initial scoping of the literature and the resulting awareness of the diverse research methods available to understand the PCC field.

2.2.5 Searching and screening

It is recognised that literature review objectives guide the direction of the review, and in this thesis, the objective is to understand the PCC of GPs in chronic disease management in the primary care setting. The possibility of iteration and refinement of the question at the later stages may be appropriate. Moreover, iteration during screening of papers and so, modification of the inclusion/exclusion criteria may also be appropriate and would then be documented to aid transparency (Booth, 2016; Soilemezi and Linceviciute, 2018).

The inclusion criteria at the **first stage of screening** included peer-reviewed empirical and original research that was relevant in terms of the phenomenon of interest and evaluation (as described in the subsections above), published in the English language, and the process involved the simultaneous screening of titles and abstracts. Article related to any chronic disease type were included.

Exclusion criteria were: Non-English articles, articles, articles not specific to primary care or general practice and not related to PCC.

During this process, close attention was paid to the SPIDER mnemonic criteria evident in the abstracts. The results were tabulated into a word document to allow an audit trail. This table recorded the paper author and year, the sample type and number, country of origin, the phenomenon of interest (e.g. PCC, PtC, SDM), study design, evaluation, research type, if the paper was included or excluded and why.

If the abstract detail was inconclusive or unclear to understand the relevance of the paper, the fuller paper was accessed to clarify and reviewed for relevance to the specific screening stage (detailed in 2.3.2 to 2.3.4).

Screening of papers was made explicit, and followed a reflective and iterative process, so papers were included/excluded at stages of title and abstract review, then at full paper review. At each stage, the decisions made were recorded and the results are presented in the results sections of this chapter.

2.2.6 Evaluation

The outcomes of research from quantitative methods are observed, but in qualitative methods, the outcomes may not be observed, or they may be subjective constructs such as attitudes, views, or satisfaction. The types of evaluation therefore included the following constructs:

- Decision making or clinical decision making – GPs in primary care make decisions around various aspects of patient care, such as drug treatment, or therapeutic decisions for referral on to allied HCPs or secondary care specialists. Including this construct

recognises that person-centred care is operationalised by decisions made in primary care.

- Treatment or therapy decisions were added to the search terms to represent the types of decisions by GPs that may be person-centred. This included terms were options or choice of treatments, initiation of medication, escalation and change of treatment.
- Health knowledge, attitudes, and practice are a group of constructs that are recognised to uphold each other and aimed at patient or healthcare professional knowledge attitudes and behaviour. Following preliminary searches, KAP was believed to be important as part of the evaluation constructs to understand the GP perspective of person-centredness. Similar research has used the triad to understand the HCP knowledge, attitudes and practice in other topic areas such as Covid-19 (Brasaite, Kaunonen and Suominen, 2015; Tegegne *et al.*, 2021)(Brasaite, Kaunonen and Suominen, 2015; Tegegne *et al.*, 2021).

2.2.7 Data extraction

After the identification of the constructs and particular concepts to be searched, the database was selected to allow healthcare research publications relevant to GP delivery and primary care. The empirical literature was identified from a search of the Medline database via Ovid which is produced by the National Library of Medicine (NLM) and covers international biomedical health literature including the allied health fields, humanities and information science related to medicine and healthcare. Due to the limitations of time and the resource of a single researcher, the boundaries of the literature review were confined to a Medline search and not extended to other databases such as Cinahl or Embase. Although this was a pragmatic decision, it also adds to the limitations of the literature review (discussed in section 2.6).

Truncations were used to incorporate permutations of the words that may apply to the same or closely similar concepts. The thesaurus of terms and truncation applied was within the context of the Ovid search engine and truncations were marked as asterisks (*).

The literature search was limited by choosing to focus on English language papers. However, the decision to restrict the search to English language papers was pragmatic and attempted to avoid the resource requirement of including studies in other languages, which involves extra time, requirement for translation services, and additional problems of conceptual differences of meaning for words and concepts during thematic synthesis processes (Soilemezi and Linceviciute, 2018).

2.2.8 Quality appraisal (see appendix 12.1)

As explained previously the included research designs were broad and heterogenous, and as a result the types of research included qualitative, quantitative, and mixed. The aim the literature review is to understand the trustworthiness of the findings of the group of studies.

A deliberate decision was made not to exclude articles during the screening phases based on their study design or type, but the quality of the papers was assessed and tabulated during the full paper review. The full appraisal is included in the appendix, although the description of the articles in the findings section discusses the papers' varying quality.

Although the papers were all peer reviewed publications, and so, an expected level of quality had been met to achieve that status. However, the appraisal of the papers required a process that allowed assessment of the papers for validity, reliability, and trustworthiness. This process required a tool which appraised the research methods beyond a quantitative scoring or ranking, and also allowed different types of research to be systematically examined and documented in an auditable manner. The Mixed Methods Appraisal Tool (MMAT) (version 2018) was chosen to meet this challenge because it was designed to appraise the methodological quality of empirical studies (Hong *et al.*, 2018). There are two initial screening questions (“*Are there clear research questions?*” and “*Do the collected data allow to address the research questions?*”) (Hong *et al.*, 2018). There are then five distinct categories: qualitative, randomized controlled trial, non-randomized, quantitative descriptive and mixed methods studies.

The appropriate category of study is chosen relevant to the specific paper being appraised. There are five core criteria for each category, which are the criteria that are most relevant to

evaluating the methodological quality of that research design and type. Each criterion is scored on a three-point scale: yes, no, and can't tell. and then twenty-five criteria. Each criterion is evaluated using a rating of "yes," "no", and "can't tell."

The MMAT checklist has an associated user guide with explanations, but for completeness, the CASP criteria for qualitative research design and the Centre for Evidence Based Medicine (CEBM) tool for appraising surveys was also used as a reference aid when reading and appraising for limitations of papers.

The MMAT (version 2018) checklist and user guide are accessible on a website for free download and usage: <http://mixedmethodsappraisaltoolpublic.pbworks.com/>.

The calculation of total quality score is not recommendation for mixed method literature reviews, and this accepts that not all domains of quality are equal. Score may give impressions of accuracy or effectiveness of research, and so, this research has not scored the papers or used potentially arbitrary cut off points to exclude papers (Noyes *et al.*, 2018). Instead, the papers have been tabulated and each paper individually appraised with commentary in the table. Methodological limitations across the papers can be considered at review findings and will be reported with the literature review findings.

The next section will explain the results of the search and the subsequent screening process that led to the final group of relevant papers.

2.2.9 Review method

The traditional narrative literature aims to summarise and interpret the identified papers relevant to the person-centredness of GPs in primary care chronic disease management. The narrative review method is flexible to allow inclusion of different types of research evidence, qualitative, quantitative, mixed. Narrative literature reviews incorporate a component of thematic analysis and allow for a synthesis of findings across included studies but is arguably crude compared to more systematic processes such as qualitative thematic synthesis and realist methods (Mays, Pope and Popay, 2005). The findings from individual studies are summarised and compared to other papers and describe the contextual differences between the papers. How the data from qualitative papers are not re-analysed into a group synthesis as may occur in

narrative synthesis, thematic qualitative synthesis, or realist synthesis methods, which are alternative methods for review analysis that may be used.

In realist synthesis methods, the main aim is to identify causal mechanisms or theories underlying types of intervention or programmes, but although the research identified included qualitative, quantitative, and mixed methods research, and were not all intervention studies (Mays, Pope and Popay, 2005). Thematic and narrative synthesis methods generate new interpretive data from synthesis of included studies, which was beyond the scope of this literature review.

The following section goes into greater detail about the process of sifting and then analysing the output included studies.

2.3 Results

This section will describe the literature review findings, including the stages of further screening which followed a systematic process (Soilemezi and Linceviciute, 2018).

2.3.1 The search findings

The search output was downloaded into a word document which included titles and abstracts. The papers were kept in numerical order for later traceable audit purposes during the screening process.

The following list details the search strategy outcome from a search performed on July 24th, 2022.

List 1: The Search Strategy illustrated by the search terms exported with the primary search output from the Ovid Medline database.

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily <1946 to July 22, 2022>:

- 1 ("general pract*" or "family practic*" or "family physic*" or "family medic*").mp. [mp=title, abstract, original title, name of substance

- word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (157954)
- 2 **(care, primary or care, primary health or health care, primary or healthcare, primary or primary care or primary health care or primary healthcare).mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (189384)
- 3 1 or 2 (311533)
- 4 **("patient-cent*" or "person-cent*").mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (52602)
- 5 **(care, patient-centered or care, patient-focused or care, person-centered or cares, person-centered or nursing, patient centered or nursing, patient-centered or patient centered care or patient centered nursing or patient focused care or patient-centered care or patient-centered nursing or patient-focused care or person centered care or person-centered care or person-centered cares).mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (27737)
- 6 **("person-cent* care" or "patient-cent* care").mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (30634)
- 7 4 or 5 or 6 (52810)
- 8 **("decision mak*" or "clinical decision mak*").mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (270104)
- 9 **"shared decision".mp. or exp Decision Making, Shared/** (13013)

- 10 **exp Decision Making/ or "shared decision".mp. or exp Patient Participation/ or exp Physician-Patient Relations/ (320056)**
- 11 **("patient participation" or "physician-patient relations").mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (102102)
- 12 **((treatment* or therap*) adj2 (decision* or option* or choice* or change* or initiat* or escalat*)).mp.** [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (373396)
- 13 **(Chronic Disease/ or "long term".mp.) adj2 condition\$.mp.** (33943)
- 14 **Diabetes Mellitus, Type 2/ or Diabetes, Gestational/ or Diabetes Complications/ or Diabetes Mellitus/ or diabetes.mp. or Diabetes Mellitus, Type 1/ (714836)**
- 15 **delivery of health care, integrated/ (14024)**
- 16 **Health Knowledge Attitudes Practice.mp.** (124472)
- 17 15 or 16 (138129)
- 18 8 or 9 or 10 or 11 or 12 or 17 (945445)
- 19 13 or 14 (745086)
- 20 3 and 7 and 18 and 19 (242)

Boolean connectors of and/or/not were incorporated and are also shown in the list below leading to step 20 and the output of 242 papers. Chronic disease or long-term conditions were accepted as terms to allow inclusion of papers that may related the complexity of person-centred care in general practice. Diabetes was still included in this literature because of the initial plans to focus on diabetes, but the 'or' Boolean connector was applied to included either diabetes or chronic disease or long-term conditions.

Time frames for the search were from 1946 to 22nd July 2022 and performed after scoping reviews identified most relevant papers were after 1997. The identification of papers during scoping highlighted impacting empirical research and indicated a transition in the focus of empirical research.

One initial finding reinforced the review process and search term criteria. Kinmonth et al published papers in 1996 and 1998 which explicitly distinguished between disease centred care and patient centred care in the empirical study of the impact of HCP training on chronic disease management (namely T2DM) in the primary care setting. The concepts of patient centred care were presented by earlier work when scoping the literature for person-centred care in primary care chronic disease management, but Kinmonth et al. arguably begin the trend to empirically research PtCC in primary care and target their empirical study on the HCP focus toward this duality of patient care from the disease-centred and (Kinmonth, Spiegel and Woodcock, 1996; A. L. Kinmonth *et al.*, 1998)96; A. L. Kinmonth et al., 1998). Even though the search dates were widened to start at 1946, the oldest empirical paper identified was from 1993 (Joos, Hickam and Borders, 1993). The Kinmonth et al paper from 1998 influenced subsequent stages of screening and arguably, justified the focus on the GP perspective of chronic disease and consideration of the contrasting person-centred approach to the disease centred focus of HCP patient care (A. L. Kinmonth *et al.*, 1998).

The following subsection will go over the stages of screening the results of this primary study identification.

The next subsection will explain the various stages of screening employed after the data extraction.

2.3.2 The 1st stage of screening

The first stage involved screening of simultaneous screening of titles and abstracts. During this process, close attention was paid to the SPIDER mnemonic criteria evident in the information provided. The results were tabulated into a word document to allow an audit trail. This table recorded the paper author and year, the sample number and type, the phenomenon of interest

(e.g. PCC, PtC, SDM), study design, Evaluation, research type, if the paper was included or excluded and why.

242 papers were thus analysed at title and abstract level, and the Prisma diagram (diagram 1) shows the numerical quantities involved at this and subsequent stages. Only one duplicate was found and removed at this stage (Pretorius, Mlambo and Couper, 2022) . 241 papers were therefore reviewed at title and abstract level.

The list of 242 paper title and abstracts were a large and time-consuming quantity for the further steps of screening. However, it is argued that the title and abstract screening allowed broad understanding of the current literature and visualise the themes within current field in person-centred care (PCC) relevant to GPs without early exclusion of relevant papers in the primary study identification process.

134 papers were excluded because they were unrelated to the topic of GP person-centred care. It was at this stage that further refinement criteria were added as part of the anticipated iterative process and with discussion with the thesis supervisors to provide feedback. The identified themes at title and abstract review revealed papers in specific categories.

The supervisor opinions and feedback also influenced the inclusion of ‘unclear’ papers. Although double screening is recommended to avoid bias (Booth, 2016), this planned literature was part of a PhD and so, a limitation is the single researchers bias and potential of exclusion of relevant papers. However, the audit trail of tables of annotated papers, and supervisor review and feedback was an attempt to minimise these limitations.

Finally, any relevant review articles were excluded from the literature review, in keeping with the protocol to focus on empirical research. However, non-empirical articles were employed to support additional background information for conceptual understanding of patient and person-centred constructs and approaches such as Eklund et al (Håkansson Eklund *et al.*, 2019). Additionally, review papers also allowed checking for additional studies that may be include

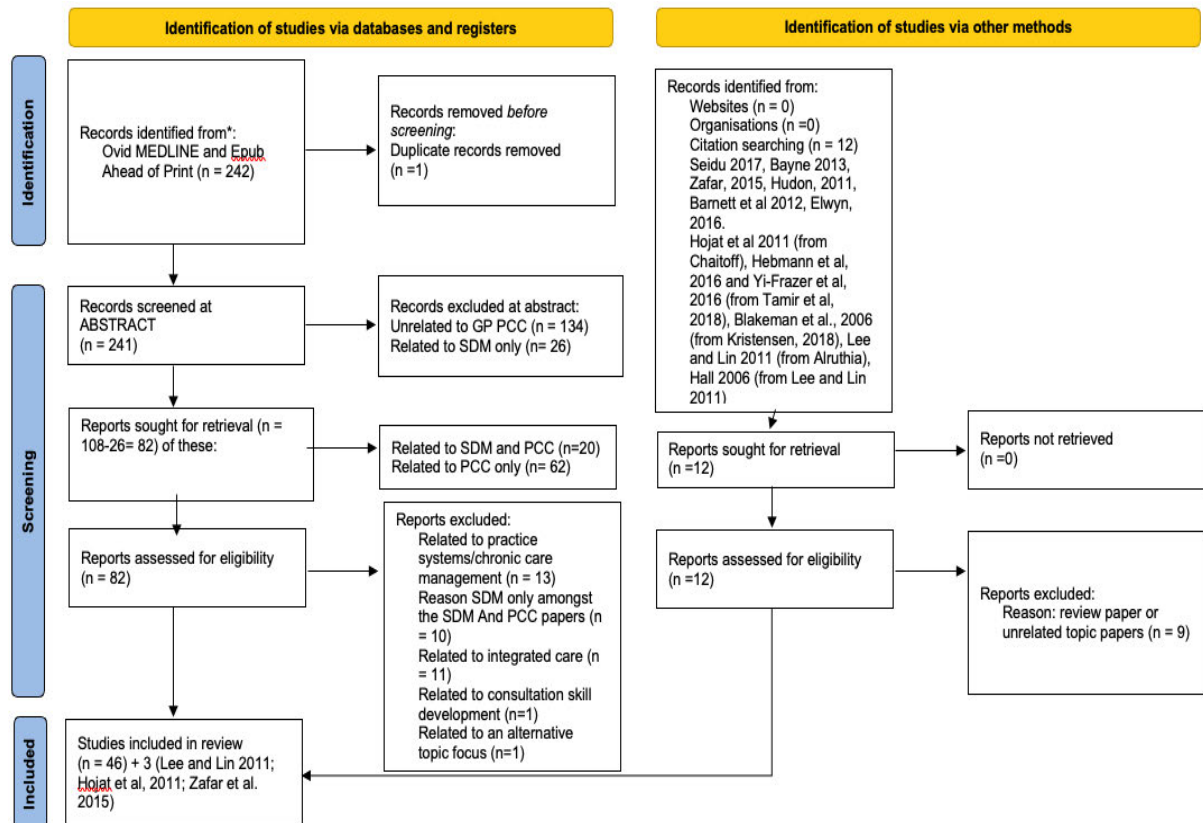


Diagram 1

The Prisma diagram of the screening process displaying the inclusion process.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

2.3.3 The 2nd stage of screening

The second stage of screening involved the exclusion of papers that focused:

- Solely on GP knowledge of biomedical management of chronic diseases such as diabetes.
- Solely on measurable biomedical outcomes of shared decision-making methods or tools such as patient decision aids.

These subcategories of papers were focused on a mechanistic process of delivering person-centred care and were not informing on contextual understanding of GPs and their individual person-centred care of patients in primary care chronic disease management. Examples of papers excluded were:

- patient decision aids (PDAs) for delivering shared decision making, such as an **SDM** tool that was compared with guideline informed usual care, where the aim to understand translation of EBM to primary care practice (Kunneman *et al.*, 2022).
- Or, a PDA tool for use in primary care diabetes care that involved a web-based decision aid called “MyDiabetesPlan” and barriers included a clinician and patient related and technical factors (Yu *et al.*, 2021).

However, this process was still at abstract level and papers that presented a person-centred perspective of GPs (PCC only) or indicated combined person-centred and shared-decision-making focus (PCC and SDM) within the abstract were included. The outcome of this stage were 82 papers and the third stage of screening involved separating the papers into two different tables of PCC only papers, or PCC and SDM combination papers. Further screening was performed at full paper review and is described in the following sub-section.

2.3.4 The 3rd stage of screening

The third stage of screening involved full paper review. This stage of screening identified and clarified papers presenting empirical research papers on *systems* of chronic disease management and integrated care management. These two areas of the wider literature of person-centred care were not synthesised into the final research paper analysis and were excluded also. These papers focused on the systematic delivery of person-centred care in two separate ways:

- How the *systems* of chronic disease management delivery within the primary care setting may improve the person-centred delivery of chronic disease management. These papers did not inform on GPs' direct influence or individual delivery of person-centred care.
- Integrated care or co-ordination of care across primary and secondary care. Arguably, co-ordination of care is vital to person-centred care, and presents a legitimate aim to improve person-centred care at systemic and institutional levels. However, the papers were presenting topics outside the boundaries of the thesis research interest and not towards individual GP person-centred (Hudon MD, MSc, CFPC *et al.*, 2011; Håkansson Eklund *et al.*, 2019).

The papers excluded at this stage can be seen on the Mindview map (Figure 1) recording a pictorial presentation of the of the screened papers.

As shown in the figure, the papers focused on various aspects of primary care systematic delivery of person-centred care. Within the empirical work investigating ways of integrating patient care to improve PCC, some papers focused on collaborative care and how multidisciplinary teams may work together to deliver PCC across primary care or with secondary care. Others mentioned systematic delivery of goal setting for patient improved self-care or motivational methods such as patient activation.

In contrast, papers trying to understand delivery of PCC at the practice level, focused on:

- Factors that make GP practices person-centred such as changing healthcare systems, or using information technology (Woodcock *et al.*, 1999; Cramm and Nieboer, 2018; Walters *et al.*, 2012; van Berckelaer *et al.*, 2012; Bosworth *et al.*, 2017).

- Interventions that may add to the way care is delivered- such as care or treatment plans, or interventional care models for patients with complexity or co-morbidity (Coventry et al., 2011; van Vugt et al., 2016; Prueksaritanond S, 2004; Goetz et al., 2013; Williams et al., 2005).
- Care co-ordination within the practice (Weeks *et al.*, 2014)
- Papers attempting to evaluate or develop specific patient- related outcomes measures for understanding the effectiveness of person-centred care delivery by HCPs (Williams *et al.*, 2016; Murphy, Hollinghurst and Salisbury, 2018).
- One paper was excluded because the focus of the paper was solely on a specific aspect of consultations skills but did not address the person-centredness of the GPs in the process (Guassora et al., 2021). The paper referred to ‘agenda mapping’ during consultations, which is the identification and prioritisation of topic areas for discussion before committing to a direction for consultation to follow. The results demonstrate a specific practical skill of opening and closing of topic areas when consultations involving multimorbidity take place. The person-centredness of GPs or feedback of patients on the potential person-centeredness of the process is not a consideration. Showing the ability of GPs to include many conditions into one consultation may be considered a person-centred action but did not address how individual GPs or patients perceived the topics, their views of what to prioritise and principles of person-centeredness they incorporated in the process.
- Another paper was discussing doctors and patients’ disparate expectations of medical care, in that patients complained of a lack of attention to their sexual history (Pretorius, Mlambo and Couper, 2022). However, the authors focused on eliciting sexual history and values of doctor and patient are not addressed. The study looked at superficial concepts about PCC and missed opportunities to consider why doctors do not focus on patient agendas such as sexual history.

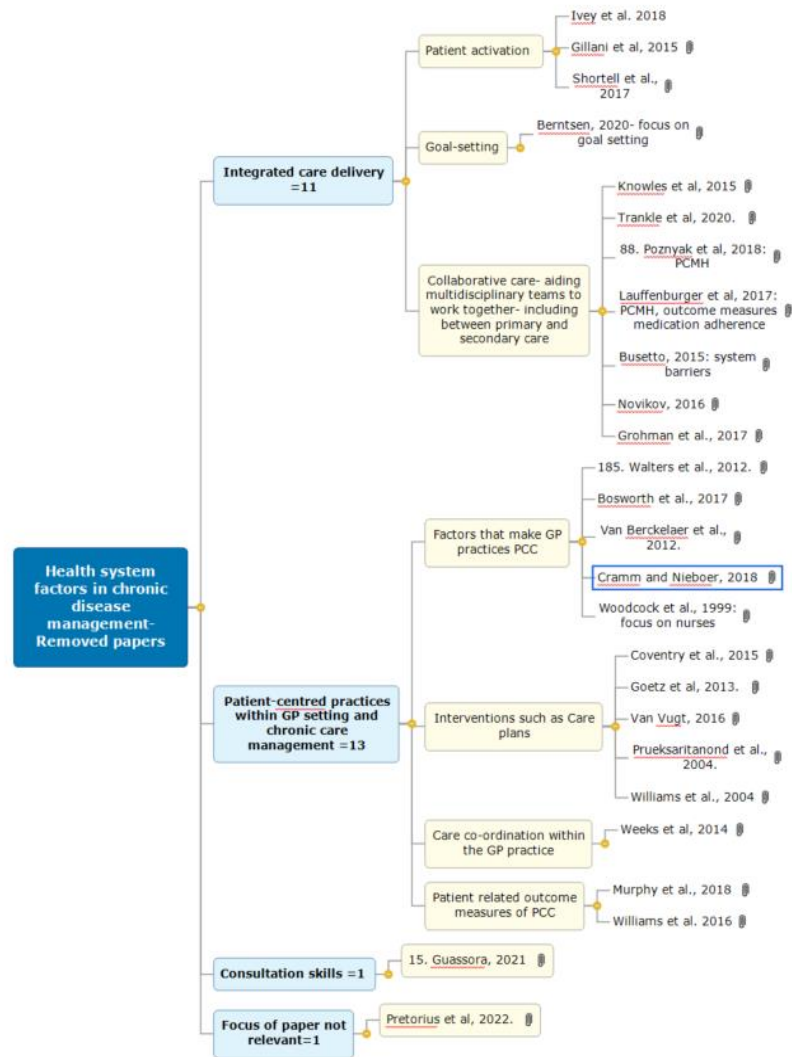


Diagram 2: Health system factors removed papers.

2.3.5 Description of the studies

The next subsection describes the final group of included papers. There was substantial heterogeneity in the group.

Forty-eight papers were included and originated from twenty-one countries, with a dominance in Western countries, notably the USA and the UK.

Table 6: The international papers included in the literature review.

| Europe | Middle East | South Asia | Africa | Americas | Oceania and Australia |
|---|---|---|--|--|---|
| <p>Denmark: 1 (Kristensen et al., 2018a)</p> <p>France: 1 (Sidorkiewicz et al., 2019)</p> <p>Germany: 1 (Wollny et al., 2021)</p> <p>Netherlands: 3 (Luijks et al., 2012; Rutten et al., 2018; van Vugt et al., 2020)</p> <p>Norway: 1 (Fagerli et al., 2005)</p> <p>Poland: 1 (Kurpas et al., 2013)</p> <p>United Kingdom: 8 (Kinmonth, Spiegel and</p> | <p>Israel: 1 (Tamir et al., 2018)</p> <p>Oman: 1 (Abdulhadi et al., 2007)</p> <p>Saudi Arabia: 1 (AlRuthia et al., 2020)</p> | <p>Indonesia: 1 (Claramita et al., 2020)</p> <p>Malaysia: 1 (Lee, Ng (Mathew et al., 2022)</p> <p>apore: 1 (Mathew et al., 2022)</p> <p>Taiwan: 1 (Lee and Lin, 2011)</p> | <p>South Africa: 2 (Haque et al., 2005; Ngassa Piotie et al., 2021)</p> | <p>United States of America (USA): 14 (Bartz and Francisco, 1999; Helseth et al., 1999; Swenson et al., 2008; Christensen et al., 2010; Hojat et al., 2011; Green, Rothman and Cavanaugh, 2012; Ratanawongsa et al., 2012; Kutob et al., 2013; Trachtenberg et al., 2014; Ali et al., 2016; McCreedy et al., 2018; Chaitoff et al., 2019; Roper et al., 2019)</p> <p>Canada: 2</p> | <p>Australia: 4 (Lawn et al., 2007; Wiley et al., 2014, 2015; Burridge et al., 2017)</p> <p>New Zealand: 2 (J. Young et al., 2017; Millar et al., 2018)</p> |

| | | | | | |
|--|--|--|--|---|--|
| <p>Woodcock, 1996; Ann Louise Kinmonth et al., 1998; Cocksedge et al., 2011; Williams, Steven and Sullivan, 2011; Griffiths et al., 2014; A Zafar et al., 2015; Methley et al., 2017; Murdoch et al., 2020).</p> | | | | <p>(Russell <i>et al.</i>, 2008; Houle <i>et al.</i>, 2012) Barbados: 1 (Adams and Carter, 2011) Brazil: 1 (de Figueiredo, Snoek and Barreto, 2013)</p> | |
|--|--|--|--|---|--|

Seventeen were qualitative studies, two were randomised control trials, (RCTs), six were quantitative non-randomised trials (e.g., cohort study, case-control, cross-sectional analytic study), seventeen had surveys and seven were mixed methods. The high number of the qualitative papers highlights the subjective and contextual nature of the topic, with the need to employ qualitative methods to research the field of person-centred care in the primary care setting. The equally high number of surveys indicates that there are known concepts in the field of person-centredness in chronic disease management, and this group of papers sought patient and providers views on these factors, such as barriers to care.

The two cluster RCTs were European, and both looked at an education intervention to improve the person-centredness of clinicians in the care of patients with T2DM. These are described in the next paragraphs, and after that, a description of the research designs amongst the mixed methods papers. The other papers will be described, with their limitations, as part of the thesis argumentation for PCC descriptive themes within subsection 2.3.6.

Kinmonth et al. used a pragmatic parallel group design with 250 patients with T2DM and randomisation into intervention (1.5 days group training of GPs and nurses) versus routine care (Kinmonth, Spiegel and Woodcock, 1996) over a 12 month period.

The baseline variables were similar for both intervention and control groups, and the practitioners were not aware of the hypothesis and so, blinded to the intervention. However, the data also relied on self-reported effects of diet and exercise and may suggest knowledge of patients, but not actual behaviours.

The intervention was a short (one and a half day for nurses and half a day for GPs, and two further half day follow up sessions) with training on a biological and psychosocial based communication style. There was a mixture of patient education and GP/nurse skills development in delivering patient education and patient centred consulting, and motivating patients to engage in discussion about complications or concerns through active listening and negotiation of behaviour change. Patients reported improved communication with doctors and greater treatment satisfaction, but body mass index (BMI) and triglyceride levels were higher. The results seemed to indicate improved HbA1c levels in the intervention group, but the results were under powered in the number of patients to achieve significance. Despite a patient centred intervention, and improved patient satisfaction, the negative biomedical measures indicate the intervention had no actual biomedical effect. The authors concluded that clinicians should be mindful and continue to aim for biomedical outcomes whilst trying to achieve PCC.

In contrast, Wollny et al. Performed a longer 24 month follow up of 833 patients with poorly controlled T2DM, and 108 GPs in a cluster RCT. The research assessed shared decision making (using the SDM Q-9 scale) and patient-centredness using the patient assessment of chronic illness care instrument (PACIC-D scale) (Wollny *et al.*, 2021). There were low levels of patient loss to follow up and positive attempts to reduce bias such as standardised interviewer training.

Study participants were not blinded, but patients and the study researchers collecting data were not aware of group allocation, but the subjective assessment of SDM and the possible inclusion of motivated GPs may have created bias. However, these limitations do not explain the negative outcome of no significant difference in patient reported PCC and the subjective measures of SDM, moreover, patients felt less involved in SDM over the research timeline. The Wollny et al. research presents greater internal validity than Kinmonth et al., but also found education of clinicians in PCC did not improve SDM or PCC (Wollny *et al.*, 2021). However, biomedical measures may be argued to be less relevant than patient satisfaction with care, and further investigation and qualitative understanding of PCC may be required.

The mixed studies were a combination of qualitative design with another method in the main, as shown in table 6. There were eight papers showing mixed methods research designs. These papers integrated a qualitative and quantitative phase within the process of the research.

Table 7: Mixed methods papers and the associated combination of research methods.

| Mixed Method paper | Aim | Design | | |
|---|---|---|---|---|
| 143. Wiley et al, 2015 (Wiley <i>et al.</i> , 2015). Australia | Whether T1DM patients engage with the MDT management processes and why. | Mixed sequential explanatory design. Cross-sectional survey and qualitative focus group interviews; MMAT 5.1 to 5.5, 1.1 to 1.5 and the CASP qualitative study checklist; survey 4.1 to 4.4. | | |
| 175. Trachtenberg et al., 2014 (Trachtenberg <i>et al.</i> , 2014) USA | To examine physician decision-making behaviours for patients with T2DM, including for those with mental health comorbidities. | Mixed methods sequential exploratory design: Qual, Quan; MMAT; 5.1 to 5.5; 1.1 to 1.5, and CASP Qualitative Appraisal checkl(Wiley <i>et al.</i> , 2014)t al, 2014 (Wiley <i>et al.</i> , 2014). Australia | T1DM patients' perceptions of the SDM delivery of different clinician groups. | Cross-sectional survey and qualitative focus group interviews. MMAT mixed sequential explanatory design. 5.1 to 5.5, 1.1 to 1.5 and the CASP qualitative study checklist; |

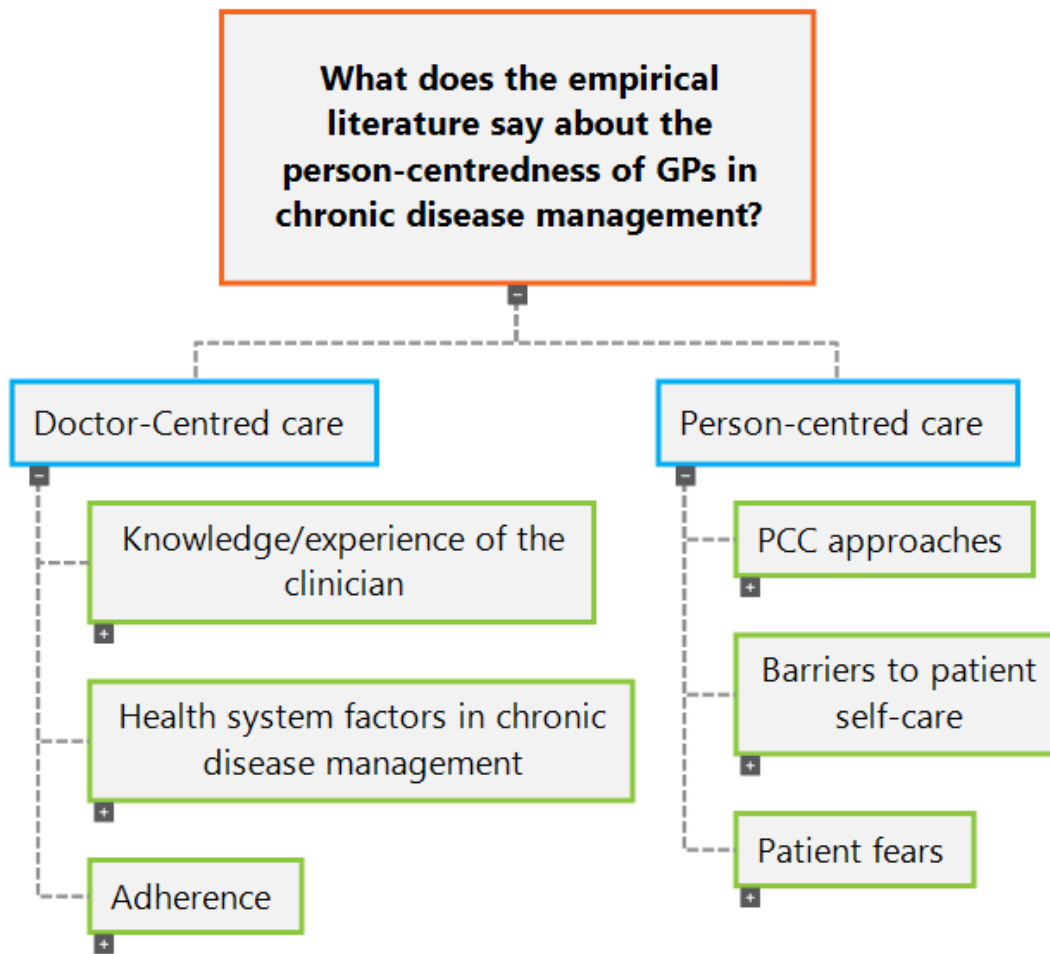
| | | | |
|--|--|---|--------------------|
| | | | survey 4.1 to 4.4. |
| 217. Lawn et al., 2007 (Lawn <i>et al.</i> , 2007). Australia | The feasibility and utility of the Flinders model: a partnership model of care between GPs, mental health case managers, and patients for people with significant mental illness. | Mixed method: sequential explanatory design: Quantitative non-randomised cohort study, MMAT 3.1 to 3.5 and qualitative evaluation: MMAT 1.1 to 1.5. | |
| 239. Kinmonth et al., 1996 (Kinmonth, Spiegel and Woodcock, 1996). UK | Aiming to develop a training programme on patient centred consulting for GPs and nurses through action research methods. | Mixed methods sequential explanatory design: qualitative Action research, and later survey. MMAT 5.1 to 5.5 | |
| 40. Claramita et al, 2020 (Claramita <i>et al.</i> , 2020) Indonesia | Doctors' perceptions through self-assessment and patient perceptions of experiences of a PCC method of partnership-orientated communication- testing the 'Greet-Invite-Discuss' guideline. | Mixed methods 5.1 to 5.5 sequential explanatory: cohort study survey 3.1 to 3.5, later qualitative focus group interviews MMAT 1.1 to 1.5. | |
| 50. Roper, 2019 (Roper <i>et al.</i> , 2019) USA | Patient and clinician perceptions of pre-diabetes care: including attitudes to the national diabetes prevention programme (NDPP). | MMAT convergent mixed methods: 5.1 to 5.5; 4.1 to 4.5 (survey), CEBM survey checklist, and the CASP qualitative study checklist. | |

2.3.6 The descriptive themes in the literature.

The main descriptive themes divide into two discernible areas: the doctor-centred and the person-centred (Map 2 below). The doctor-centred themes in the papers investigated knowledge, skills or experience of the clinician, the health system factors influencing clinicians' PCC in chronic disease management (CDM) and the ways clinicians or researchers viewed patient adherence in care. Adherence was framed in this research as a biomedical, disease-centred or doctor-centred perspective and accepts the Janes and Titchener view that adherence is not a person-centred concept, and within the concept of adherence clinicians lack of understanding of patients person-centred needs and the doctor-centred conception of adherence is a barrier to the person-centred relationship (Janes et al., 2013).

The person-centred themes were barriers to self-care, patient fears, and the person-centred care approaches identified in the empirical research. Each group will be explained in turn.

Map 2: the descriptive themes within the literature on PCC of chronic disease management in primary care.



2.3.7 Doctor Centred

Doctor-centred care describes significant semantic themes amongst the papers describing doctor centred knowledge, skills attitudes and behaviours that were reported by the empirical research. Doctor-centred themes involved evidence of lack of knowledge and experience in biomedical care, communications skills, and care of diverse populations, and are relevant to core medical skills necessary for patient care (Board and Education, 2013; GMC, 2013b).

This section will explain these subthemes before the patient related barriers are explained in section 2.3.8.

2.3.7.1 Knowledge and experience of the clinician

Clinicians' knowledge and skills of PCC when delivering healthcare were evidenced as semantic themes in the literature in few papers. Semantic themes in reflexive thematic methods are expressed explicitly and present overtly meaningful data (Braun and Clarke, 2022; Braun, Clarke and Hayfield, 2022). The papers studied the topics of cultural diversity, communication skills, patients' satisfaction in their HCPs clinical competence, lack of knowledge in the area of insulin initiation and GPs' knowledge of multiple sclerosis (Kinmonth, Spiegel and Woodcock, 1996; Bartz and Francisco, 1999; Fagerli et al., 2005; Haque et al., 2005; Abdulhadi et al., 2007; Kutob et al., 2013; Ali et al., 2016).

Research explicitly aimed at considering cultural diversity in PCC was infrequent amongst the literature. Two papers identified were underpowered to generalise the outcomes data but remain included because they indicated a ke(Kutob *et al.*, 2013; Ali *et al.*, 2016) et al., 2013; Ali et al., 2016).

The papers aimed to understand clinicians' practices and knowledge of culturally diverse patient care. Ali et al. investigated clinician practices and knowledge of diabetic patient care during Ramadan (Ali *et al.*, 2016). Although this was a pilot study with small numbers of participant HCPs which limits generalisation, the data displayed arguably valuable information in an under researched area of diabetic care. The self-reported data indicated clinicians' lack of knowledge of fasting practises and many clinicians admitted discomfort when managing patients with diabetes during Ramadan. More research is needed to understand the context of this discomfort, as well as whether other factors, such as attitudes toward diversity management in healthcare, are involved.

Kutob et al. assessed the impact of a cultural competence training course and outcomes were measured using a self-reported assessment tool (Kutob *et al.*, 2013). This was a quantitative randomised case-control study which also had small numbers of physicians recruited in an urban USA city clinic. The model aimed to increase the skills of clinicians in four areas: non-judgemental enquiry of patients views of the cause of disease and treatment, sharing biomedical opinion, comparing patients' and providers views, and n(Kutob *et al.*, 2013)tment plan (Kutob *et al.*, 2013). Although the paper showed no significant differences in the self-reported cultural

competence score, and so a negative outcome, the results conflicted with previous research by the same group, which did show positive change. The exposure to diverse cases in the course, as well as the encouragement of participatory decision-making, may have caused participants to reflect on and question their own cultural identity, which the authors suggest, may have reduced their confidence in assessing a patient's cultural views (Kutob *et al.*, 2013). To highlight this point further, cultural barriers were implicit in the complaints and challenges felt by Norwegian clinicians when they found Pakistani patients to be more passively accepting and less autonomous in behaviour than expected and is explored further in the 2.3.9.3 (Fagerli *et al.*, 2005). In comparison, in Oman, the clinicians' culture had no impact on patient satisfaction with care. These studies suggest the cultural dominance of clinicians from American and Norway in above-mentioned studies may have been a factor in cultural barriers or communication issues identified (Abdulhadi *et al.*, 2007) but the contrasting patient views may need further investigation.

Bartz *et al.* performed a case study of a GP working with a native American population and is described in detailed in section 2.3.9.2 describing how 'trust' presented in the literature. The population was bilingual, and language was no barrier, yet the mistrust that resulted was not identified to be associated between cultural value differences between the Caucasian white doctor and her native American population. The analysis indicated one barrier to the trust and relationship between patient and provider was her biopsychosocial approach to the illness and failure to use a more collaborative. This paper provides evidence of the "*physician culture*" of the doctor (Bartz and Francisco, 1999). This tension between the doctor's biomedical focus and the patient's own agendas towards PCC infrequently mentioned explicitly.

This literature search was not designed to specifically include diversity as a search term and may be a limitation of this literature review. However, the papers on diversity experience of patient and clinicians skills and awareness of caring for diverse populations indicates a gap in the larger body of knowledge.

Abdulhadi *et al.* interviewed patients to understand their view of clinician communication skills and clinical competence during their care, and through subjective feedback from patients provided a positive perspective of clinicians' skills that may be related to trust building and patient relationships indirectly (Abdulhadi *et al.*, 2007). In qualitative research from the UK, GPs admitted a lack of knowledge of multiple sclerosis treatment options and managing their

care in restricted appointment times was a barrier to care. Furthermore, training was also disregarded by GPs who felt they could not prioritise the small numbers of MS patients on their practice list over other chronic diseases, such as diabetes and hypertension which were also linked to the Quality and Outcomes Framework (QOF), which is a type of pay-for-performance system (Methley *et al.*, 2017). The qualitative evidence reported by Methley *et al.* contrasts the knowledge from a RCT developed to understand the impact of patient-centred training. In contrast, Kinmonth *et al.* focused on developing a training course on patient centred consulting for GPs and nurses and found no impact on disease measured outcomes one year later (Kinmonth, Spiegel and Woodcock, 1996; Ann Louise Kinmonth *et al.*, 1998). The implication from these three papers was that clinician training in PCC may be valued by patients, but there may not be an impact on biomedical outcomes. However, even then, GP themselves may not value skills in managing complicated conditions if they infrequently encountered the condition or had no incentives from pay-for-performance health systems.

In another area of clinician skills, Haque *et al.* investigated clinician barriers to insulin initiation and found lack of knowledge and experience of insulin initiation in T2DM were identified amongst other barriers relating to doctors, patients, and systems (Haque *et al.*, 2005; A Zafar *et al.*, 2015).

In the UK the lack of expertise and ability to escalate oral and insulin therapy in diabetes management was identified by primary care leads in diabetes and attributed to the transfer of T2DM care from GPs to nurses. Zafar *et al.* explored clinical inertia and barriers to medication escalation in T2DM from the perspective of primary care prescribers and found a lack of awareness of the concept of clinical inertia. Additionally, the clinicians also had a subjective understanding of their QOF target achievement and low QOF achieving was described as ‘fair’. This discrepant understanding of the meaning of QOF target achievement between the researchers and participants may indicate that clinicians do not value QOF as a measure of quality, despite taking partial responsibility (explained in 2.3.7.2) for clinical inertia and some expression of “*room for improvement*” (A Zafar *et al.*, 2015).

Haque *et al.* report clinician lack of knowledge and experience of T2DM management or insulin initiation in the primary care setting, and the benefits of insulin for poorly controlled T2DM patients. Together with observations of patients’ socio-economic disadvantage, and

system barriers (section 2.3.8.1), the South African research indicated clinician views of patients and their observations may influence them when individualising decisions to offer or delay insulin in T2DM and how they address this individualisation in person-centred ways remains unclear.

In summary, clinician knowledge of PCC may be considered in terms of having skills and knowledge and lack of knowledge of biomedical care, and their observations of patients may influence their personalisation of care when escalating therapy. Additionally, even if patients may express appreciation of clinicians' knowledge and skills through patient satisfaction, evidence shows no impact on measurable biomedical outcomes. Moreover, clinicians themselves may not value clinical knowledge about certain diseases if they infrequently encountered them. A lack of value in knowledge in some areas of healthcare may be compounded by a lack of self-awareness in their role in providing a quality of care. In terms of diversity care, lack of knowledge and skills in the care and understanding of diverse populations appeared an under researched area in relation to PCC. Research and understanding of primary care clinicians' subjective and contextual views and roles in delivering healthcare may reveal further understanding of clinician perspectives beyond the measured outcomes patient satisfaction in care.

The next subsection describes the health system themes influencing chronic disease management decisions by HCPs in the papers.

2.3.7.2 Health system factors in Chronic Disease Management

As previously mentioned, patients from low-income countries may face their own financial restrictions impacting on access to healthcare, such as travel, of cost of therapy, but systemic factors may multiply their inability to improve their health. Medical officers (MO) in South Africa reported short appointments (three minutes in illustrative quotes), lack of continuity with an MO, excessive workloads, inadequate insulin supply, lack of dietician support, inability to test appropriately i.e. HbA1c and high staff turnover (Haque *et al.*, 2005). These healthcare system hurdles remained an issue in South Africa almost two decades later, according to another survey of primary care nurses and MOs (Ngassa Piotie *et al.*, 2021).

As previously discussed, cost of healthcare was also an issue for patients in other more affluent countries. Canadian doctors and patients fed back on the systematic lack of resources to support the Chronic Illness Management (CICM) plan that comprised of three aims: systematic management, patient involvement in care planning and a holistic approach (Russell *et al.*, 2008). Similarly, in New Zealand, cost became a barrier to patients seeking healthcare from their GPs and out-of-hours (OOH) provider, suggesting that how funding of primary care is delivered may present a direct barrier to patients in healthcare systems across the world (Millar *et al.*, 2018). However, the contrast between the South African, New Zealand and Canadian systems appears stark and highlights the inability of the South African MOs to contemplate PCC in addition to escalation of therapy when health resources were fundamentally deficient.

However, in affluent countries, plans to systematically deliver chronic disease management in PCC ways across populations could be perceived negatively by clinicians. The CICM was a Canadian systematic approach to patient-centred chronic care delivery in the primary care setting with aims to review medications, education and self-care, psychosocial issues, community integration and social support, and prevention, and each care plan was compensated with \$300 (Russell *et al.*, 2008). The purposive sample was from small practices in Ontario already involved in research so, may have been overrepresented by enthused family physicians (FPs) which reduces transferability of the findings. The FPs also nominated patients with possible bias toward patients with positive experiences. Despite these limitations, many clinicians were unenthusiastic and dismissive of the CICM, finding it difficult to implement in current systems, believed it was not their role to deliver it, that their patients were incapable of engaging with it, and even felt financial support was insufficient (Russell *et al.*, 2008). Very few patients noted improved community support or self-management skills, and though all appreciated the extra appointment time, some commented on the cost or time-effectiveness of this for doctors. However, enthusiastic FPs of the model appreciated the CICM aim to move from a more traditional reactive family practitioner behaviour to a responsive and proactive model of chronic care management. Importantly, the ongoing implementation of the CICM was unlikely to be successful. Despite the enthusiasts' positive appreciation, the individual FP barriers, and lack of systemwide support for its implementation made the CICM unlikely to succeed in primary care in the long term. The authors called for practitioner attitudinal change

towards collaborative healthcare and seeing patients “*as their own primary care giver*” (Russell *et al.*, 2008).

This research highlights the clinician attitudes and professional oppositions at a cultural and systematic level were factors within the complex problem of implementing person centred care into general practise. Understanding these attitudes may allow support and training to family doctors as they adjust to a more collaborative role involving patient responsibility for their own care.

Clinician responsibility and self-awareness in care or healthcare outcomes seems infrequently investigated in the identified papers. When trying to understand the contextual nature of clinician views on the barriers to escalation in chronic disease management, Zafar *et al.* investigated T2DM lead clinici(A Zafar *et al.*, 2015) inertia (A Zafar *et al.*, 2015). Qualitative research to understand the depth and contextual nature of the issues involved are insufficient, but one qualitative empirical research by Zafar *et al* investigated GP perceptions of this therapeutic inertia (A Zafar *et al.*, 2015). They found interviewees acknowledged a degree of responsibility for therapeutic inertia, whilst linking their explanations for their involvement with the complex interaction between the perceived patient and organisational system barriers. The researchers interpreted the GPs’ perceptions of patient barriers, such as failure to attend appointments, as a sign of the GP transferring the responsibility for therapeutic inertia to patients (A Zafar *et al.*, 2015).

The group purposively sampled both high QOF performing and low QOF with the aim of seeking varied clinician sample, but some participants lack knowledge of the concept of clinical inertia varied and their definitions of high and low QOF scoring appeared subjective compared to the criteria-led view of the researchers’ used of QOF to indicate the effectiveness of T2DM care at their respective practices. The clinicians acknowledged the “*room for improvement*”, and the data indicated the clinician willingness to take responsibility for clinical inertia. However, they also deflected responsibility for inertia to blame barriers of patients, organisations, and diabetes itself. They offered external explanations such as low SED, communication barriers, polypharmacy, the nature of diabetes, time and workload pressures, and conflicting demands of GP work(A Zafar *et al.*, 2015). GPs were found to have difficulty reconciling the conflict between delivering person-centred care whilst maintaining a chronic

disease management approach based on guidelines. Understanding individual GPs beyond this conflict and their lack of engagement in person-centred care requires further research.

From the T1DM patient perspective in Australian healthcare systems, identified barriers were time constraints, conflicting advice from HCPs, inaccessibility of services, variety of standard services, cost of attending, failure of clinicians to refer appropriately, lack of therapeutic relationships with clinicians, and failure of clinicians to engage in SDM (Wiley *et al.*, 2015). The authors also questioned if the funding processes of diabetes programmes disincentivised GPs to refer patients to allied healthcare professionals and required more research. Like the Canadian research above, the research indicates a further need to understand how family physicians engage with systems to deliver PCC.

More positive research on PCC consultation model delivery has been reported in the Netherlands. Physicians and nurses rated the model as applicable, most physicians' consultation time was less than 25 minutes, and most patients reported feeling more involved in decisions and more satisfied with consultations. Patients reported that they were informed of treatment options and the pros and cons in 86% of consultations, involved in goal setting in 94.5% (Rutten *et al.*, 2018). These positive views were in an affluent country, with markedly more resourced consultations compared to the previously mentioned African studies. However, there was also less dissenting practitioner opinion of the systematic barriers compared to Canadian data, indicating a more PCC accepting primary care culture in the Netherlands within adequately resourced systems.

In summary, the healthcare systems across the world varied in the resources for chronic disease management, which impacted on individual person-centred care by clinicians. Sharp differences in inequalities between South Africa, Europe, and North America show the importance of meeting individuals' basic healthcare needs in terms of access, medicine, and self-care abilities. However, even in affluent countries, practitioners could be negative about efforts to deliver person-centred chronic disease management within healthcare systems because of perceived lack of time, staff and funding.

2.3.7.3 Adherence

Adherence is a biomedically framed concept described in several papers, As previously identified by Janes and Titchener, adherence relates the clinicians' perception of patient compliance with medication and lifestyle advice (Janes *et al.*, 2013; Janes and Titchener, 2014).

Positively, patient-centred internal medicine and family doctors may acknowledge how diabetes affects the patients' lives beyond biomedical aspects of medication, diet and exercise, showing person-centred awareness (Helseth *et al.*, 1999). However, negative attitudes to patient adherence were reflected in biomedical management advice in terms of healthcare goals that ranged at one end to ideal management to more 'realistic' goals (Helseth *et al.*, 1999). Patients were viewed as being in denial at one end, to accepting and motivated at another. Even if clinicians identify biomedical aspects of patient self-care that they may influence such as diet or medication, they felt ineffective in supporting patients in behavioural change if patients were viewed as not adherent to the recommendations they made.

Clinician negative perceptions of patient adherence can have a substantial impact on their decisions to escalate medication, and in the case of diabetes, clinician perceptions of patient adherence can be a barrier to insulin introduction. (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021). The clinician perspective may be justified because of understandable patient circumstances such as basic lack of resources to refrigerate insulin (Haque *et al.*, 2005).

However, when views of patient adherence to medication or therapy were compared in Brazilian survey of clinician-patient dyads, clinicians were found to underestimate patient adherence to all medications and self-care activities (de Figueiredo, Snoek and Barreto, 2013). The implication is a lack of understanding by clinicians with a potential to make poor person-centred care decisions. Similarly, when investigating the aspect of the patient provider relationship (PPR) that affected insulin related behaviours, in Singapore, fear of being judged for non-adherent behaviour negatively impacted the patient-provider relationship (Mathew *et al.*, 2022).

Moreover, a more positive agreement in patient engagement in therapy between physician and patient may lead to better healthcare outcomes. Christensen *et al.* found that when physicians

and patients had similar beliefs in the patients' level of personal control using the concept of 'health locus of control', patients had higher medication adherence and lower BP measurements than dyads where the patient had stronger beliefs than the physician (Christensen *et al.*, 2010). Adherence agreement between patient and clinician may reflect the importance of positive relationships between HCPs and patients.

Another mixed methods cohort intervention trial investigated a partnership orientated method of communication in Indonesia, doctors reported greater comprehension of patient-centred communication, whilst patients reported that doctors listened and responded more to their satisfaction (Claramita *et al.*, 2020). Patients self-reported better adherence outcomes in four areas: medication, physical exercise, diet and regular monitoring (self-monitoring was a requirement of the national insurance system) (Claramita *et al.*, 2020).

In conclusion, although adherence has been argued as biomedically framed and doctor-centred construct of patient engagement with medication and self-care, when positive relationships between patient and clinician may lead to better agreements on adherence and even improved measurable outcomes.

2.3.8 Person Centred

2.3.8.1 Barriers to patient self-care

Another group of papers investigated patient self-care and identified barriers to self-care. These barriers divided into those related to:

- Low socio-economic demographic (Haque *et al.*, 2005; Houle *et al.*, 2012; de Figueiredo, Snoek and Barreto, 2013; Kristensen *et al.*, 2018a; Rutten *et al.*, 2018; Ngassa Piotie *et al.*, 2021);
- Access to healthcare (e.g.(Adams and Carter, 2011; Wiley *et al.*, 2014, 2015; Methley *et al.*, 2017; Roper *et al.*, 2019);
- Cost of healthcare (Wiley *et al.*, 2014, 2015; Millar *et al.*, 2018);
- Mental health (Joos, Hickam and Borders, 1993; Lawn *et al.*, 2007; Swenson *et al.*, 2008; Green, Rothman and Cavanaugh, 2012; Luijks *et al.*, 2012; Ratanawongsa *et al.*,

2012; Griffiths *et al.*, 2014; Trachtenberg *et al.*, 2014; Sidorkiewicz *et al.*, 2019; AlRuthia *et al.*, 2020).

- Cultural diversity as discussed in section 2.3.7.1

These papers highlight PCC relevant barriers that may influence how PCC approaches are delivered.

Being from a **low socio-economic demographic (SED)** was negative influence on chronic disease management experience amongst the identified papers. When insulin initiation was being considered for people with T2DM, the medical officers (MOs) in a South African setting believed that low SED was a barrier and persisted between two similar studies investigating insulin initiation almost two decades apart. (Haque *et al.*, 2005; Ngassa Piotie *et al.*, 2021). Factors that were identified by the MOs and nurses were related to the poverty of South African patient population: low income and so unachievable cost of glucometers or medicines, irregular meals, inability to refrigerate insulin, no access to phones for emergencies or lack of transport. Barriers related to the elderly were an HCP's fear of an increased risk of hypoglycaemia, which was exacerbated by impaired vision, a lack of awareness of T2DM, and family support or escorts to appointments. (Haque *et al.*, 2005; Ngassa Piotie *et al.*, 2021). The former qualitative research by Haque *et al.* involved focus groups followed by individual semi structured interviews with MOs. Knowledge, beliefs, and fears are grouped together as constructs for doctors and separation may have made the physician attitudes clearer. There was little information of the researchers and the role or potential bias. However, the triangulation with focus group, one to one interviews and feedback to the participants added validity, though detail i(Haque *et al.*, 2005)k outcomes (Haque *et al.*, 2005). The later research by Ngassa Piotie *et al.* was a survey adapted from another credible source to all(Ngassa Piotie *et al.*, 2021)Os (Ngassa Piotie *et al.*, 2021). Even then, the process of inclusion and exclusion of the participant HCPs were not detailed to confidently know if there could be selection bias, and the sample was small so statistical power calculations were not possible or mentioned, and the results are not generalisable.

Despite methodological concerns of these studies, the data from two different regions in South Africa reinforce the HCP perceived patient self-care barriers to therapy escalation with insulin for a low-income population.

From the patient perspective, a Canadian cross-sectional survey of chronic disease management (CDM), patients of lower educational levels evaluated their chronic illness care as low, and reported less ‘talk’ during consultations, indicating they were experiencing lower levels of care than more educated populations (Houle *et al.*, 2012). This conclusion also assumes that low education levels is an indicator of low SED. In Brazil, de Figueiredo *et al.* found that patients of low SED were less likely to agree with their clinicians over their diabetic management, including the risk of diabetic related complications, and may indicate a lack of patient understanding of the biomedical illness, or lack of engagement of clinicians in PCC care in the subgroup of patients (de Figueiredo, Snoek and Barreto, 2013).

In Denmark, T2DM patients from low SED groups were found to prioritise self-care routines, to increase their well-being, over medical recommendations (Kristensen *et al.*, 2018a). In contrast, in the Netherlands, researchers looked at the delivery of PCC with the aid of a consultation model for T1DM and T2DM patients. Although patients overall felt more informed about treatment decisions, in 28% of cases, care providers felt the model was not suitable and excluded patients because of social complaints, and the authors argued that the model may have benefitted these patients as part of the (Rutten *et al.*, 2018) of health (Rutten *et al.*, 2018). However social issues may have been confounding factors for diabetes control and, the GPs and nurses may have required more training in the model for this subgroup, or the model was not adequate to meet the needs of patients from various socio-economic groups.

In summary, low SED is a factor in PCC that is associated with lower perceptions of healthcare by patients, a barrier to insulin escalation in T2DM, and may be associated with less agreement between patients and clinicians on healthcare priorities. Even attempts at PCC delivery through specially developed consultation models may fail. The implication is more research is needed into how HCPs can deliver PCC to people from low socio-economic groups.

In terms of **access to healthcare**, patients with different chronic illnesses experienced similar issues around wait times for clinicians and access to clinicians when unwell. However, the impact it had on patients varied between some conditions. Barriers to healthcare access may be as simple as scheduling and transportation to clinics such as the national diabetes prevention programme (NDPP) in the USA for pre-diabetes patients (Roper *et al.*, 2019). A New Zealand survey of patients living with multimorbidity found they had too much to deal with in the short

appointments and one third could not see a clinician within 24 hours of being unwell (Millar *et al.*, 2018).

In Barbados, patients living with T2DM and hypertension complained of systematic problems of excessive waiting times to see clinicians on the day of appointments, additional waits at the pharmacy, especially if there were medication shortages at public sector pharmacies (Adams and Carter, 2011). In Australia, T1DM patients complained of the lack of flexible access to clinicians to assist self-management, and welcomed electronic solutions such as emails. This mixed methods research recruited 80% females who were highly educated, indicating a socio-economic and gender bias that limits transferability of the findings (Wiley *et al.*, 2014, 2015). However, the findings of a UK study on multiple sclerosis patients (MS) supported this need for flexible access to specialist clinicians. Delays in and rearranged appointments for secondary care clinics were compounded by their lack of flexibility for MS patients who could suffer relapse quickly and with significant acute disability. Moreover, clinicians could vary in their interpretation of symptoms of MS patients to diagnose relapses, which were unpredictable and uncertain, and so, impacted on how promptly patients were referred to specialists.

Cost of healthcare was infrequently mentioned in the papers but may be a significant problem for patients in countries with payment processes for clinician appointments or therapy. In New Zealand, in the survey of patients' mentioned above, one fifth of patients with multimorbidity chose not to attend the GP or out of hours services due to cost of the appointments, even though when they did present one third felt they had too much to discuss for one appointment (Millar *et al.*, 2018). Similarly, Australian T1DM patients also felt the cost of attending endocrinologists' appointments was an additional barrier to their care (Wiley *et al.*, 2015). However, the cost of healthcare may impact significantly for low SED patients in low-income countries. As mentioned before, the specific issue of the lack of financial resources for South African patients was a barrier to insulin initiation with inability to afford glucometers, travel, or access to emergency care, despite the free healthcare appointments and medications (Haque *et al.*, 2005).

The **mental health barriers to self-care** identified in the papers were health care access, person-centeredness, self-care management and engagement. (Joos, Hickam and Borders,

1993; Lawn *et al.*, 2007; Swenson *et al.*, 2008; Green, Rothman and Cavanaugh, 2012; Luijks *et al.*, 2012; Ratanawongsa *et al.*, 2012; Griffiths *et al.*, 2014; Trachtenberg *et al.*, 2014; Sidorkiewicz *et al.*, 2019; AlRuthia *et al.*, 2020).

From the *patient perspective*, clinicians may fail to meet the social and emotional needs of patients during consultations. In Poland, patients living with chronic illnesses felt doctors were less interested in their psychosocial issues and health-related fears or concerns than in their biomedical illnesses (Kurpas *et al.*, 2013). Based on previously published surveys and validated through focus groups, this survey of 232 patients discovered a correlation between male gender and satisfaction with PCC aspects of primary healthcare, but the lack of information regarding women and their opinions of the quality of primary healthcare introduced gender-based bias in the findings. Similarly, this gender bias to male patients was intrinsic to the survey of veterans of unmet needs in a university-affiliated clinic in the USA (Joos, Hickam and Borders, 1993). The researchers also found clinicians lacked interest in patient social and emotional needs with resultant reduced patient satisfaction (Joos, Hickam and Borders, 1993). Information on female gender opinion of their unmet healthcare needs from primary care clinicians may further support the negative finding.

In contrast, in a study aimed at determining whether having more depressive symptoms were associated with less patient-centred communication in primary care diabetes clinics, researchers discovered that 20% of patients who had major depression, were more likely to be female, unmarried, non-white, and had higher HbA1c scores (Green, Rothman and Cavanaugh, 2012). There was no relationship between depressive symptoms, appointment duration, and communication characteristics of patient-clinician consultations in PCC. However, the doctor-centredness of consultations was significant, with most clinical encounters scoring poorly (less than 1) on the Rota Interaction Analysis System scoring for patient-centredness. The investigation was limited by a lack of clarity on recruitment sample and response rates. It also utilised the terms doctor-centeredness, disease-centeredness, and biomedical focus interchangeably, ignoring the potential confounding factors that contribute to doctor-, disease-, or biomedical-centeredness and will be revisited in section 2.5. However, this study was important and timely because diabetic patients have twice the risk of depression compared to the general population (Anderson RJ, Freedland KE, Clouse RE, 2001). At the time of the research, patients were not routinely evaluated for depression outside of the study protocol.

The authors highlight that this paper's finding contrasted with others that showed better patient-centred consultation scores (Bensing, Roter and Hulsman, 2003; Cooper *et al.*, 2003; Johnson *et al.*, 2004; Johnson, K.B. *et al.*, 2005). These latter papers researched different populations (paediatric primary care, internal medicine primary care visits, and hypertensive patients), whilst the multiple chronic conditions of the Green *et al.* research into a diabetic population may have driven the doctors' biomedical agenda and doctor/disease centredness (Green, Rothman and Cavanaugh, 2012). Nonetheless, it is possible that the mental health issues of the patient also added to the burden of chronic care and multimorbidity appointments and resulted in increased doctor-centredness or reliance on biomedical agendas.

In comparison, when diabetic patients in Denmark considered their own priorities in clinical encounters, they valued self-care routines to maintain mental health over the biomedical recommendations from clinicians (Kristensen *et al.*, 2018a). This patient-led disengagement from medical care may further exacerbate the distance placed between the doctor and patient in consultations with patients with multiple chronic conditions.

This disengagement may be compounded by a patient lack of trust in their clinicians. In Saudi Arabian research, diabetic patient trust in primary care professionals was quantitatively measured and compared with patient depression scores (AlRuthia *et al.*, 2020). Patients with significant mental health diagnoses were not included and the results apply to patients with mild or moderate depression or anxiety only. Patients' recall bias may reduce internal validity and Psycho-social issues or other medical/non-medical problems were not sought and may have been important confounding factors. Despite these limitations, the positive association between trust in the clinician and lower levels of depression and anxiety in diabetes indicate the value of the patient-clinician relationship in multimorbidity.

To understand the patient perspective differently, Griffiths *et al.* investigated the potential typologies presented by patients living with the chronic illness of diabetes and back pain. Two of these typologies aligned with depressed mood (Griffiths *et al.*, 2014). "*Stuck and struggling*" was defined by a sense of floundering and inability to move on, whilst "*submerged*" had a sense of overwhelm, feelings of loss and no expectation of change. The typologies were the result of semi-structured interviews and were limited by a lack of diversity in the patient participants, but this limitation may indicate further typologies may be developed

to understand patient multimorbidity conditions (Griffiths *et al.*, 2014). Significantly, the typologies provide a patient perspective to help clinicians understand patient mental health and emotional agendas in consultations including chronic disease or multimorbidity.

From the **clinician perspective**, a Dutch focus group exploration of GP perspectives of multimorbidity consultations found that co-existing mental health (MH) problems, cognitive impairment, anxiety over multimorbidity were all complicating factors and perceived as patient barriers to engagement (Luijks *et al.*, 2012).

To support this view, MH was a factor related to patients' inability to self-care and perceived by primary care professionals as a barrier to insulin initiation in the USA. This MH barrier was amongst other additional factors of psychological fear of insulin: fear of needles, insulin side effects, and disease progression (Ratanawongsa *et al.*, 2012). The cross-sectional survey approach used to interview GPs for this study was hampered by potential recollection bias, a small population size, and a lack of statistical power estimates. However, the research from the clinician perspective uncovered clinicians' unwillingness to prescribe insulin for patients they believed to lack the ability to self-care: 80% reported that patient non-adherence was a barrier to initiation (Ratanawongsa *et al.*, 2012). The implication is that clinician perception of patients' behaviour influenced their decision to offer therapy.

In another American study, physician decision making behaviours for patients living with T2DM and mental health comorbidities were different in patients with significant mental health diagnosis of schizophrenia. The researchers showed primary care physicians video vignettes of patients with uncontrolled T2DM and analysed discussions with them regarding their clinical management. Physicians ranked schizophrenia higher than diabetes when prioritising the conditions behaved as '*minimalists*' and performed fewer examinations and tests (Trachtenberg *et al.*, 2014). Although these doctors in the Trachtenberg *et al.* paper may be argued to be less patient-centred from the biomedical perspective, the Kristensen *et al.* findings indicate that patients may also prioritise their mental health over their biomedical diabetic care (Kristensen *et al.*, 2018a). Consequently, the 'mental-health-focused minimalist' style of patient management in T2DM may be patient-centred after all, but only if the patient is informed.

Clinicians' and patients' may prioritise chronic conditions differently from their differing perspectives and so, further support the idea that patients' mental health and emotional needs may be unmet. In a French cross-sectional survey of 153 patient-GP pairs, physicians and patients independently ranked the chronic illnesses impacting patients, as well as the GP and Patient health priorities. Depending on the disease reported, agreement varied widely, e.g high for hypothyroidism, and low for chronic anxiety. Twenty-nine percent of patients' top priority conditions did not appear on the corresponding GP lists. Significantly, there was a poor agreement between the GP rankings of chronic anxiety compared to patient rankings (Sidorkiewicz *et al.*, 2019), highlighting the low priority of MH conditions for GPs and the patients' unmet needs.

Cultural diversity knowledge and its presentation in the literature as a barrier to care was presented in this review from the doctor-centred perspective and is argued to represent a lack of knowledge. However, cultural diversity is mentioned under the theme of barriers to PCC as a person-related barrier, although it was infrequently mentioned in the papers. The design of the literature review search may have been the reason for this lack of representation, nonetheless, investigation of person-centred care of chronic disease patients from diverse populations may require further research,

In conclusion, patients' diagnosed MH needs add to the multimorbidity of chronic disease patients. Consequently, the patient reported unmet mental health needs of patients in chronic care and multimorbidity may be associated with increasing doctor- or disease- centred behaviours within the doctor-patient interactions. Patients' lack of trust in clinicians and patient prioritisation of their mental health over biomedical recommendations adds to patient disengaged behaviour in self-care and adds to the distance between the patient and doctor in chronic condition consultations.

GP perspectives of patients supports the concept that MH is a barrier to patient self-care, and specific clinician beliefs about patient self-care, such as lack of medication adherence, may influence them to refrain from therapy escalation. With significant mental health issues such as schizophrenia, clinicians become 'minimalists' that perform fewer examinations and tests, or in chronic anxiety, doctors may prioritise MH lower than patients do themselves. Additionally, in mild anxiety and depression, patients may prioritise their MH and feelings of

well-being over medical recommendations, and further exacerbate the distance between patient and clinician. However, ‘minimalists’ may also be viewed as more person-centred if patients also believe their MH *is* a priority over their biomedical needs.

The next section describes how patients’ fears are presented in the papers.

2.3.8.2 Patient fears

Patients’ fear fell into two types, the fear of blame and the fears specific to the disease or therapy. These fears were explicit themes amongst the literature and may have been associated with barriers to health.

Patient fear of disease was health deterioration, and specific to diabetes, the implication that insulin initiation meant disease deterioration, the associated psychological fears of insulin (PIR), specifically the fear of needles, and side effects of insulin: hypoglycaemia, weight increase and the rare risk of death (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021). Arguably, the fear of health deterioration may transfer to other chronic conditions such as chronic lung disease, kidney disease or cardiovascular disease. Notably, the first group of fears was biomedically connected and was described in two studies reflecting patient HCP views.

In contrast, from the patient perspective, the patient fear of blame was a distinct concept that related to patient provider relationships. Patients feared they were blamed for lack of adherence to medication, diet and lifestyle change to self-care and prevent their own disease deterioration. This fear of being judged by their HCP provider impacted on patient trust and the patient-provider relationship (Mathew *et al.*, 2022). The irony is that if physicians are expected to be person-centred, they must accept patient responsibility for their own treatment, and learn to understand and improve patients’ barriers in a collaborative way (Janes and Titchener, 2014). As previously explained in the section on barriers to self-care, doctors may make decisions to offer therapy based on their judgement of the patients capacity to manage the therapy and was most evident for socio-economically deprived groups or people living with MH diagnoses (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; de Figueiredo, Snoek and Barreto, 2013; Trachtenberg *et al.*, 2014; Ngassa Piotie *et al.*, 2021). External barriers to both the patient and the clinician may make such collaboration impossible in the poorest socially deprived groups

but may be achievable if PCC approaches are employed for patient and clinician-related barriers. The next section describes the PCC approaches identified in the empirical papers.

In summary, the descriptive themes in the person-centred empirical literature identified main themes of barriers to self-care, patient fears and the PCC approach themes, and cultural.

As seen in the sections on self-care amongst the low socio-economic demographic populations and systems factors, the healthcare received by patients is dependent on their individual resources and systematic delivery of care that patients can access healthcare. Barriers to PCC were evident across all healthcare systems and though significantly lacking in deprived countries, even affluent countries may have professional and systematic healthcare cultures not accepting of PCC delivery.

The impact of cultural diversity on PCC was infrequently explicit as a topic of investigation across the papers on PCC, but where it was apparent, it appeared to be associated with clinician lack of knowledge and patients' culture from a minority group.

As healthcare cultures evolve towards more person-centred care, patients' expectations of self-care, both from themselves and from HCPs, may need a recognised non-judgmental person-centred approach offered by HCPs and accepted as the standard by patients.

2.3.9 The PCC approach.

This section will describe the identified PCC-approach identified in the empirical papers.

Respect, trust, autonomy, empathy, and holism were significant PCC related themes that may be present throughout PCC approaches and are described early in this section. Later in the section, more specific constructs will be described that are related to PCC approaches: the patient-HCP relationship, involving patients in decisions.

2.3.9.1 Respect

Making **patients feel respected** was a theme pertinent to communication skills and creating relationships with patients. From the patient perspective, both positive and negative experiences could be described in papers and was important internationally (Ann Louise

Kinmonth *et al.*, 1998; Abdulhadi *et al.*, 2007; Adams and Carter, 2011; Lee and Lin, 2011; Kurpas *et al.*, 2013; J. Young *et al.*, 2017; Millar *et al.*, 2018). Respect was part of value ethics that supported patient-clinician relationships in some papers (Lee and Lin, 2011; J. Young *et al.*, 2017; Millar *et al.*, 2018).

However, in other papers, respect was a value that showed the doctor held the patient with sufficient regard and may impact trust. In focus group research with T2DM patients in Barbados, feeling encouraged and supported was part of respectful attitudes for some patients, but the lack of respect was associated with failure to consider the ‘whole person’, having a biomedical focus and negative attitudes experienced by patients that made them feel a sense of low esteem (Adams and Carter, 2011). Alternatively, a sense of kindness or willingness to help, and respect for the patients’ privacy indicated the HCP was holding the patient with a sense of esteem and was highlighted in a Polish survey of patients with chronic illness (Kurpas *et al.*, 2013). In a qualitative study from Oman, patient perceptions of medical encounters exemplified negative experiences of communication ranging from simple gestures of unfriendly welcoming and poor eye contact to lack of involvement of the patient in the medical dialogue or understanding patient concerns. There was contrasting opinion from less educated female patients who felt they had to stay quiet to be treated well, which contrasted with educated young female patients and male patients who believed asking questions and actively showing understanding would lead doctors to treat them better (Abdulhadi *et al.*, 2007).

2.3.9.2 Trust

Trust on the other hand was frequently mentioned across the papers and was a feature of both ethical values and a necessary part of patient-clinician interactional relationships. From the patient perspective, trust in the professional allowed patients to feel supported and was integral to patient provider relationships (Lee and Lin, 2011; Houle *et al.*, 2012; L. A. Young *et al.*, 2017; Kristensen *et al.*, 2018a; Mathew *et al.*, 2022). When clinicians described their experience of ‘holding’ relationships with patients, they stated that constancy and no expectation of a ‘cure’ required trust and respect as a foundation (Cocksedge *et al.*, 2011).

When trust was measured in varied quantitative studies, trust positively correlated with improved patient satisfaction and even biomedical outcomes. When Lee and Lin investigated

patient preferences for decision-making, trust was positively related to glycaemic control, physical health related quality of life (HRQoL), and satisfaction (Lee and Lin, 2011). The research was a one-year longitudinal study which recognises the inherent long-term nature of patient care in contrast to cross-sectional surveys and used a credible survey that deconstructed patient self-reported health. Patients with high preferences for autonomy in decision-making and high trust levels felt more confident that they were listened to and respected (Lee and Lin, 2011). Similarly, trust in HCPs when measured with the healthcare relationship scores were compared to depression and anxiety scores in a survey of 367 T2DM patients in Saudi Arabia, trust in primary care professionals was associated to lower levels of depression (AlRuthia *et al.*, 2020). Trust was also found to be neutral in its association in an American cross-sectional survey of T2Dm patients with depression. Swenson *et al.* found that despite a high prevalence of depressive symptoms (severe 35%, mild 31%, none 34%, diabetes patients with severe depression were more likely to report suboptimal clinician-patient communication. Significantly, depressive symptoms were not associated with trust (Swenson *et al.*, 2008).

A contrasting negative experience of trust was the result of a reflective case study with a doctor working with a low socio-economic demographic Native American population (Bartz and Francisco, 1999). After nine consultations had been audio-recorded and analysed using discourse analysis, Dr M reflected on the interviews and found she unexpectedly experienced bidirectional mistrust and misunderstanding with her patients. Dr M sensitively used patient-specific narratives to understand the patient illness experience. Moreover, the stories were the result of cumulative interactions with individual patients and other HCPs, signifying established continuity of care and illness narrative as identified in chapter 1 (Mead and Bower, 2000; Stewart, 2005; Entwistle and Watt, 2013a; Elwyn *et al.*, 2014; Britten *et al.*, 2017). Although her consultations showed evidence of partnership, The basic value differences between Dr M and her patients were problematic for her- believing patients did not value health as a priority. She was reframed to appear a less empathic and patient-centred doctor during the iterative process of the interactive ethnographic case study. The doctor tried to change the patient perspective of illness toward her own biopsychosocial understanding of disease. The lack of co-construction of illness narrative between patient and doctor in some consultations meant a less collaborative approach to patient care and so, resulted in a failure of person-centredness.

The paper provides valuable insight into the conflict between her biopsychosocial approach and her approach to change patients perspectives to adapt to her biomedical understanding of disease, resulting in an “*unabridged gap in communication*” between doctor and patients, and a lack of person-centredness (Bartz and Francisco, 1999).

2.3.9.3 Autonomy

Autonomy was infrequently mentioned explicitly across the empirical papers but was implicit to papers investigating person-centred shared decision-making.

Many papers described supporting patients to feel empowered in health care decisions, especially when shared decision making was being considered, and showed implicit acceptance of personhood and autonomy (Cocksedge *et al.*, 2011; Williams, Steven and Sullivan, 2011; BurrIDGE *et al.*, 2017; Lee, Ng and Low, 2017; Claramita *et al.*, 2020; Murdoch *et al.*, 2020). Some of these papers are detailed in further subsections in this chapter (2.3.9.6 and 2.3.9.7). This subsection will explain relevant papers displaying the autonomy concept.

As previously mentioned, Lee and Lin investigated patient preferences for autonomous decision making, and found positive correlations with trust, confidence and feeling respected (Lee and Lin, 2011). When Young *et al.* investigated the in-depth longitudinal knowledge between patients and providers to create an agreed vision of care (VoC), autonomy in decisions was amongst the values underpinning the patient-HCP relationship (J. Young *et al.*, 2017). Similarly, when Luijks *et al.* observed that GPs valued individualisation of treatment in multimorbidity management, autonomy was implicit in the GP positive attitudes towards shared responsibility for decisions between patients and providers (Luijks *et al.*, 2012).

A contrasting negative view of autonomy was presented by a cross-cultural qualitative study on Norwegian HCP beliefs about their encounters with patients of Pakistani origin when providing dietary guidance to T2DM patients. All the GPs recruited to the semi-structured interview were women, and limited transferability. However, the interview guide was loosely followed to allow the participants to freely express themselves and added to validity. An iterative process was followed with successive transcription and analysis of each interview, although the authors described an informal discussion with some of the participants regarding the findings that may not add to credibility. Notably, some HCPs expressed the opinion that patients wanted them to be more authoritarian and challenged their expressed beliefs in

autonomy. (Fagerli *et al.*, 2005). Yet, these negative observations concerning ethnic minority perspectives on autonomy might be the consequence of a bidirectional and cross-cultural lack of understanding or communication between Pakistani patients and Norwegian clinicians and indicate the need for more research.

2.3.9.4 Empathy

Empathy was another value-based concept that was mentioned in the empirical papers. Fagerli *et al.* found two fundamental values—**empathy** and equality—that led primary care physicians and dieticians in Norway to feel they were patient-centred based on their self-reported views (Fagerli *et al.*, 2005). Despite their self-beliefs, and a credible qualitative study, the person-centeredness of the HCPs remained unconfirmed by patient perspectives.

Two American quantitative non-randomised cohort studies performed similar research comparing physician empathy with patient satisfaction and measurable outcomes of HbA1c and LDL-cholesterol in diabetic patients (Hojat *et al.*, 2011; Chaitoff *et al.*, 2019). Hojat *et al.* had published research in 2011 showing a link between physician empathy and laboratory outcomes and used the Jefferson Scale of Empathy (JSE) which defines empathy as an understanding of the patient's experiences, concerns, and perspectives, with ability to communicate this understanding and intention to help (Hojat *et al.*, 2011). The limitations were the small sample of physicians (n=29) and patients (n=891), and multiple other confounding factors (culture, race, ethnicity, severity of disease). The setting was academic with bias towards possibly motivated GPs, and so overestimating the empathy scores (Hojat *et al.*, 2011).

On the other hand, Chaitoff *et al.* used the same credible quantitative empathy scale, and conceptually linked to measurable outcomes, which were measured over 3 years. It replicated an earlier study (Hojat *et al.*, 2011) with a larger cohort (4176 primary care patients) and diversity of patient population, adding validity, but found no relationship between physician empathy and patient clinical outcomes. The study's different setting and time may account for the likely unfavourable outcome for Chaitoff *et al.*, with increased CDM care, and systematic processes in the intervening years in the USA, potentially confounding results (Hojat *et al.*, 2011; Chaitoff *et al.*, 2019). As such, interventions to promote empathy may impact PCC, but clinical outcomes may not be improved.

2.3.9.5 Whole person care

Whole person care (WPC) or holism was another infrequent concept explicitly mentioned in the papers. In New Zealand, Young et al. found holism to be another common value amongst HCPs that allowed them to develop understanding and insight into their patients and create a shared vision of care (SVoC) (J. Young *et al.*, 2017). Although the term "holism" was used in the report, the meaning portrayed in the paper was the medical term akin to WPC, which emphasised whole-person care as an attitudinal approach for HCPs, rather than alternative therapies, as explained in chapter one.

In contrast, patient expectations for WPC and respect were unfulfilled for certain patients in the qualitative examination of barriers to T2DM and hypertension therapy in Barbados and indicated the clinicians' negative engagement with patients and lack of WPC (Adams and Carter, 2011).

Similarly, and as previously described in section 2.3.5, Canadian research to systematically deliver WPC in the form of chronic illness care management plans (CICM), found most family physicians retained a biomedical perspective and few were enthusiastic, with some explicit opinion that their patients were not capable of engaging with the plans, which implied paternalism (Russell *et al.*, 2008).

The person-centred concepts described in the early part of this section were part of the approaches to person-centred care evident in the empirical data. The next section describes identified approaches: delivering PCC and the patient-healthcare professional relationship,

2.3.9.6 Delivering PCC

This subsection will describe the approaches to delivering person centred care presented in the empirical papers. Two significant types of PCC approach were evident when researchers tried to investigate how to deliver person-centredness:

- Involving patients in decisions
- Agreement and /or collaboration between patient and provider

Consultation or communication factors may be argued to be part of delivering PCC were evident and are argued to be intrinsic to the doctor-centred knowledge and skills of PCC themes previously described (section 2.3.7.1). They are accepted as important to the delivery of PCC but are seen in this thesis as part of trained clinician communication skills and distinct from PCC approaches which are attitudinally relevant to the research question seeking the person-centredness of GPs in chronic disease management in primary care.

Involving patients in decisions

When attempting to understand the involvement of patients in decisions, the empirical research looked at strategies to improve participation and involvement of patients and providers with person-centred care. This section will first describe a survey designed to better understand the patient experience of healthcare decisions when living with multimorbidity (Millar *et al.*, 2018). Then, seven other papers will be discussed that investigated interventional strategies to promote practitioner person-centeredness and patient involvement in decision-making. Table 7 summarises the interventions.

Millar *et al.* in New Zealand performed a cross-sectional survey across two large primary care organisations to understand the healthcare experiences of patients living with multimorbidity (Millar *et al.*, 2018). The survey was based on existing questionnaires that were nationally relevant to New Zealand and considered topics of access, health literacy, social support, and finance. Highly positive outcomes were reported by patients: positive interactions with GPs (99%) and feeling involved in decision-making (98%). The majority also felt their GP knew their history 'quite' or 'very well' (96% CI 96,1-99.5). The study had a low response rate to invitation, and recruitment bias toward motivated patients. Similarly, non-responders may include individuals who were concerned that their GPs would see their response, causing the results to overestimate the population perception of their doctor. Less positive patient experiences and the associated barriers to involvement have been discussed for this and other papers in subsection 2.3.8.1 (Abdulhadi *et al.*, 2007; Russell *et al.*, 2008; Wiley *et al.*, 2014, 2015; Methley *et al.*, 2017; Millar *et al.*, 2018). According to Millar *et al.* GPs may have a high level of personal effectiveness in providing person-centeredness when compared to the systemic health system issues that patients complained about. However, it was unclear how the

individual practitioner person-centred care was delivered to warrant the positive patient feedback.

Lee et al. presented the VISIT tool which allowed patients to share concerns into a website tool prior to the appointment, and the interviews with doctors and patients were thematically analysed (Lee, Ng and Low, 2017). The recruited doctors worked at a university primary care clinic, where patients and doctors may be more academically and motivationally engaged. Since the tool required patients to be computer and internet literate, it had limited transferability to various population demographics, especially poorer socioeconomic groups, and the elderly. Positively, the VISIT tool allowed doctors to understand how illness impacted on patients' lives and so facilitated the GPs to prioritise the appointment to the person's needs, understand their narrative, and respecting the individual whilst working collaboratively. The tool's benefits included communicating the patient's full agenda, highlighting unmet needs, facilitating rapport, and assisting in the organisation of the consultation around the patient's concerns; however, it disrupted the doctor's usual consultation style, especially if the list of concerns was lengthy.

Similarly, the educational interventional delivered to GPs in a German study by Wollny et al. aimed at improving the GP PCC approach through improvement of the GP understanding of the patient's narrative and personal priorities and aiding the GPs to deliver SDM with a visual decision aid. First, a peer outreach trainer discussed difficult patient cases with participant GPs and explained narrative-based communication. The training focused on poorly controlled diabetes patients' needs and behaviours such as resignation. The second part involved learning about a visual patient decision aid for shared decision making when counselling patients about CVD risk and the benefit of medications (Wollny *et al.*, 2021). The research was a cluster RCT and its limitations were discussed in section 2.3.5. However, the educational intervention itself was based on qualitative data showing that GPs lower expectations for T2DM patients with poorly controlled T2DM. The educational intervention aimed at GPs led to no significant increase in patient reported patient-centeredness and subjective SDM. Moreover, patients felt less involved in SDM throughout the research (Wollny *et al.*, 2021).

The lack of impact of the intervention draws to question the premise that GPs lower their expectation of health for poorly controlled T2DM patients. How GPs perceive poorly

controlled T2DM patients, as an example of a chronic disease, may require further research. The following publications by Russell et al. and Murdoch et al. offer more insight into challenges faced by individual clinicians while attempting to provide PCC. (Russell *et al.*, 2008; Murdoch *et al.*, 2020).

Table 7: The empirical papers investigating interventional methods to improve patient involvement in decisions.

| Paper, year, country | Aim | Intervention |
|---|--|--|
| Wollny, 2021 (Wollny <i>et al.</i> , 2021). Germany | Whether an educational intervention increases PCC and SDM for patients with poorly controlled T2DM (HbA1c = 64mmol/l) | The steps of GP training: 1. Peer visit from a GPs training in patient centred communication; 2. GPs encouraged to use a patient SDM tool to understand the risk of CVD events and effects of treatment; 3. |
| Murdoch et al, 2020 (Murdoch <i>et al.</i> , 2020). UK | Goal setting for patients with multiple long-term conditions (LTC). | A brief 3 h training workshop using patient-centred approaches in established communication models (Kurtz, Silverman and Draper, 1998; Elwyn <i>et al.</i> , 2017). Patients completed a goal-setting questionnaire to set up 3 goals prior to the first GP appointment, wherein GPs supported the patients to achieve their goals. Control GPs continued with usual care. |
| Rutten et al. 2018 (Rutten <i>et al.</i> , 2018). Netherlands. | Patient and provider perspective of a consultation model to aid PCC. | Providers were trained in a consultation model consisting of 1. disease and patient related factors 2. goal setting, 3. treatment choice and, 4. determining a care plan |
| Lee et al. 2017 (Lee, Ng and Low, 2017). Malaysia | Identification of patient concerns prior to consultations (pre-consultation agenda) with doctors to address patient unmet needs during chronic disease interactional consultations | Patients reported their concerns into a website tool: Values in Shared Interactions Tool (VISIT), and doctors viewed the information before consultations. |
| Young et al, 2017 (J. Young <i>et al.</i> , 2017). New Zealand | Reframing of healthcare teams with the aim to improve shared care and SDM for patients. | Development of an in-depth knowledge of the patient over time allowed primary care professionals insight into the patient's vision of care (VoC), shared vision of care (SVoC) and the patient's own care network- 'community of clinical practice' (CoCP). |
| Russell et al., 2008 (Russell <i>et al.</i> , 2008). Canada | To qualitatively evaluate the impact of the chronic illness care management plan (CICM) on patients and family physicians: whether they understood principles of care planning and whether they implemented practice change. | CICM was perceived to have three components: systematic management, patient involvement in care planning, and the holistic approach. |
| Kinmonth et al. 1998 (Ann Louise) | The effect of additional training of GPs and practice nurses on patient satisfaction and measurable | The intervention (1.5 days group training of GPs and nurses) on lifestyle, physiology and psychology of newly diagnosed patients with T2DM. |

| | | |
|--|---|--|
| Kinmonth <i>et al.</i> , 1998). UK | biomedical markers (BMI, lipid levels and HbA1c. | |
|--|---|--|

Murdoch *et al.*, planned GP education and training on communication models, SDM and achievement of specific, measurable, attainable, realistic and time bound (SMART) goals (Murdoch *et al.*, 2020). The qualitative research then employed conversation analysis to analyse 22 video-recorded consultations between patients and doctors, and identified three interactional patterns: GP reframing, GP aligning to patients, patients' active and passive resistance to reframing.

According to the data interpretation, shared framing of the consultation led to GPs providing support, and the interactions demonstrated a power parity between GPs and patients. The authors argue that asymmetry became evident when GPs biomedically reframed the patient's issue and disregarded the patient's personal goals. There was associated evidence of patients shifting from passive to active resistance, and GPs retreating from a biomedical stance to re-imposing the authority as expert (Murdoch *et al.*, 2020). Notably, some GPs would satisfy the patient's goals based on it being acceptable within a biomedical context. Hence, the researchers interventional plan to improve GP skills in goal setting highlighted the tensions between the biomedical and PCC approaches to patient care.

Similarly, Russell *et al.* also found biomedical bias when physicians failed to engage with the chronic illness care management plan (CICM). The qualitative analysis identified practitioner perspectives to chronic disease management through a phenomenological approach (Russell *et al.*, 2008). The research focuses on the importance of personal attributes and perspectives of individuals involved in person centred care and separate to the larger system issues. Attitudes and professional cultural oppositions are identified as factors within the problem of implementing person centred care into general practise. Understanding the position attitude may allow support and training to them as they adjust to a more collaborative role involving patient responsibility for their own care.

This pattern of behaviour by clinicians is reinforced by the trial of a consultation model in the Netherlands by Rutten *et al.* (Rutten *et al.*, 2018). Most patients reported feeling more involved in decisions and more satisfied with consultations. However, as previously discussed in section

2.3.8, there was a large group of patients (28%) that care providers excluded for social or other complaints and again, implicating the biomedical bias of the clinicians.

A contrasting intervention delivering a shared vision of care (VoC) between clinician, the patient and the patient's community of carers and was described by the authors as "*an aspirational concept*" because it was so at odd with the current practice (J. Young *et al.*, 2017). This ethnographic study looked at nine patient cases and interviewed patients, people involved in their care and documented the care maps in patients' records. The significance of the VoC intervention was to go beyond the accepted shared care visions of practice which aim to improve co-ordination of care across the health sector.

Instead, the aim is seeing the patient at the centre, with their values and priorities driving the care plan, delivered by HCPs, carers and even the patient. For HCPs, the narrative knowledge of patients, their VoC appeared key to the success of the shared care model to succeed. Identified barriers to SVoC were organisational, e.g. lack of communication, or interactional between HCPs, paternalism of HCPs, and individual personality clashes. The VoC model of care includes the important aspects of the Gothenburg person-centred routines of care: partnership through the patient's narrative, SDM and documentation (Britten *et al.*, 2017; Ekman, Ebrahimi and Olaya Contreras, 2021). However, arguably, the VoC model may have lacked the pragmatism as offered by Stewart, if staffing, time barriers or resources are considered (Stewart, 2005).

Kinmonth *et al.*'s RCT interventional training for GPs and practise nurses resulted in positive patient reports of patient satisfaction, and better GP and nurse communication, thus, supporting the message to improve PCC. (Ann Louise Kinmonth *et al.*, 1998). There was a mixture of patient education and GP/nurse skills development in delivering patient education and patient centred consulting, and motivating patients to engage in discussion about complications or concerns through active listening and negotiation of behaviour change. The biomedical results showed significantly higher BMI and triglyceride levels. There seemed to be improved HbA1c levels in the intervention group, but the results were under powered, in number of patients to achieve significance. The lack of biomedical outcome may have been more significant with a longer-term cohort study, but the study indicates a potential impact on patient satisfaction when delivering an organised PCC training to GPs.

In conclusion, the various interventions to deliver PCC in general practice identified in the papers indicated positive patient reported outcomes that encourage further pursuit of PCC delivery, showing potential ways that PCC may be delivered in primary care. However, a negative message of HCP biomedical focus persisted, and doctors even resisted PCC approaches if they thought it compromised biomedical focus.

Agreement and collaboration

Following on from the section on involving patients in decisions, there was another theme of across the papers of agreement and collaboration trying achieved through person- centred interventions (Ann Louise Kinmonth *et al.*, 1998; Lawn *et al.*, 2007; Burridge *et al.*, 2017; Rutten *et al.*, 2018; Sidorkiewicz *et al.*, 2019; Claramita *et al.*, 2020; Murdoch *et al.*, 2020). Table 8 summarises the identified papers with evidence of agreement or collaboration objectives.

Kinmonth *et al.*, has been previously described, and led to positive patient feedback, but no improvement in biomedically measured outcomes. The interventional training involved 1.5 days group training of GPs and nurses in patient-centred consultation skills, active listening and motivating patients to engage in self-care and so, focused on creating a more collaborative and agreement focused patient care.

The Flinders model approach to creating a partnership between patients, their mental health workers and GPs employed problem and goal focused approach. Patients reported self-management improvements including understanding their illness, symptom control, SDM and collaboration at three to six months follow up. The positive outcomes reinforce the structured approach to chronic conditions self- management (Lawn *et al.*, 2007).

In comparison, an Indonesian intervention trained doctors in the guideline, “Greet-Invite-Discuss” guideline which was a partnership orientated communication technique which aimed to be equitable, allowed two-way dialogue and shared decisions (Claramita *et al.*, 2020). The doctors received individual feedback and then reflected on their consultations in groups afterwards. The mixed method cohort design of the intervention involved doctors’ self-assessment of and patient perceptions of the doctors’ communication skills (survey), and

biological outcomes 6 weeks later. Then, six focus groups were conducted. Doctors' self-assessments and patients' perceptions of doctors' communication increased. There were correlated improvements in patient BP and fasting blood glucose. Doctors reported greater comprehension of PCC communication, whilst patients reported that doctors listened and responded more to their satisfaction. Patients also self-reported better adherence in four areas: medication, physical exercise, diet and attending monitoring. The limitations involved a short follow up of six weeks, small numbers of participants from local populations to make the data less credible and transferable. However, compared to the Kinmonth *et al.* interventional training, the Indonesian research training had supportive individual feedback and learning from recorded consultations with real patients, and the qualitative data supports the doctors and patients positive experience of the effect of the training (Ann Louise Kinmonth *et al.*, 1998; Claramita *et al.*, 2020).

The consultation model to aid PCC investigated in a cohort non-randomised intervention trial in the Netherlands, trained providers in biomedical and patient related factors of chronic illness goal setting, sharing treatment options and determining care planning (Rutten *et al.*, 2018). As another method and model to deliver collaborative and shared care management with people living with chronic disease, this model also had positive feedback from patient reports as previously explained. An interesting outcome was the high proportion of patients who felt an increased involvement in treatment decisions after doctor consultations than nurses. This greater impact of the model on doctor consultations has remained unexplained, and the authors hypothesise that physicians are more overarching and less directed by patients in their usual practice, arguing that the model created a more significant shift in behaviour for doctors towards strategies to achieve mutual agreement in treatment goals.

(Rutten *et al.*, 2018).

The long-term viability of such interventions continues to be a challenge for chronic conditions care models, particularly the objective of embedding such methods into existing systems and structures that may resist change. However, the positive clinician and patient feedback amongst the discussed interventional studies imply that rigid organisational boundaries and cross-discipline professional variation regarding patient attitudes may change based on professional training and underlying beliefs.

Table 8: the interventional papers with agreement or collaboration.

| Paper, year, country | Agreement or collaborative objective |
|--|---|
| Sidorkiewicz et al. 2019 (Sidorkiewicz <i>et al.</i> , 2019). France | Agreement between patients and GPs on the chronic conditions affecting patients and 2. on health priorities. |
| Rutten et al, 2018 (Rutten <i>et al.</i> , 2018). Netherlands | A mutual agreement achieved on treatment options, goals-setting and pro/cons of treatment. |
| Cocksedge et al. 2011 (Cocksedge <i>et al.</i> , 2011). UK | The concept of ‘holding’ as an established and maintained constant between clinician and patient, with ongoing support and no expectation of cure. |
| Claramita et al, 2020 (Claramita <i>et al.</i> , 2020) Indonesia | Doctors were trained in a partnership orientated communication guideline “Greet-Invite-Discuss”, then an update on hypertension and T2DM; the doctors then received an individual feedback session on videotaped consultations with real patients followed by group learning reflection. |
| Lawn et al | The feasibility and utility of combining a clinician led and a peer led self-management group approach for people with significant mental illness: patients identified their self-management needs with the help of a partnership model of care between GPs, mental health case managers and patients (the Flinders model). |
| Rutten et al., 2018 (Rutten <i>et al.</i> , 2018). Netherlands | Providers were trained in a consultation model (consisting of 1. disease and patient related factors 2. goal setting, 3. treatment choice and, 4. determining a care plan). |

In conclusion, there were two overarching types of interventions that were investigated in the empirical papers for **delivering PCC: involving patients in decisions and collaboratively working to achieve agreements**. There was evidence of positive patient feedback and satisfaction data that is both qualitatively and quantitatively reported. No one particular intervention appeared more effective than others, but collaborative care planning was common interventional models to aid individuals in the delivery of PCC may struggle to integrate into resistant systems and structures. However, the positive clinician and patient feedback amongst the discussed interventional studies imply that clinician attitudes may change based on professional training, and underlying attitudes, beliefs and behaviours may remain barriers. However, there is still a lack of clarity as to what these barriers from clinicians to PCC interventions are beyond current financial and staff resource systems, a lack of belief in patient engagement and even exclusion of those not believed to engage, not identifying with the role to deliver PCC, and a disease-centred or biomedical focus.

2.3.9.7 The patient-healthcare professional relationship

The patient-HCP relationship was mentioned by several papers and represents a concept mentioned in chapter one. The interactional relationship between the patient and HCP had differing subcomponents depending on the approach taken in each empirical paper. For example, a more collaborative relationship with recognition of clinicians as persons in the Mead and Bower presentation compared to the capabilities approach (Mead N, 2000; Entwistle and Watt, 2013b). The relationship related papers provided empirical evidence of both positive and negative patient-provider relationships and are discussed in this section.

A qualitative analysis of patients' experiences with medical care shed light on Oman's chronic disease management system and primary care physicians' communications skills (Abdulhadi *et al.*, 2007). Negative experiences of communication ranged from simple gestures of unfriendly welcoming and poor eye contact to lack of involvement of the patient in the medical dialogue or understand patient concerns. Organisation of clinics, lack of patient health education and questions of professional competency in T2DM care were also raised. The cultural background of HCPs from other nationalities was not considered a barrier by patients.

These negative patient-provider experiences contrasted with other research from across the world and displayed the potential spectrum of PCC patient experience. For instance, from the perspective of GPs in the Netherlands, and as previously discussed in 2.3.9.3, patient centredness was key to GP participants objectives of the successful management of multiple morbidities and was a welcome outcome for the authors (Luijks *et al.*, 2012). In Canada, Houle *et al.* discovered that patients rated their chronic illness care favourably when they also rated their relationship with their physician highly, whilst interdisciplinary care and technical quality of care were only modestly related to PACIC scores (Houle *et al.*, 2012). Similarly, in Singapore the value of relationships between clinician and patient were further supported by a qualitative study with twenty-one patients. The research highlighted the factors that positively influenced insulin initiation: trust, effective patient-provider communication, patient centred decisions, and continuity of care. As previously stated, fear of being judged for non-adherent behaviour negatively impacted the relationship (Mathew *et al.*, 2022).

In New Zealand, the service innovation to deliver a person-centred Vision of Care (VoC) found that the in-depth knowledge developed over time underpinned the insight that the provider had into the patient's narrative, and so, their VoC. Common values between patient and provider

were identified including respect authenticity, autonomy compassion, trust, care ethics, and holism (J. Young *et al.*, 2017).

However, attitudinal symmetry may also be a valuable factor in the patient-provider relationship. USA research compared the attitudes of physicians and patients in paired dyads with quantitatively measured outcomes. Christensen *et al.* found that when patients and physicians had similar beliefs about the personal control that patients had over health outcomes, patients displayed higher medication adherence and lower BPs. When the patient had stronger beliefs than the physician, they were less likely to adhere to their medication (the non-adherence rate was 50% higher) (Christensen *et al.*, 2010). Additionally, the authors argue that although prescription refill requests are an indirect measure of compliance, the method was believed to be the most reliable measure of adherence. The results are limited by recruitment bias toward the older Caucasian male veteran population, limiting generalisability to diverse populations and women.

However, the construct of health locus of control may help understand how motivated patients' self-care. Although the authors discuss possible psychological behavioural hypotheses to explain the imbalance in patient-provider beliefs, there was no clear explanation (Christensen *et al.*, 2010). Moreover, this paper also gives insight into a potentially negative physician. The fear of being judged may be demotivating and reinforce lack of engagement behaviours.

Despite the lack of clarity on the asymmetrical relationship, the results show that attitudinal symmetry between patients may strengthen the patient provider relationship. If self-aware healthcare professionals considered their own and patients' perspectives of personal control, they might approach the clinical encounter with more optimism and confidence in the patient outcomes. The consequence may then be better patient-provider relationships based on the doctor as a person recognising the patient as a person, with mutual understanding and agreement on a therapeutic alliance achieved (Mead and Bower, 2000, 2002).

A therapeutic alliance was also evident in the GP-patient relationships explored in qualitative research by Cocksedge *et al.* The authors defined the concept of holding as “*establishing and maintaining a trusting, constant, reliable relationship that is concerned with ongoing support without expectation of cure*” (Cocksedge *et al.*, 2011). For GPs, ‘holding’ was considered a small but routine part of GP work and had benefits of support to patients with a focus away

from biomedical care. Patients described their GP relationships as “*reassuring positive and securing*” with a focus on life history, past narrative of health and a ‘special’ relationship. The ‘holding’ patient-provider relationship confirmed values of mutual respect and trust, which appeared bidirectional to reinforce the PCC approach akin to the Gothenburg and Capabilities approaches.

Burrige et al explored Australian patient views of a service innovation aimed at supporting T2DM management of their diabetes and maximise patient engagement (Burrige *et al.*, 2017). Multidisciplinary clinics were led by GPs with a special interest in diabetes (GPwSIs), aiming to assess patients, stabilise diabetes and screen for complications, in the place of traditional secondary care clinics. Patients reported enabling experiences and feeling that they were partners in care and so a positive important role of the patient-clinician relationship in engaging patients in self-care. However, there were negative dissenting views of a small minority of patients on the disease centred focus of diabetes care, indicating a barrier to their engagement in T2DM selfcare.

In summary, the patient-provider relationship was an important and common theme across the empirical papers and highlighted the tensions disease centred care could present for both patients and clinicians in chronic disease management. There was evidence of PCC approaches being investigated and positive outcomes from patient qualitative and quantitative reports. In addition, clinician perspectives also showed positivity toward delivering PCC in practice, but there was evidence of resistant disease centred attitudes. Internationally, these patient and provider perspectives of chronic disease management reinforce the importance of patient-physician relationships, trust, autonomy and holism as valuable person-centred domains. However, negative PCC physician attitudes persist across the literature in various forms: poor physician communication skills that may imply a lack of respect to patients (Abdulhadi *et al.*, 2007); possible judgemental attitudes of clinicians and patient fear of blame which may or may not be related (Mathew *et al.*, 2022); and disease-centred focus that may be a barrier to patient engagement (Burrige *et al.*, 2017). Further exploration to understand these negative attitudes and the lack of PCC in primary care may progress the patient-centred agenda to improve chronic disease management care. Specifically, the clinician position in patient-provider relationships and their delivery of PCC in primary care in chronic disease care remains a gap in the wider field of PCC literature.

Table X: Relationship constructs identified in the empirical papers and overall positive or negative outcomes.

| Author, year country | participants | aim | Relationship | POS | NEG |
|----------------------------------|---|--|--|-----|-----|
| Abdulhadi et al. 2007. Oman | 27 patients with T2DM from 6 primary health centres | Patients views of medical encounters and quality of interactions | Negative experiences of communication; lack of involvement in dialogue | | neg |
| Luijks et al. Netherlands | 25 GPs | To explore GP perspectives of the management of multimorbidity | Individualization, an integrated approach, SDM, sharing responsibility and emphasis on individual and PCC, biomedical has reduced emphasis. Continuity associated with positive Pt-Dr relationship | pos | |
| Houle et al. 2012. Canada | 364 patients with diabetes, hypertension or COPD, from 9 teaching primary care practices. | The patient assessment of chronic illness care (PACIC) score evaluated the patient perspective of their care, patient physician relationship, interdisciplinary care | Low scores overall for PCC care, but higher PACIC scores indicated relational continuity, patient focused communication, interdisciplinary care, and technical quality of care. | | neg |
| Mathew et al. 2022. Singapore | 21 patients | Aspects of the patient provider relationships (PPR) that affects insulin related behaviours: initiation and adherence | trust, effective pt-provider communication, patient centred decisions, and continuity of care. (fear of being judged was negative). | pos | |
| Young et al. 2017, New Zealand. | 9 patients, 15 clinicians | patient and HCP perspectives on the concepts of a vision of care and the patient's own care network as a 'community of clinical practice'. | Continuity supported VoC. Ethical Values: respect, authenticity, autonomy, compassion, trust | pos | |
| Christensen et al., 2010. USA | 246 patients with T2DM and hypertension, and 18 primary care physicians | The degree of similarity of patient and physician attitude to health locus of control (HLOC) and patient outcomes. | Similar beliefs between patient and doctor about HLOC, i.e. attitudinal symmetry – lower BP and adherence. Negative relationship arguably is HCP attitudinally low expectation of the patient locus of control: indicates lack of therapeutic alliance and relationship. | | neg |
| Cocksedge et al., 2011. UK | 11 GPs and 14 patients | Explores the concept of 'holding' as a management strategy in primary care. | Therapeutic alliance built on ethical principles: trust, continuity, reliability. | pos | |

| | | | | | |
|-----------------------------------|-------------|---|---|-----|--|
| Burridge et al, 2017 Australia | 25 patients | patients views of a new model of integrated care and doctor-patient interactions in the delivery of PCC care. | Enabling/supportive experience and partners in care/therapeutic alliance. Disease centred biomedical care-barrier (negative) | pos | |
|-----------------------------------|-------------|---|---|-----|--|

2.3.10 The quality of the papers

Qualitative research analysis and synthesis is challenging because comparing papers of mixed methodologies, with varying philosophical disciplines, is problematic because of the diverse basis of their expected understanding of the truth. This is most obviously exemplified by the opposing traditions of positivist quantitative research and qualitative methods. A numerical system of quality appraisal was not applied, and a decision was made to not exclude the research based on a quality scoring method alone. As previously explained, to understand the quality of the papers and retain a systematic approach to the literature review process, the Mixed Methods Appraisal Tool (MMAT) was employed to understand the individual quality of the papers on the merits of the method each article used (Hong *et al.*, 2018; Noyes *et al.*, 2019).

All papers were peer reviewed original empirical research of qualitative, quantitative, or mixed methods. Results were tabulated and recorded the outcomes of the MMAT questions with a specific narrative of the value and limitations of the individual papers. This allowed recording of the quality data, and comparison could be made of similar papers. However, all papers remained included after quality appraisal.

2.3.10.1

2.4 The limitations

This section will explore the limitations of the literature review and highlight the criticality required when considering the interpreted results of the review.

Research question and objective was to understand the literature on the person-centredness of GPs in primary care chronic disease management.

The sample of interest was GPs, and this decision was taken at an early phase of the research planning, reflecting interest of the researcher and the departmental interest in primary decision-making when the research began. Although the review excluded research that was solely focused on other HCPs such as nurses only, the literature search did not exclude papers that included GPs with other HCPs involved in delivering PCC in primary care chronic disease management. The literature did include research that included GPs or family physicians internationally, and other HCPs involved in the care of chronic disease management, including primary care nurses secondary care doctors, nurses, specialist nurses. Furthermore, research recruiting secondary care HCPs, such as hospital interns in the United States, and who do see patients from the community, was included.

However, it could be argued that understanding PCC from the perspective of other primary care professionals will be of benefit, but as previously outlined the GP sample set has different roles and functions in primary care. Research with another group of professionals will result in outcomes to their specific profession. Moreover, research relating role-boundaries as primary care healthcare delivery develops, such as practice nurses or practice managers becoming leads and experts in primary care chronic disease management, may be welcome, relevant but recognisably a different type of research and outside the boundaries of the literature search.

The phenomenon of interest was person-or patient-centredness in chronic disease management within the primary care setting. The literature review aimed wide to include chronic diseases beyond diabetes, to understand person-centredness of GPs wider in the primary care setting and not be limited by one chronic disease. PCC is a topic that spans across all chronic disease in primary care and the search terms were planned to try to capture that breadth. This was a strength because as explained in chapter one, PCC is not a well-defined term in the literature, and although a consensus PCC approach is developing, the narrowing to diabetes alone may not capture primary care relevant person-centredness research.

The database searches were limited to Medline via Ovid, National Library of Medicine (NLM) and covers international biomedical health literature including the allied health fields, humanities and information science related to medicine and healthcare. Other databases such as Cinahl and Embase were not additionally searched and is a limitation of the review. The balance between the workload of a literature review, single researcher and the time for the research was considered to make this decision.

There were in 242 papers at abstract screening level and can be argued to be large amount for a single researcher. However, due to the breadth of chronic disease and wide PCC focus require, the initial number at initial title and abstract level was acceptable. Narrowing the PCC terms too early may have risked losing important and relevant research, especially as the PCC terms are not clearly defined in the wider literature as explained in chapter one, and the database bibliographic indexing may also lack precision in definition. Databases are also known to have poor bibliographic indexing for qualitative research, and although the types of research recognised and indexed has widened over years, relevant research can be missed (Soilemezi and Linceviciute, 2018; Flemming *et al.*, 2019; Noyes *et al.*, 2019).

To counter these search limitations, citations were searched and found within the empirical literature and in review papers relevant to the topic of PCC. With the advice of experts in primary care research, including the research supervisors.

The research terms used included diabetes, but also including chronic diseases. When other diseases were added such as asthma in trial search runs, the results were similar. The design was made to utilise the Boolean term ‘or’ to include diabetes *or* chronic disease. It is

acknowledged that the research was planned to research diabetes later in the thesis, and it is possible that this bias influenced the researcher during the sifting process. To counteract this, the researcher used reflexive self-awareness during the sifting process, and it is hoped this will have remedied the issue to a degree.

The worldwide inclusion of papers across the research field is viewed as a strength, but comparison of healthcare systems across the world are complex, and beyond the bounds of the literature review, so the results may provide an arguably superficial comparison of healthcare systems across the world. Larger systematic literature reviews focusing on individuals in various healthcare systems and their experiences with PCC could provide more information.

The design did not include research solely focused of shared decision making as ‘mechanistic’ processes of PCC delivery by groups of professionals in healthcare systems, such as developing and delivering PDA tools. This helped to boundary the research toward individual and personal delivery of PCC by HCPs in primary care. However, papers that did provide information of SDM *and* researched PCC delivery by individuals were included, and fuller papers were sought if there was uncertainty.

The literature review design was planned to include quantitative, qualitative, and mixed methods research. The MMAT appraisal tool employed for the process has recognised limitations (Hong *et al.*, 2018; Nha HONG *et al.*, 2018). As explained at the design stage, quantitative scoring for the quality of the studies is not recommended by experts and was not performed (Noyes *et al.*, 2018). Instead, each study was assessed in terms of the design and method employed, and commentary made. Even with the answers to the MMAT questioned were unclear or “can’t tell”, papers were still included if they had relevance into the results and are discussed in the narrative of the literature review findings and individual methodological limitations were accepted. The transparency is hoped to add to the credibility of the literature findings.

Significantly, although there is an accepted difficulty to compare across types of research, within research appraisal was detailed, but are acknowledged to be limited by the appraisal skills of the single researcher, and mixed methods appraisal are recommended to be performed by more than one person (Noyes *et al.*, 2018). Statistical appraisal was also not a strength of

the researcher and there was a reliance on the papers' presentation of power calculations and methodological detail such as standard deviations. The opinion of supervisor was helpful in uncertain cases.

The use of the CASP tool for qualitative research assessment and the CEBM checklist for survey appraisal added the quality and it is hoped, the credibility of the literature appraisal. However, the CASP tool aims focuses on the aims of research and not the philosophical approach, and so, this literature review has not critically appraised the philosophical approaches of the qualitative research papers, some of which lacked the detail to do this. However, the use of other qualitative research tools such as QARI require additional resources for example two researchers (Booth *et al.*, 2016; Soilemezi and Linceviciute, 2018). In addition, the aim of the literature search was to be narrative literature review and summarise the past empirical papers to understand the topic or phenomena in a comprehensive way. Synthesis of the qualitative studies would have required such depth of critique of philosophical interpretations, and this was not possible with a single researcher in a limited time frame.

With more resources or group of researchers, an alternative method is a meta-narrative review of the literature. This may accommodate a large, diverse, and mixed methods empirical and review literature to generate a narrative from each paper and thus, highlight the problem and areas for further action or research. For example, a meta-narrative reviewing a PCC approach in primary care across the world internationally may generate characteristics, attitudinal approaches and schools of thought of worldwide cultural differences in PCC delivery in primary care (Wong *et al.*, 2013; Booth, Sutton and Papaioannou, 2016).

Finally, conflicts of personal bias of the researcher are relevant to be acknowledged related to cultural background: the biomedical perspective, insider GP with potential bias towards the GP-related research, ethnic origin, female. The design was to plan the research with the use of an insider GP to access the thoughts, language, and experience of practice. From an ethnic minority and female perspectives, the researcher may have been more aligned to recognising feminist philosophies and research recognising diversity.

Finally, the scope of interpretation and discussions of the papers can be limited by the experience of the researcher. Criticality, ability to understand different philosophies,

methodologies and epistemes, quantitative statistics limit the quality of appraisal of the research, and ability to recognise the most important salient features compared to researchers longer in experience. However, the consideration of the person-centred field through the eyes of a practitioner with an openness to PCC delivery may be advantage, aiding criticality towards papers that state a person-centred focus. As previously mentioned, there is a recognised biomedical culture which was infrequently mentioned explicitly, but was implicit across the papers in the papers, and arguably requires further acknowledgment and self-awareness amongst healthcare professionals. This critical self-awareness applies to the ensuing research and analysis itself.

2.5 Summary

This section summarises the literature review findings before the chapter concludes.

The introductory chapter explained various person-centred care (PCC) approaches that represent prior concepts (table 4) to inform the empirical literature review. Subsequently, this literature review has systematically searched the current field of empirical research on the person-centredness of GPs in primary care chronic disease management.

Following systematically refining the empirical evidence according to criteria described in section 2.3, 49 papers were included in the final thematic analysis. The findings show doctor-centred and person-centred themes, as well as identifying PCC approaches in current primary care chronic disease management.

Positive patient satisfaction with clinician competence was evident when research surveyed patient views (Millar *et al.*, 2018), or improved patient satisfaction with PCC care when collaborative or patient centred care plans were implemented (Lawn *et al.*, 2007; J. Young *et al.*, 2017; Lee, Ng and Low, 2017; Claramita *et al.*, 2020). However, when clinicians received training in person-centred care, there is a lack of evidence of biomedical impact (A. L. Kinmonth *et al.*, 1998; Abdulhadi *et al.*, 2007) and even recent cluster RCT evidence of lack of patient reported impact on PCC (Wollny *et al.*, 2021).

Moreover, there is evidence of no notable PCC delivery or low levels of PCC, as measured by a patient reported cross-sectional survey (the previously mentioned PACIC survey), (Houle *et al.*, 2012); patient dissatisfaction with care (Joos, Hickam and Borders, 1993; Abdulhadi *et al.*, 2007; Adams and Carter, 2011), and patient, health care systems and doctor barriers. Despite the above positive reports from patients in some papers, overall, PCC care was not commonly occurring or impacting from empirical data. Whether or not the ambiguity in PCC definitions that have been translated to PCC measures contributed to the lack of clarity in the

identified research is unclear. Further understanding of PCC approaches in primary care chronic disease care is indicated.

The papers that describe clinician knowledge and skills in caring for diverse populations in a person-centred manner as explicit topic themes demonstrated clinician lack of understanding and discomfort in this situation (Kutob *et al.*, 2013; Ali *et al.*, 2016). On the other hand, clinicians may feel challenged if patients do not engage with person-centred principle as expected, such as passive acceptance rather than autonomy (Fagerli *et al.*, 2005). Behaviors that may be attributed to a specific ethnic group may be the result of difficulties in communication and cultural barriers between the clinician and the patient.

Moreover, the doctor's biomedical approach has been identified as a barrier to person-centred trust and patient-provider relationships and can be argued to be a cultural approach specific to healthcare professionals (Bartz and Francisco, 1999; Adams and Carter, 2011). Understanding care of diverse populations is essential to medical practice and the papers suggest patient dissatisfaction, clinician discomfort and possible cultural barriers in countries where diverse populations exist and are a minority, and so, may represent an understudied area of PCC.

Internationally, the contrasting inequality in healthcare resources showed how basic healthcare needs such as access to care and medicines is required, and impacts on the type of PCC decisions made such as avoidance of escalation of therapy (Haque *et al.*, 2005; Ngassa Piotie *et al.*, 2021). Even in affluent countries, negative practitioners' attitudes to person-centred chronic disease management within healthcare systems may result from a perceived lack of resources in terms of time, staff, and funding, and patient observation of a lack engagement of clinicians in SDM may be the result (Russell *et al.*, 2008; Wiley *et al.*, 2015; Millar *et al.*, 2018).

Adherence to biomedical management represented a doctor-centred perception of patients ranging from ideal to low expectations, which impacted on decisions such as goal setting and therapy escalation (Helseth *et al.*, 1999). These clinician-led decisions may be significant if the therapy was not escalated as was exemplified in poorly controlled T2DM in South Africa (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021). Evidence of clinicians' ability to underestimate patient adherence, patients own fear of being judged for non-adherent

behaviour and a mismatch between clinician and patient views of adherence may negatively impact patient-provider relationships, and so, collaborative person-centred decisions (Christensen *et al.*, 2010; de Figueiredo, Snoek and Barreto, 2013; Claramita *et al.*, 2020; Mathew *et al.*, 2022).

Barriers to person-centred care included low socio-economic demographic (SED), access to care, patient resources and the cost of healthcare, and patient mental health, and the previously discussed cultural barriers. Negative clinician attitudes to low SED included judgements over patient personal resources, low expectations of patient health and reduced 'talk-time' in consultations (Houle *et al.*, 2012; de Figueiredo, Snoek and Barreto, 2013; Rutten *et al.*, 2018). Patients' complaints about access to healthcare may range from long wait times to see clinicians in primary or secondary care, and lack of flexible access to care and clinician variability in clinical competence to recognise complications of disease, such as MS relapses (Adams and Carter, 2011; Wiley *et al.*, 2014, 2015; Methley *et al.*, 2017; Millar *et al.*, 2018; Roper *et al.*, 2019).

Mental Health needs of patients with chronic disease not only adds to the multimorbidity, but both patient and providers may prioritise MH differently, causing distance between patient and provider in potentially collaborative care. Patients may value their MH self-care more than biomedical health, whilst clinicians may prioritise biomedical management over MH issues such as anxiety. However, when significant MH issues are involved, clinicians may lower the expectations of patient engagement and self-care, and so align to patient preferences to prioritise MH, indicating possible collaborative approaches when doctors were found to be 'minimalists' (Joos, Hickam and Borders, 1993; Lawn *et al.*, 2007; Swenson *et al.*, 2008; Green, Rothman and Cavanaugh, 2012; Luijks *et al.*, 2012; Ratanawongsa *et al.*, 2012; Griffiths *et al.*, 2014; Trachtenberg *et al.*, 2014; Sidorkiewicz *et al.*, 2019; AlRuthia *et al.*, 2020).

Equally, the decisions made by primary care clinicians may impact the quality of care across their local populations. Indications of a lack of awareness or a potential lack of value for health quality indicators may indicate that primary care clinicians have other agendas in chronic disease management, even in the case of common diseases such as T2DM (A Zafar *et al.*, 2015) and warrants further research,

Patient fears however, divided into those related to the fear of disease and therapy, or fear of blame for lack of self-care and deterioration in health (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021; Mathew *et al.*, 2022). These fears may be related to a lack of trust in healthcare and medicines in general, or in the individual HCP, and thus may have a negative impact on patient-provider relationships and patient engagement (Bartz and Francisco, 1999; Mathew *et al.*, 2022).

In UK General practice it is known that although GPs purport to value patient involvement in decisions of their care and self-management, there may be significant contextual barriers beyond effective communication skills and include GP values and attitudes toward their own responsibility and patient self-care management (Blakeman *et al.*, 2006a)

Ethical concepts that underpin person-centredness were evident in the empirical data. Respect, trust, autonomy, and empathy were described, evident or sought for through research.

Patients reported both positive and negative experiences of respect, and the latter was associated with less consideration for the person, and were related to autonomy, a biomedical focus and patient low self-esteem (Abdulhadi *et al.*, 2007; Adams and Carter, 2011; Kurpas *et al.*, 2013). Similarly trust in the clinician was both positively and negatively reported by patient reported data. Trust was associated with seemingly strong collaborative patient-provider relationships and ability to be less biomedical (Cocksedge *et al.*, 2011). Whilst quantitative research provided evidence of links between trust and positive patient outcomes, including biomedical outcomes (Lee and Lin, 2011). Trust could also be bidirectional in qualitative evidence and indicated a gap between the clinician biomedical expectations of care and patients' unmet person-centred needs (Bartz and Francisco, 1999).

On the other hand, autonomy was implicit amongst the PCC papers, but was explicitly investigated and found to have links with patients' feelings of trust, confidence, and respect (Lee and Lin, 2011). However, clinician expectations of patient autonomous behaviour could be challenged if patients behaved in passive acceptance of HCP as authorities in healthcare delivery (Fagerli *et al.*, 2005). Significantly, belief in autonomy, empathy and equality may be reported by clinicians in credible qualitative data from Norway, but patient reports failed to confirm clinician person-centredness (Fagerli *et al.*, 2005). In addition, efforts to promote

empathy and impact PCC have not confirmed any links with positive clinical outcomes (Hojat *et al.*, 2011; Chaitoff *et al.*, 2019).

As may be expected from previous published literature review described in chapter 1, when WPC was explicitly mentioned in this group of papers as a desirable clinician attitudinal approach, it was infrequent, but appeared synonymous with person-centred approaches (Russell *et al.*, 2008; Adams and Carter, 2011; Lee and Lin, 2011; J. Young *et al.*, 2017; Thomas *et al.*, 2018).

Two different aspects of delivering PCC were evident amongst the empirical papers: involving patients in decisions and collaboration or agreement between patient and provider. When it comes to involving patients in decisions, there is evidence indicating highly positive person-centred care by primary care doctors in New Zealand, but lack of contextual information on the person-centredness of the clinicians involved (Millar *et al.*, 2018).

However, less positive patient experiences are associated with doctor-centred barriers of lack of knowledge and skills, attitudes toward adherence and a biopsychosocial attitude as previously described (Bartz and Francisco, 1999; Helseth *et al.*, 1999; Haque *et al.*, 2005; Abdulhadi *et al.*, 2007; de Figueiredo, Snoek and Barreto, 2013; Janes and Titchener, 2014; Methley *et al.*, 2017; Ngassa Piotie *et al.*, 2021; Mathew *et al.*, 2022).

Various interventions to deliver PCC in general practice were researched in the papers and indicated positive patient reported outcomes that encourage further pursuit of PCC delivery in practice and research. The interventions included training in PCC approaches and assessing methods or consultation models to achieve collaborative agreements. No one method stood out as more effective than another from patient satisfaction ratings, but positive patient and clinician feedback on most interventions imply clinicians may be open to change their practice through PCC training.

Clinicians' negative feedback towards interventions to improve PCC, on the other hand, may be associated with a lack of resources to sustain them, indicating a challenge of including interventions into existing systems which were a barrier from the clinicians' perspective; or alternatively, the barrier of clinicians' own attitudinal negativity (Russell *et al.*, 2008). In addition, negative PCC attitudes from clinicians persist in the form of poor communication

skills or judgemental attitudes to patients (Abdulhadi *et al.*, 2007; Adams and Carter, 2011; Mathew *et al.*, 2022). Furthermore, tensions of disease-centred focus by clinicians remained problematic for patients, and doctors may even resist PCC approaches if they perceive a compromise in biomedical care (Bartz and Francisco, 1999; Russell *et al.*, 2008; Adams and Carter, 2011; Rutten *et al.*, 2018).

Despite these indications of GPs' positive and negative attitudes to PCC that was found in qualitative and quantitative research, there was still a lack of clarity regarding their PCC engagement and approach.

2.6 Conclusion

Family physician approaches to PCC and person-centred chronic disease management remains unclear in the empirical literature. Although GPs may aim to work within structured chronic disease management care plans within the National Service Frameworks (NSF) and General Medical Services (GMS), primary care is increasingly managing chronic disease and multimorbidity delegated from specialist secondary care services (Blakeman *et al.*, 2006b; Dennis *et al.*, 2008).

The aging population and improved healthcare have meant an increased prevalence of multimorbidity, which is the presence of two or more diseases in an individual and has occurred across all age groups (Barnett *et al.*, 2012; Whitty *et al.*, 2020). A fragmented approach single disease approach to multimorbidity and chronic disease patient care with single disease research healthcare delivery and professional education has meant unmet patient needs and poorer outcomes (Barnett *et al.*, 2012; Whitty *et al.*, 2020), and increasingly present to primary care GPs (Schjøtz *et al.*, 2017)

Consequently, T2DM represents such a multimorbid condition, framed also as a 'cluster' of diseases of the cardiovascular, eyes, kidneys, and nervous systems, and remains a worldwide and growing problem that is increasingly managed in primary care. It represents a chronic disease that requires managing by individual primary care professionals and healthcare systems in person-centred ways.

The literature review on the person-centredness of GPs in primary care chronic disease management found evidence of PCC approaches being investigated and some positive outcomes from patient perspectives. In addition, clinician perspectives also showed some positive attitudes towards delivering PCC in practice, but there was evidence of resistant disease-centredness and indication of doctor-centredness. Internationally, these patient and provider perspectives PCC in chronic disease management reinforce the importance of patient-physician relationships, as well as principles of trust, autonomy, and holism as valuable person-centred. However, negative PCC physician attitudes persist across the literature in various forms: poor physician communication skills may imply a lack of respect to patients (Abdulhadi *et al.*, 2007); possible judgemental attitudes of clinicians and patient fear of blame which may or may not be related (Mathew *et al.*, 2022); and disease-centred focus that may be a barrier to patient engagement (Burrige *et al.*, 2017).

Overall, the review of the available empirical literature has found that PCC is not commonly delivered, that interventions may or may not increase patient satisfaction, do not improve measurable outcomes, and that doctors, patients, and the system itself continue to act as barriers.

As healthcare cultures evolve towards more person-centred care, patients' expectations of self-care, both from themselves and from HCPs, may need recognised and non-judgmental person-centred approaches offered by HCPs and accepted as the standard by patients.

Further exploration to understand these negative attitudes of primary care physicians and the lack of PCC in primary care may progress the person-centred agenda to improve chronic disease management care. Specifically, the clinician position in patient-provider relationships and their delivery of PCC in primary care in chronic disease care remains a gap in the wider field of PCC literature.

2.7 The research questions.

T2DM remains a worldwide and growing problem, as discussed in chapter one, and is increasingly managed in primary care. T2DM also represents a chronic disease that requires managing by individuals and healthcare systems in person-centred ways. Escalation of therapy in T2DM, including insulin initiation is an example of a decision requiring a person-centred approach and was identified amongst the empirical literature. Exploring the person-centredness of GPs using T2DM and insulin initiation as an example of a person-centred decision may provide contextual lived experience knowledge of how GPs perceive PCC care when considering a chronic disease management. The use of a point of escalation in medication is supported by the literature where papers have considered GP roles and identify person-centred care as part of the solution to improve T2DM care (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Wiley *et al.*, 2014, 2015; A Zafar *et al.*, 2015; Ngassa Piotie *et al.*, 2021). Insulin initiation can be a necessity when all other avenues of medication and lifestyle change have been considered; but if insulin is avoided, the reasoning requires considering of the individual circumstance of the patient in person-centred ways.

In chronic disease management, the empirical research has shown that GPs can lower expectations of health for patients with poorly controlled diabetes, rather than engaging to improve health through person-centred ways (Wollny *et al.*, 2021).

Moreover, according to Scottish research, power asymmetry may be evident when GPs biomedically reframe the patient's issue with disregard to the patient's personal goals. There was associated evidence of patients shifting from passive to active resistance, and GPs re-imposing the authority as expert (Murdoch *et al.*, 2020). Notably, some GPs would satisfy the patient's goals based on it being acceptable within a biomedical context, which reinforced findings by Russell *et al.* who showed professional attitudes and cultural oppositional behaviours are barriers to PCC delivery (Russell *et al.*, 2008).

Therefore, understanding the GP perspective and person-centred behaviour further may provide in roads to understanding how to encourage GP engagement in reflective practice to improve PCC delivery.

Using insulin initiation to investigate GP views on providing person-centered care in a chronic condition may assist GPs in focusing their decisions on the balance of biological need against person-centred need. This person-centred knowledge of how GPs approach T2DM as an example of a chronic disease management in primary care, especially at a point of escalation of medication to insulin still remains unresolved, and so a gap in the wider knowledge of PCC delivery in the primary care setting. Exploration through qualitative methods may provide alternative insights to add to the growing knowledge of how GPs consider PCC in primary care chronic disease management more widely.

Consequently, the research questions are as follows:

How do GPs approach person-centred care when considering insulin initiation in T2DM?

Subsidiary questions to seek in the data:

1. What do the GPs say about their relationships between patients and doctors?
2. What do GPs say about delivering PCC when considering insulin initiation in T2DM?

The next chapter explains the methodology and methods.

3 Method

3.1 Introduction and research aim

Based on the previous chapter literature review and the identified gap in the evidence, the aim of this research is to explore GP person centredness when managing a chronic disease employing the example of insulin initiation in T2DM.

This chapter will describe and justify the qualitative methodology used to answer this research aim; it will begin by introducing a conceptual framework that summarises this thesis's assumptions and theoretical perspectives. This is followed by a consideration of the ontological epistemological assumptions in this research. The remainder of the chapter comprises a transparent and reflexive account of what was undertaken in terms of the qualitative sampling, data collection and analysis; in particular, the use of both thematic and narrative structural analysis will be introduced and argued to provide a unique opportunity to explore this topic. The planned research design for this process involves reflective interviews with GPs and employing a reflexive thematic analysis and a different narrative analytical approach.

3.2 Conceptual framework

The literature review has shown inroads and gaps into understanding clinicians' attitudes, views and observed behaviours towards PCC in chronic disease management. The insight, understanding and ability to derive meaning from research data result from the sensitisation of the researcher from experience and reading in the field (Crotty, 1998; Braun and Clarke, 2013). From the literature, key concepts of person-centred approaches, barriers to PCC from the clinician and patient or person perspective, and visible PCC approaches explored qualitatively and investigated as interventions empirically in the literature. Barriers to PCC in the patients with chronic disease were low SED, cost of healthcare, mental health, cultural barriers.

Specific to insulin initiation, barriers identified were low SED, cost of healthcare, lack of social support and older age (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021). Clinician related barriers to PCC were lack of knowledge and experience in areas of clinical competence and communication skills from patient reports (Abdulhadi *et al.*, 2007); lack of communication and lack of skills in care of diverse population and cultural barriers (Kutob *et al.*, 2013; Ali *et al.*, 2016).

Additionally, clinician negative attitudes were identified: low prioritisation of infrequently encountered disease (Methley *et al.*, 2017); lack of value for quality indicators in diabetes of T2DM- a commonly encountered disease; prioritising medical issues over mild mental health problems (Trachtenberg *et al.*, 2014; Kristensen *et al.*, 2018b), or viewing adherence negatively in a biomedical way to impact their decision making when goal-setting, or escalating medication like insulin in T2DM (Helseth *et al.*, 1999; Christensen *et al.*, 2010; Ratanawongsa *et al.*, 2012; de Figueiredo, Snoek and Barreto, 2013; Ngassa Piotie *et al.*, 2021). Not all judgements are argued to be negative, and judgements towards patients' resources and ability to self-care impacted the clinician's decisions and are arguably neutral (Haque *et al.*, 2005; Ngassa Piotie *et al.*, 2021). However, the potential for clinicians to have negative attitudes that influence judgements or decisions towards person-centred care indicates the importance of exploring the issue of person-centredness of GPs in a chronic condition like diabetes further. Overall, the empirical papers appear to indicate that PCC is uncommon and interventions may not improve measured outcomes, and has persistent doctor, patient, and system barriers. Lack of clarity of patient-centred definitions, as described in chapter one, may contribute to the current ineffectiveness of PCC delivery and improvements in PCC approach delivery for chronic diseases in primary care may result from further research into what PCC entails in practice.

Significantly, from the empirical evidence, person-centredness manifested as delivering PCC (involving patients in collaborative agreements) and patient-clinician relationships. These are outcome sensitising concepts to be sought in research data. Significantly, the subconstructs of these major themes have underlying barriers and facilitators. Some of these barriers and facilitators are present in both but are argued to present in a different combination.

To deliver PCC, a clinician must communicate effectively, align to the patient, and have relational continuity, whilst avoiding negative attitudes to the lack of finances, system barriers, negative beliefs of the patient, and biomedical focus.

On the other hand, positive patient – clinician relationships require positive communication, shared responsibility and aim for a therapeutic alliance, and relational continuity; whilst avoiding attitudinal asymmetry, judgmental attitudes, and biomedical focus.

| | facilitators | barriers |
|--------------------------------|--|--|
| Delivering PCC | Positive communication, individual GP effectiveness, aligning to the patient, and relational continuity | Doctor-centred negative perceptions: lack of financial and staff resource systems, a lack of belief in patient engagement and even exclusion of those not believed to engage, not identifying with the role to deliver PCC, and a disease-centred or biomedical focus. |
| Patient-Clinician relationship | Positive communication, shared responsibility, continuity, therapeutic alliance, and ethical principles (trust, respect, autonomy, authenticity, compassion) | Attitudinal asymmetry, judgemental attitudes, and biomedical focus. |

It is also relevant to acknowledge the insider researcher's professional and personal practice provided relevant sensitising concepts. In general practice, the researcher's diabetes management experience has been as a sessional GP in the South Yorkshire region, and not involved in diabetes lead roles in practice. Consequently, a limited diabetic experience sensitised the prior research concepts, and the findings focused on the interviewees' accounts. Immersion into and learning about narrative inquiry through the literature and a course with specialist Arthur Frank solidified the value of individual contextual experience of patients and the need to understand the clinician to achieve that (Frank, 1995, 2004; Eldershaw and Winkler, 2007). The commitment to placing the patient at the centre professionally and personally has been central to this thesis, and it is recognised that although PCC is considered a core professional value, there is evidence to show that delivery of PCC does not occur in practice (Russell *et al.*, 2008; Houle *et al.*, 2012; Wollny *et al.*, 2021) Houle . Consequently, despite the attempts to employ reflexivity through the thesis process from the early phases of design, there is acknowledgement of the prior biomedical conceptual influences that led to the thesis design and framing in terms of a biomedical decision in the journey of T2DM patient care. However, it was believed at the time of design that starting insulin in T2DM would frame GPs

as the designated prescriber, allowing scrutiny of person-centred attitudes and behaviour in the midst of what appears to be a biomedical decision.

3.2.1 The Insider GP and PCC

For the insider GP researcher, working in the UK general practice during the thesis journey influenced the awareness of an evolving profession, and the challenge of an arguably necessary rhetorical signalling for the need for PCC when managing chronic disease care (Whitty et al, 2020). Delivering PCC care and even performing quality of care in the limited resources of time, staff and finance felt challenging and is supported by GP opinion in the empirical literature (Russell et al., 2008). Academic awareness of patient-centredness and the contradictory daily practice schedules of short appointments for chronic disease care for GPs felt like a perplexing problem at the time of the design of this research. For example, shared decision-making tools appeared to add to appointment time and no plans were to be made to add the tools in longer separate chronic disease appointments - the GP chose to deliver the tool and add appointment time, or complete it later in administration time, not at all.

Delegation to allied professionals such as nurses, clinical pharmacist and physician assistants, appeared to solve part of the problem for meeting NSF service delivery, but much of chronic disease care and multimorbidity presentation, with requirement for shared decisions continues in GP consultations. The delegation varies across GP practice from the insider GP experience. For example, the insider GP experience of diabetic chronic disease management delegated to the nursing team, but the nurses may not be trained to perform CVD risk counselling, prescribe cholesterol prevention therapy, or escalate hypertension management. There has been an acknowledgement of the evolving nature and scope of general practice within an increasingly specialised medical system (Goodwin *et al.*, 2011). Previously in chapter one, the increasing burden of T2DM care internationally, increasing needs for primary care involvement has also collided with a move away from professionalism centred primary care service. There has been recognition of an arguably more bureaucratic service delivery that implies uniformity and certainty, when more credibly, generalism involves uncertainty (Reeve, Irving and Dowrick, 2011). Delivering chronic disease care in uncertainty, combined with multimorbidity related consultations is explicitly challenging to the insider GP. Understanding the perspectives of individual GPs is especially important when one considers that they work in a system that is pushed toward biomedical specialisation while attempting to be more person-centred with

approaches explained in chapter one and recommended by academics, guidelines and medical authorities.

The General Medical Council regulations for medical practice is ethically derived guidance that direct and inform professional practice (GMC, 2013a). Since the early 1990s, professionalism has been debated publically and believed to be associated with the changes in society. Medical practice has arguably been directed by society, media and government towards managerialism and is reflected in the GMC guidance on good medical practice (Gill and Griffin, 2010). This research acknowledges the changes in practice for GPs since the publication of GMC ethical guidance to doctors, whilst recognising the PCC approaches are still evolving and yet to be established in individual clinician's practice.

Perceiving patient health and wellbeing from the physician's perspective has been argued to be a singularly biomedical observation and does not represent the whole reality of what is recommended to be a dialogical and collaborative relationship. The clinician view has been described as a one-sided monopoly of knowledge of the patient to direct the patient into a compliant state (Loewe and Freeman, 2000).

“a one-sided emphasis on patient experience and belief and presupposes a one-sided model of care in which the physician monopolises knowledge of the other (i.e. the patient) and uses it to wrestle and cajole him into a more compliant state. In contrast, a research agenda which takes into consideration physician experiences and feelings not only presupposes a more dialogical model of care, but can be used to promote self-reflection on the part of the practitioner.”

The view suggests the clinician has a Parsonian psycho-socio-cultural opinion of the patient's perspective (Gallagher, 1976). The emphasis is on the subjective context through which the physician and the patient differently perceive patients' health. Moreover, patients and physicians may disagree on their perceptions of reality which leads to tensions such as difference in prioritisation of biomedical measures of health and mental-health self-care (Trachtenberg *et al.*, 2014; Lee, Ng and Low, 2017; Sidorkiewicz *et al.*, 2019).

The empirical research has shown how PCC appears to show aspects of PCC approaches in recommendations, whilst delivering PCC and patient-clinician relationships are key themes to inform PCC practice. Improving the understanding of the clinician's subjective views in the context of chronic disease management such as diabetes may allow learning and development to inform further understanding of collaborative and person-centred practice in chronic disease management (Elwyn *et al.*, 2014; Health Foundation (Great Britain), 2016; Britten *et al.*, 2017). The following sections explain the methodology chosen to explore the research question that aims to understand the person centredness of GPs in chronic disease management using the example of insulin initiation in T2DM.

3.3 Methodology

The decision to employ a qualitative methodology and rather than a quantitative method was based on the need to explore the topic area further. Qualitative methodologies can provide rich insights into experiences patients and professionals have in the health care setting (Braun and Clarke, 2014). The research design chosen involved a methodology aiming to lead to inductive and exploratory research methods.

Alternatively, the empirical data identified survey methods to understand the phenomenon within the topic of person-centred care. Questionnaire designs for example, may allow broad impression of participants experiences or views, and may provide results at scale that can be generalisable. However, a method that provides depth and breadth may be better suited to the investigation of a subject that is thought to have many unresolved questions. For example, Houle et al., 2012, applied the PACIC score to evaluate the patient perspective of the patient-doctor relationship and found low scores overall for PCC care- indicating a lack of PCC care. Relational continuity, patient focused communication and technical quality of care (TQC) were associated with higher PACIC scores and arguably, expected findings. Since cross-sectional designs are snapshots in time, they cannot determine the direction of observed associations or the presence or absence of potential confounding variables (PCC). However, the depth of our understanding of PCC was enhanced by the work of Lujks et al., 2012, who explored GP perspectives and identified constructs like the sharing of responsibility between clinician and patient.

First, the ontological and epistemological stance of this research will be discussed, followed by an explanation of the research design.

3.3.1 Ontology

The ontological position relates to understanding and assumptions about reality, which has implications about knowledge claims related to various aspects of the world. In this section, the ontological position chosen for this research - critical realism – will be introduced and argued to best represent the researcher's worldview.

The realist and relativist stances contrast and aid understanding of the critical realist view. From a realist's rationalist view, the truth can be objectively found by identifying causal relationships between phenomena. Within the positivist paradigm, this objective truth presents through a closed system that is controlled and predictable to provide scientific knowledge (Williams, Rycroft-Malone and Burton, 2017).

Realism assumes that there is only one reality, and truth can be observed. Realists believe truth is understood through appropriate research techniques that observe reality (Braun and Clarke, 2013).

In contrast, relativism is an opposing ontological position to realism and presents reality as multiple constructions that differ according to the time and the context of an investigation. For the relativist, reality depends on how and the way that knowledge was generated. (Braun and Clarke, 2013).

Understanding the influencing factors on a phenomenon like the subjective behaviour of clinicians can be achieved through interpretations of reality (Williams, Rycroft-Malone and Burton, 2017). Although "naive" realists equate truth and reality, they are criticised for failing to account for the perspective of the observer when doing so (Braun and Clarke, 2022).

Therefore, for this thesis, the critical realism philosophical stance states that reality exists and operates independently of our observation and knowledge. It therefore follows that when acquiring knowledge or constructing our versions of reality, any ontological or epistemological position can be fallible or mistaken (Haigh *et al.*, 2019). Notably, CR does not claim the multiple realities as a relativist may state. CR accepts multiple perspectives, interpretations, or possibilities of reality.

CR stratifies reality into three domains, the real, actual, and empirical:

- Real - comprised of objects, individuals, or structures with properties to activate mechanisms that affect other structures.
- Actual - comprised of events caused by activated mechanisms.
- Empirical - Events or effects that have been observed or experienced.

There are a few features of CR that depict the ontology more clearly. These will be explained before linking them to the chosen epistemological position for the thesis.

From the critical realist view, objects or entities of the world can be “*human, social, material, complex or simple, structured or unstructured.*”(Collier, 1994). These entities have powers that can be activated to create events. However, these entities can be indirectly observable, invisible or visible because of the basic premise of CR that reality is independent of the observed (Haigh *et al.*, 2019). Consequently, entities can be non-physical and include institutions, ideas, theories, and concepts that are not empirically available to be observed and measured, but the effects of their powers once activated can be seen as measurable outcomes. CR also recognises that the absence of entities can have powers. For example, access to health may be argued to be limited by institutions that make access more favourable to the health literate, and although health literacy is difficult to define and measure, health inequalities across health literate and illiterate groups may be measurable (Nutbeam, 2017). Thus, the individual’s lack of health literacy skills can lead to poorer health outcomes.

Another key aspect of CR is that knowledge of phenomena can develop and change. Our construction of knowledge is fallible and result in misconceptions, and so, CR recognises that knowledge is open to challenge and change (Cruickshank, 2012; Haigh *et al.*, 2019). Finally, CR stratifies the world into complex layered systems composed of many different entities which can interact in multiple ways, and the mechanisms through which they act may be working at any time. For example, an individual with multiple roles such as doctor, parent, and patient may act within the healthcare situation when presenting with their child. Each entity in that individual is empowered with different properties and may act and react with another doctor or healthcare institution in enabling, constraining or blocking ways (Haigh *et al.*, 2019).

Roy Bhaskar’s interpretation of critical realism is acclaimed as a different perspective that allows acknowledgement of the complexities in healthcare, alongside otherwise empirical knowledge (Cruickshank, 2012; Williams, Rycroft-Malone and Burton, 2017; Haigh *et al.*, 2019). Therefore, within research methods, when formulating theories of how mechanisms of observed empirical phenomena generate events, tendencies or patterns may be evident. Moreover, the properties of these entities and how they empower them may also be evident (Haigh *et al.*, 2019).

Finally, methodologically, CR also recognises that multiple methodological approaches may be required to understand the complex multilevel relationships between entities and the mechanisms through which they work, and so provide knowledge from different epistemological stances (Cruickshank, 2012; Haigh *et al.*, 2019). Critical realism thus allows truth and reality to be distinct and separate from the knower and methods of knowing. The knowledge that results is then judged by the quality of epistemology and methods. Furthermore, the credibility of epistemological methods is dependent on the transparency of the research design and how it is employed. It is hoped that the transparency of methods in this research creates the trustworthiness required to provide a potentially credible representation of observed reality.

Ontologically, critical realism also allowed the researcher in this thesis to accept the existence of alternative versions of the truth and reality and so, be aware of the epistemology beyond the biomedical disease-focused conception of diabetes. Critical realism offered the researcher meaningful incorporation and transition from the positivist empirical-based early years of medical training towards alternative philosophical stances. Consequently, CR is the appropriate way to frame this research because it offers an ontological stance to view people, organisations, attitudes, and resources. CR is a credible ontological stance to the researcher, can accommodate multiple methodologies, does not prescribe to only qualitative or quantitative methodologies, and finally, CR can credibly support healthcare research (Cruickshank, 2012).

Specific to qualitative research and the later explained reflexive thematic analysis, CR offers a critical eye, and acceptance that participants views and experiences are their version of reality, shaped by their cultural and language context. To achieve these interpretations, the interviewer will similarly generate perspectives of reality through the lens of their own worldview and culture (Braun and Clarke, 2022).

An important related concept is about epistemology, and related knowledge claims that we can make and observe about the world, and the next section will argue the compatibility and implications of a constructionist view. The next section will link CR to the important concepts of epistemology and how we can acquire knowledge about the world which is relevant for empirical healthcare research.

3.3.2 Epistemology

In qualitative research, it is essential to clarify what status and claims can be made about any collected and analysed data, which requires consideration of epistemology. In this section, epistemology will be considered in more detail to provide an understanding of the nature of human knowledge and its meaning in the context of this research (Mautner, 1999).

To accept that acquiring knowledge is a fallible process, post-positivists claim knowledge is still objective, but is affected by the observer values, culture and stance. Therefore, for post-positivist epistemologies, language and so, discourse, can reflect a reality that is objective and separate from the language itself. Participants can describe their reality in a literal way. Consequently, this desire for objective knowledge is accepted to be ultimately impossible but remains something to aim for by demonstration – such as methods that require coding reliably in qualitative analysis processes (Braun and Clarke, 2022; Braun, Clarke and Hayfield, 2022).

On the other hand, contextualism is different epistemology where multiple realities are evidently found, but the knowledge is within the context within which it is situated. So multiple accounts of a reality may be related by participants, but the knowledge cannot be separated from the person, and the researchers' values shape the knowledge they generate through observation. Therefore, the researcher is not independent of the participant; rather, the researcher is embedded within the participant's context during the interview and thus, co-produces the resulting knowledge (Braun and Clarke, 2022). Significantly, like post-positivists, contextualists also see language as a reflection of reality, but it is a reality that belongs to the perspective of the individual participant (Braun and Clarke, 2022).

In contrast, constructionist epistemology accepts that meanings and truth are not discovered or independently observable but are constructed by the observer when they engage with the world and the phenomena they are interpreting. Human knowledge is constructed through the processes of interaction between human beings and in the context of their social world (Crotty, 1998). Therefore, constructionism challenges the positivist assumption that the nature of the world is revealed through observation alone. (Gergen and Gergen, 2013). Constructionism sees

the researcher as creating the reality- generating the knowledge through interpretation of data. Moreover, language is not neutral, and does influence the reality it generates. Rather than just being socially situated, the participant describes and constructs their world.

Constructionism acknowledges, therefore, that interpreting the object or subject of investigation requires an observer. Furthermore, both observer and subject's social culture and processes shape the knowledge and meaning generated (Gergen and Gergen, 2013; Sparkes and Smith, 2013). Significantly, constructionism has been argued to be compatible with critical realism and provides a scepticism through which to view knowledge claims, especially experts such as healthcare professionals (Elder-Vass, 2012). Realities exist independently of our comprehension, and this is something that constructionists and critical realists agree on, which forms a fundamental principle for this thesis (Madill, Jordan and Shirley, 2000).

Constructionism may have different approaches and this thesis has aligned to the radical constructionist approach explain by Madill et al (2000). As stated above, it is considered a realist claim to say that results emerge form the data, and constructionist analysis is interpretive and so has generates the data (Madill, Jordan and Shirley, 2000; Braun and Clarke, 2022).

Therefore, constructionism benefits from a criticality toward participants' views, and does not accept them as a complete explanation of reality, rightness, or acceptable behaviour (Madill, Jordan and Shirley, 2000). This understanding of criticality towards interviewee accounts is reinforced by Silverman who warns that participants' accounts are shaped by potentially unreflective and conventionalised perceptions of their constructed world (Silverman, 1989).

It is important to acknowledge the constructivist approach has been claimed to be an alternative epistemology that can be confused with constructionism. Constructivism, which is sometimes used synonymously with constructionism, reflects disciplinary differences, and so, sociologists may use constructionism, whilst psychologist use constructivism. Both acknowledge that the researcher actively generates knowledge (Braun and Clarke, 2022). However, it is argued that constructivists focus on how individuals' cognitive, psychological, and perceptive capacities construct the world and have been associated with learning and development (Gergen and Gergen, 2013). Braun and Clarke provide a convincing analysis of the differences between the

two philosophies and accept this more psychological orientation of constructivism. Alternatively, constructionism holds that meaning is created by individuals, but does so in a social and relational manner that may still be individual but does not probe into the individual's psyche (Braun and Clarke, 2022). Madill et al. argue that constructionism aligns to critical realism because of its scepticism of all foundationalist claims to knowledge, and both are also critical of claims of objectivity and reliability of knowledge acquisition by other epistemological tradition such as realism. As previously explained, knowledge that is reinforced by inter-rater reliability in analytical coding is rejected by constructionist and reflexive TA views and requires credibility criteria (Madill, Jordan and Shirley, 2000). As such, quality criteria can still be applied to constructionist reflexive thematic and narrative methods such as internal consistency, analysis of outliers, and transparency or openness (Madill, Jordan and Shirley, 2000).

This thesis accepts the reductionist version of constructionism and in application to the data, allows consideration of how GPs may perceive insulin and people with diabetes within the setting of general practice. Consequently, the analysis aims to generate constructions of how GPs perceive and explain their work in T2DM, including how they construct themselves, their working environment, their knowledge, and the patients they care for. The GPs descriptions will be individual, but patterns generated across them may show how GPs approach person centredness and form the epistemological stance to observe and analyse the research data.

A final feature of constructionist inquiry is that, like CR, it is also amenable to different approaches and offers flexibility and opportunity to use different methods such as different forms of analysis and means that constructionism is compatible with thematic and narrative analysis methods applied in this thesis. These two different and complementary methods to analyse the data with an aim towards triangulation (Elder-Vass, 2012; Sparkes and Smith, 2013).

Firstly, a reflexive thematic analysis approach is applied to understand the data and highlight common experiences whilst illuminating wider contexts (Robichaux, 2002; Braun and Clarke, 2006; Robichaux and Clarke, 2006; Lainsou, Braun and Clarke, 2019). Reflexive TA also explores what and how reality has been made or constructed, and is consistent with the constructionist approach to generate, rather than reveal, data empirically (Braun and Clarke, 2022). Secondly, narrative inquiry can also be performed within the constructionist episteme,

because narrative analysis involves understanding human realities and social interactions within the context of the participant's socially constructed world (Elder-Vass, 2012; Sparkes and Smith, 2013). Narrative is the main way people organise and communicate their worldview, and the interpretive process of understanding a story is central to human knowing (Bruner, 1986, 1987a, 1991).

The “travelling” researcher (Kvale, 1996, 2007)

When considering the process of interviewing the GPs, the use of a narrative method was planned early. The plan to use insulin initiation as the opening topic was purposeful and aimed to aid the initial process of rapport building and frame from the initial healthcare related topic. However, the interview was loosely semi-structured in the interview guide which facilitated a flexible openness to allow the participant to relate their narrative. Kvale draws on a metaphor to describe the interview process as mining or travelling. Mining involves revealing, uncovering, or digging deep for meaning. The output data is constantly maintained, consistent and objective facts or meanings are revealed, and so, more consistent with realist epistemes. However, the travelling metaphor is more suited to the constructionist and CR ontology in that the interviews were not bound by the interview topic guide, the knowledge was generated by the interviewer. The researcher is also influenced by the journey and the participants shared experiences, and the constructed narratives are analysed for meaning through interpretation. The narratives are retold through the lens of the traveller, and validation is confirmed by the audience, who in turn reflect on the impact the traveller tale has had on them. By accompanying the participant on the journey, the interviewer can lead them to predetermined "sites" along the way, as described by Kvale's metaphor (Kvale, 2007).

The initial planned goal for the interviews was to understand the GPs experience of insulin initiation in T2DM, to seek their perspectives. During the journey, reflection by the insider GP caused reflective learning, initially, in terms of biomedical knowledge of T2 DM management, insulin delivery and insights to how practice leaderships may manage delegation at their practices, and later in how GP may attitudinally behave in PCC.

3.3.3 Triangulation

Triangulation involves using alternative perspectives to validate, challenge or deepen understanding of existing findings (Turner and Turner, 2009). Different types of triangulation can be applied: data triangulation, investigator triangulation, theory triangulation, methods triangulation (Flick, 2020). This research has employed methodological triangulation, which meant using more than one method to expose different perspectives when understanding phenomena in qualitative research (Flick, 2012).

Triangulation may add to the quality of the research by extending the researcher's activities beyond usual qualitative practice and so enhance the validity of that research, and particularly applies to mixed qualitative and quantitative methods (Flick, 2012). However, it has been argued that extending, deepening and challenging the data with different mixed qualitative approaches is more valuable than data validation (Flick, 2018). Between-methods triangulation involves several stand-alone methods to create data, whilst with-in methods triangulation is the systematic combination of two or more theoretical approaches to data within the same method (Flick, 2012).

The results of mixed qualitative methods research may then provide complementary findings that illuminate different facets of the issues being studied. The effect has been argued as providing multiple lenses to examine the data within a qualitative inquiry and has been described as 'multi-genre crystallisation' (Denzin, 2012; Ellingson, 2014). The findings then provide thick interpretation, reflexively embed the researcher in the inquiry and make explicit the subjective nature of the outcome findings, leaving aside positivist claims for objectivity (Guba and Lincoln, 2005; Denzin, 2012; Flick, 2012).

This research has aimed to combine two complementary and yet different analytical approaches. The use of thematic and narrative analysis methods to understand data from interviewing participants has been presented by Robichaux, who explained a narrative structural analysis and thematic analysis of nurses' reflective accounts of their experiences in the critical care setting (Robichaux, 2002). Robichaux's methodological approach was acclaimed by Riessman for the effective combined use of narrative SA and thematic analysis in her authoritative text on narrative methods (Robichaux, 2002; Robichaux and Clarke, 2006;

Riessman, 2008a). Her support for the combined and triangulated use of the two methods has been supported since then by other narrative researchers including Braun and Clarke (Lainson, Braun and Clarke, 2019; Braun and Clarke, 2021a).

The commonality between reflexive TA methods and Narrative SA methods employed in this thesis have been more recently valued for specific congruences by Braun and Clarke (Lainson, Braun and Clarke, 2019). Recognisably, the similarities are rooted in respectful attention to participant subjective accounts:

- Reflexive TA conceives themes as constructions and rejects positivist methods of inter-coder reliability, saturation or quantified prevalence that may signify significance in quantitative methods.
- Like constructionist epistememes, reflexive TA does not seek essential truths or objective researcher reporting but embraces researcher interpretive and subjective use of resources.
- Accountability takes the form of the researcher's openness in epistemological assumptions, social location and research decisions.
- Openness, methodological congruence, and consistency with the researchers' chosen theoretical framework all make a significant contribution to rigour and validity.
- Knowledge is co-created by the researcher and the participant, in terms of explaining the experience, social structures and discourses that shape the resultant story told.
- Close attention to detail and awareness of the implicit in the accounts makes the reflexive account and the story meaningful.
- Encourages the researcher's reflexivity in conducting the research.
- Utilises the participant own words and contextual meanings to report the analysis, adding the rich description.

It is hoped that making explicit the ontological and epistemological position of this thesis clarifies the grounding for the employed reflexive TA and narrative structural analysis (SA) in the form of a crystallisation or triangulation of method has aided accountability. The following sections go over the reflexive TA and narrative SA.

3.3.4 The reflexive thematic analysis approach

Thematic analysis (TA) methods were popularised in health research after Braun and Clarke published a seminal paper describing its use in psychology (Braun and Clarke, 2006). TA methods have since been used in a variety of forms and within different epistemological paradigms and methodological approaches such as grounded theory (GT) methods, interpretive phenomenological analysis (IPA), discourse analysis (DA), narrative inquiry. Other methods were considered for this research, such as GT, DA and IPA, which are theoretically informed and methodologies in their own right. The research design employed in this research used the reflexive TA approach because it was most suitable for the context and research aim. Reflexive TA offers a more theoretically flexible technique that can also be applied with the narrative approach and achieve triangulation of data (Lainson, Braun and Clarke, 2019; Braun and Clarke, 2021a).

The reflexive TA method requires analytical and interpretive work by the researcher to develop hierarchical themes (Lainson, Braun and Clarke, 2019; Braun and Clarke, 2021a). Coding evolves from the researcher's deepening understanding of the data, and themes are developed later after an initial coding and refining process. Themes "*are patterns of shared meaning, unified by a central concept or idea*" (Braun and Clarke, 2014). Themes are not the predetermined topics, and participants may talk about a topic, but the themes generated are multifaceted and could draw together data that appear disparate. For example, a topic such as biomedical diabetic knowledge and the themes generated during analysis draw upon GP confidence, attitude to EBM and guidance.

The researcher generates themes through engagement with the data. There is an acknowledgement of the researcher's prior conceptual influences rather than seeking the inter-coder agreement intrinsic to GT methods. The researcher applies a reflexive approach by constantly reflecting on their assumptions that may determine, shape or even limit their coding (Braun and Clarke, 2021a). Interpretation is integral to reflexive TA and more than a simple descriptive or summative process. Subsequently, reflexivity is critical to the TA process and allows the researcher to consider the prior knowledge available in the topic area and make explicit the position and stance (Braun and Clarke, 2021b).

The reflexive thematic process of coding and theme development is explained in more detail in section 3.9. The next section explained the narrative approach.

3.3.5 The narrative approach

This subsection will discuss the narrative approach used in this thesis based on the premise that by telling a story, the constructs and meanings in that story can be found. It is a retrospective shaping and ordering of experience (Riessman, 2008a). It has developed from a concern to find meaning from everyday aspects of life that are otherwise taken for granted. Narrative approaches can be understood in terms of theories and methods (Riessman, 1993; Phoenix, Smith and Sparkes, 2010; Sparkes and Smith, 2013). Epistemologically, narratives provide a way for people to construct stories about their lives- the ‘telling’ and a method or means of knowing about their lives (Bruner, 1987b). Narrative constructionism attends to the social interactions and so how people act and behave in relation to others. Therefore, meaning is generated not simply through explicit expression by the participant but through the way they have explained their narrative about themselves, others and the context in which the narrative occurred (Sparkes and Smith, 2013). Notably, that context is from the teller's perspective. It is not relevant for reported events from a personal narrative to correspond to or be supported by other kinds of evidence. The aim is not to verify the facts but to understand the meanings for individuals and groups and is exemplified by the constructed stories of alcoholics by Cain, where the value of the narratives was in the meaning and not whether the detailed sequence of individuals alcoholism was correct (Cain, 1991).

Consequently, accounts in narrative inquiry methods are comprised of descriptions of events organised by the teller in meaningful ways, explanations of the actions of the teller and others involved, and the connection between events and actions over time (Chase, 2005). However, the meaning that narrative methods provide can be enduring through time and generations. Rather than being a simplistic case-based qualitative descriptive method, narrative can provide elevated meanings of complex experiences that resonate with communities of the audience. It is hoped that the GPs’ accounts in this research can similarly resonate with the GP and broader primary care audience.

The narrative approach offers an interpretive research method to reveal knowledge of GPs' working lives and a perspective of their reality by looking at the concepts of structure, agency and the relations between them (Greenhalgh, 2016). Significantly, this thesis is mindful that the ontological approach of critical realism reinforces that truth exists independent of the knower and the researcher and the employed narrative constructionist epistemology. Consequently, narratives allow the revelation of memorable, evocative, and inspiring stories from the teller's perspective and interpretation by the listener. The truth remains outside of both the teller's and listener's perspective, and narrative methods do not profess to present the truth in the deductive epistemological sense or any other positivist direct sense (Greenhalgh, 2016). However, this thesis hopes to inductively reveal the narratives of GPs who listen and interact with patients and others in their working environment. Thereby, the GPs may explain their understanding of the complexity involved in their medical practice and may provide understanding of the GP interpretation of biomedical health, person-centred perspectives and how that translates to healthcare management.

The narrative aim to understand individuals' culture and life experiences is a case-based inquiry, which contrasts thematic analysis, which seeks commonality across the group. Reissman clarifies the difference between narrative methods and qualitative methods that seek commonality across cases to identify themes- such as grounded theory (GT), interpretive phenomenological analysis (IPL) (Reissman, 2008c). Narrative analysis methods retain a case-centred analysis of the data, and the aim is to keep the story intact during interpretation with often longer segments of text. The long segments of text retain sequence and detail and provide rich context without fracturing the data into smaller units of text, such as line-by-line coding within GT methods (Reissman, 2008c). Other special features of narrative approaches:

- Prior theoretical concepts are made explicit as part of reflexivity but do not drive analysis in narrative methods.
- Sequences in the narrative are preserved during interpretation, and the story is kept intact. The researcher will determine the boundaries of the narrative segment interpretively.
- The context detail of time and place are attended to because of the subjective interpretation of the data and place the methodology firmly amongst the qualitative methods that cannot be generalised to other groups, but generated knowledge may be transferable.

In a narrative, we incorporate our sensations and perceptions and desires and ideas into a form that we first tell ourselves and then tell others (Charon, 2004). The narrative can create order, contain emotions and search for meaning and connection between events and people. In this way, participants may create a structure of experience and purposefully construct events that occur in life. Jerome Bruner even argues that the individuals do not just tell their life story they become the autobiographical narratives they tell to explain their lives. The very narrative is part of their identity and meshes with the community of life stories and deep structures in any one culture (Bruner, 1986). Furthermore, culture itself may be characterised by the narrative models. Bruner described a 'toolkit' belonging to a culture that is made up of 'canonical' life narratives like heroes and tricksters. There are also stances and circumstances that members of the culture can use to construct their own life narratives (Bruner, 1987a).

Therefore, narrative analysis methods aim to make sense of the story that people tell their listening audience (Spooner, 2013). The audience may be the listening interviewer and the wider community, organisations, or institutions, and this audience hears constructed stories helping to shape their understanding of individuals within their culture.

This research employed a narrative structural analysis method as a different approach to the data and displayed tensions identified in the data. From a narrative perspective, tensions can be driving forces in a narrative that direct the action taken by the participant in his or her account of events.

The work of Kenneth Burke presented a key concept of "*trouble*", which is a type of tension that may present in a narrative account. Kenneth Burke described five key terms in a structural narrative that represent strategic points at which motives or reasons for action may arise (Burke, 1945):

- The agent describes the person that performed the act.
- The action describes what took place in thought or in deed.
- The agency or instrument describes the means used to perform the act.
- The scene or setting describes the situation the act occurred in.

- The purpose or goal for the act describes the outcome aim of the act.

Similarly, Labov employed narrative structural analysis *to understand and explain events* in terms of the three main aspects of a story- the moral, plot, and genre (Labov, 1972; Robichaux, 2002).

More latterly, within fully formed narratives, Robichaux employed six main elements of narrative to understand the accounts of critical care nurses and was commended as a credible adaptation of Labov's approach by identifying structural aspects of the nurses' accounts combined with a thematic analysis (Robichaux, 2002; Riessman, 2008b). *These elements are:*

- *the abstract, summary or points of the story,*
- *the orientation in time and place character or situation,*
- *The complicating action, the event sequence or plot,*
- *The evaluation where the narrator steps back and comments on the meaning and communicates emotions,*
- *The resolution or outcome of the plot,*
- *And finally, the coda where the narrator ends this story brings the action back to the present.*

Robichaux's research was sensitized by her own insider experience of working with critical care patients and encouraged nurses to reflect on patient care that they believed to have shown aggressive medical intervention that was futile for the patient (Robichaux, 2002). Thematic analysis showed recurrent themes that Robichaux developed further into typologies of nurse activities, such as protecting the patient or experiencing frustration.

Robichaux also applied triangulation of methods using the structural analysis with the thematic analysis. By identifying the structural elements of the nurses' narrative accounts, she found patterns of accounts such as an introductory abstract or summary and an orientation (Robichaux, 2002; Robichaux and Clarke, 2006). Throughout the research, the patient's situation was viewed from the nurse's perspective and was resolved positively or negatively according to their experience and evaluation. Robichaux's illustrative example of combining

thematic analysis and narrative structural analysis to achieve triangulation was an endorsed exemplar of the methodology and was similarly applied for this research with GPs (Riessman, 2008b). The next section will explain the methods employed in this research.

3.3.6 Trustworthiness

Trustworthiness in qualitative research has been described as the quality of ‘theoretical knowingness’ (p268 in Braun et al., 2022). Quality criteria can be formulated as checklists to aid identification of rigor. Braun and Clarke advocate such criteria whilst being mindful to approach such checklists as ‘recipes’, but to engage with the data, employ reflexivity and deliberately apply theory to achieve trustworthy accounts.

Quality requires thoughtful immersion in the data, identifying and interrogating their positions, decisions, and beliefs, rather than frequent and repetitive accuracy (p14 of Braun and Clarke 2022). As such, reflexivity is a journey which begins with the acknowledgement of the philosophical stances, the critical realism ontology and constructionist epistemology have already been clarified, and the researchers’ prior assumptions and insider GP sensitising concepts were explained in section 3.2. It is important to acknowledge researcher prior assumptions in addition to the insider GP (section 3.2.1). These include past biomedical training as under and postgraduate doctor in UK institutions such as the RCGP, Royal College of Paediatrics and Child Health, and Faculty of Family Planning.

Researcher training in qualitative research literature reviews (School of Health and Related Research at the University of Sheffield, 2019), and content analysis course in December 2018 narrative methods courses add qualitative methodological assumptions to overlay a positivist medical training. For example, a narrative methods course in 2008 with Arthur Frank impressed a particular person-centred view through patient narratives to orientate this thesis early in its design (Frank, 1995, 2004). At the point of research design in 2008, narrative methods were chosen and reported in the initial MPhil dissertation in 2009. Immersion in narrative methods (Labov, 1972; Burling and Labov, 1975; Bruner, 1987a; Polkinghorne, 1995; Riessman, 2008a) with a plan for triangulation with thematic analysis and reflexivity formed the basis for the later use of reflexive TA at the time of supervisor change in 2016. Professional assumptions of the insider GP were explained in section 3.2.

Additional perspectives of social privilege may come with the GP status, but additional consideration for individuality and personhood also come the researchers' own social marginality views as a female British Indian woman. The associated life experiences of identity and racism add to an arguably more liberal world view and theoretical commitments to views of individualism, personhood, feminism, Hindu religion and racial equality.

The approaches other types of thematic analysis may take to confirmability and trustworthiness contrast with reflexive TA (Braun and Clarke, 2021a) and narrative approaches (Riessman, 2008a). Coding reliability approaches to TA, the frequency of themes and use a structured coding frame or coding book (Braun and Clarke, 2021a, 2021b). There may be multiple coders working independently, so the reliability of the data is assumed because of the consensus of agreement between multiple and independent coders. The premise then is that individual coder subjectivity is a bias and contrasts with *reflexive* TA in which the independent researchers' reflexive interpretation is valued. Braun and Clarke argue that coding reliability methods apply positivist research values that typically are associated with quantitative methods because of the emphasis on reliability, generalisability, and objectivity (Braun and Clarke, 2021a).

The third type of thematic analysis involves a structured codebook approach that employs the values of reflexive TA. There is early theme development and conceptualisation of themes as topic summaries. There may be a team of coders who independently code different parts of the data set, and the codebook is a pragmatic chart to manage the coding process in a time frame and facilitates the teamwork required. Reliability is not an integral aim for this type of codebook process, and there is recognition of the need for internal reflexive practice of each coder when generating themes. The methods and explicit way the TA process has been followed create the credibility.

The internal reliability of qualitative research conveys the extent to which the research consistently achieves categorisation during analysis and interpretation (Braun and Clarke, 2013, 2021a). This was addressed in this thesis using verbatim representations of interview data and focus on interpretation. The recorded interviews were an accurate record of the interview data. During analysis, the recordings helped to clarify participant meaning if the transcribed data was unclear. Context and tone can provide additional depth to descriptions and

interpretation, and familiarity with the recorded interview adds to the persuasiveness of data (Riessman, 2008d).

Braun and Clark provide an updated quality checklist for thematic analysis research and is applied in this thesis. Although it was developed for reflexive TA purposes, within the premises that reflexive TA combined with narrative SA is supported by Braun and Clark (Lainson, Braun and Clarke, 2019; Braun and Clarke, 2022). The checklist considers key aspects of the PhD journey: journaling recording in the NVivo data, analysis over time, insights from discussing with supervisors and peers, naming themes with care over iterations, inspiration from published examples, audit trail (Nowell et al., 2017; Braun and Clarke, 2022). The criteria are explained in the table below. (The criteria definitions have been rephrased and the table headings are referenced to avoid plagiarism).

Table of quality criteria as explained as 15-point checklist by Braun and Clark (at p269 of Braun and Clarke, 2022).

| Process | Criteria |
|------------------------------|---|
| Transcription | Transcription of the data in appropriate detail, and checked against the original recordings |
| Coding and theme development | Each case has been thoroughly and repeatedly examined. |
| | Coding as a “ <i>thorough, inclusive and comprehensive process</i> ”, and themes are not superficial or anecdotal (Nowell et al. 2017; Braun and Clarke, 2022). |
| | All coded extracts for themes are categorised and collected. |
| | Themes checked again back to the original codes and dataset. |
| Analysis and interpretation | Internal coherence, distinctiveness and consistency of themes, with a central organising concept. |
| | Data has been analysed and interpreted, not described. |
| | The reported analysis and quotes coherently match each other |
| | Analysis is convincing as an organised story of the data and research topic. |
| Overall | A balance between the analytical report and the quotes provided. |
| Written report | Time and attention applied to the analysis process. |
| | The theoretical positions and assumptions are explicitly written |
| | Consistency between the method and the reported analysis findings |
| | The report language and concepts match analysis ontological positions. |
| | The researcher is active in the research process, generating the data. |

Reflexive journaling involved the annotations and memos recorded in the NVivo journal during analysis. These annotations allowed recording of immediate reflexive analytical reflection and

later additional commentary during cross-comparison of cases and later, themes. Multiple iterations of the NVivo journal were recorded and held by the software as an audit trail.

The interviews were transcribed as soon as possible with the help of a professional transcription service; the initial coding of the data began and continued whilst further data was collected—this allowed reflection on and comparison with the earlier interview data.

Additionally, the analysis took place slowly over years of immersion in the data. The researcher's earlier coding of transcribed data, detailed field and annotation notes, and the recorded data supported the ongoing analysis. Both recorded and transcribed data were used to provide interpretation of the data confidently. The early supervisor and later new supervisors for the thesis were encouraged by and supported the researcher's engagement with the data through feedback and discussion of data interpretation.

The outcome findings may be transferable rather than generalisable to another setting, group, or population. Accountability is accomplished by stating explicit researcher conceptual and epistemological assumptions as described in sections 3.2, 3.3.1 to 3.3.5, and explained in these preceding sections (Lainson, Braun and Clarke, 2019). It is hoped that rigour and validity are shown through the transparency of the methods employed within this theoretical framework. The six-phase process for reflexive TA methods is explained in section 3.9, and the narrative structural analysis process in section 3.12. Additionally, external reliability relates to how transparent the research processes allow others to replicate the study design and sampling processes. It is hoped that this has been achieved through the detailed methodology and methods explained in this thesis, such as the descriptions of how theory informed the researcher conceptually and making explicit the concepts of co-constructed interviews between participants and the insider researcher GP.

Specifically, the insider GP role has been considered conceptually and practically through the detailed descriptive account of the recruitment methods and interviewing of colleague GPs and is further reflected upon from the perspective of the findings. It is hoped that the transparent process of data collection, analysis, interpretation of the findings, and coherence of the interpretations creates a persuasive theoretical argument to add trustworthiness and, so, reliability of the findings (Riessman, 2008d; Braun and Clarke, 2021b). Reflexivity has been considered during the research journey, was recorded as annotations during the data collection

and analysis process, and researcher reflections occurred during supervision or after reflection on supervisory feedback. Reflection as an insider GP is documented in this thesis at different points: when reflecting on the literature conceptual framework and literature review (section 3.2.1), and later in the thesis journey.

3.3.7 Generalisability

Generalisability represents the information gained from research on a particular sample and setting that can be applied to a wider population or context (p143 of Braun and Clark, 2022). In the positivist sense, generalisability has been argued to be inappropriate and irrelevant to qualitative research because the samples are small and statistically not relevant or generalisable (Braun and Clarke, 2022). Lincoln and Guba offer helpful criteria of consistency and dependency in place of reliability or internal validity of research, and transferability as a form of external validity (Lincoln and Guba, 1985). Transferability refers to the reader's ability to view the data and judge how much they can apply the findings to their own context (Braun and Clarke, 2022). Rich description is required to meet the criteria.

Braun and Clark identified three issues in their recent explanation (Payne and Williams, 2005; Braun and Clarke, 2022), and the following questions may help clarify what may be sought to understand the generalisability of a piece of qualitative research:

- Can the findings be generalised beyond a specific context or setting?
- How has generalisability been defined in this research?
- Has a different concept been used to represent generalisability in the qualitative research, such as transferability?

The indication is that generalisability has evolved into qualitative formulations, and arguably may evolve further if researchers argue for more possible formulations within the boundaries of the ontological and epistemological foundations of the research. Braun and Clarke explain different types of generalisability that are currently recognised (at p 144 of Braun and Clarke, 2022), and imply an evolving field of qualitative research:

1. Intersectional generalisability: qualitative work that tracks patterns of the marginalised and oppressed social groups across the world, e.g., colonialism and its effects across

the world for oppressed peoples, such as the aboriginal cultural experience (Fine, Tuck and Zeller-berkman, 2023).

2. Flexible generalisability (FG) (Goodman, 2008): originates in discourse analysis methods where language and its content can produce pattern effects and may be shown by several studies that show the methods applicable across a range of settings. Braun and Clark use the example of discourse analysis (Goodman, 2008), and note that FG may apply to reflexive TA combined with discursive approaches that employ critical realist and constructionist approaches (as described below) (Terry and Braun, 2016).
3. Idiographic (Sandelowski and Leeman, 2012), analytical (Ritchie, Ormston and Morrel, 2014), or vertical generalisability (Goodman, 2008): richly theoretical and deductive forms of reflexive TA may produce new theory relevant to future research.
4. Transferability, inferential or case by case generalisation: the reader has the burden to decide of the specific context, participants and settings may transfer to their situation, whilst the researcher demonstrates reflexivity and explicit awareness of the context of the research to improve transferability.
5. Naturalistic or representational generalisability (Ritchie, Ormston and Morrel, 2014): the researcher demonstrates reflexivity and awareness of the context of the study, whilst the reader identifies personally with the data, or the findings resonate personally to them.

Narrative methods have been argued to represent ways to seek recognisable knowledge across different topics, finding patterns of meanings across analysed stories, and may suit the flexible generalisable category. For example, Cain's narrative exploration of self-understanding and identity through the personal stories of people attending Alcoholics Anonymous (AA) groups. Patterns within the personal narratives of individuals helped them identify as alcoholics (Cain, 1991). Cain's concept of a "*personal story as a learned form*" (Cain, 1991) may represent a method to explore identity, beyond the AA setting, to other forms of supportive growth groups and how individuals may internalise the narrative of an establishment or group for growth, learning or healing.

In terms of generalisability, the narrative structural analysis method employed in this research may fall under the category of flexible generalisability. Terry and Braun employed critical

thematic analysis and discursive analysis were combined to explore mens body hair and found new themes of negative representation of excessive male body hair (Terry and Braun, 2016), which unsettled the culturally dominant view that mens body hair was natural and unproblematic. The research was relevant to other research areas which considered how young men construct their body images as forms of self-expression (Gill, Henwood and Mclean, 2005). However, several studies may be required to show the discursive patterns of speakers on a topic will be produce similar meaning making in other settings (p144 of Braun and Clark, 2022).

To be able to apply qualitative research to other settings and contexts requires a consideration of ‘reasonableness’ test to apply to the findings, i.e., that findings can be reasonably extrapolated beyond the specific research setting and context (Braun and Clarke, 2022). This argument still reflects transferability, and requires the research to be reflexively presented, to consider how the findings may reasonably fit amongst the wider knowledge in the topic area, to reflect on the characteristics of the participants, context and settings and how that may have affected the results (Braun and Clarke, 2022). Overall, the theory and academic discourse on generalisability has extended beyond transferability, but generalisability in the qualitative sense remains rooted in each individual research retains integrity and any claims align with the ontological and epistemological philosophical basis, and the context and setting has been made explicit.

Whilst this thesis will not claim a positivist generalisability, the data may be transferable, and the thesis attempts to show consistency and dependency in methods and findings.

In summary, this research claims a critical realism ontological and constructionist epistemological approach to form the basis for reflexive TA and narrative structural analysis methods to analyse participant interview data. The data has been achieved through a loosely semi-structured interview approach and the researcher is positioned as a ‘traveller’ in the thesis journey to investigate the PCC approaches, experience, and attitudes of GPs in the setting of South Yorkshire, England.

The next section will explain the research methods.

3.4 Research Methods

This section will overview the specific qualitative methods employed in this research based on the methodological approach outlined previously. The planned research design was to recruit and interview 12 to 20 GPs and analyse their experience of insulin initiation in T2DM, including the complexity and context within which the GPs managed T2DM and planned insulin initiation. The aim was to provide descriptive and interpretive data to understand how they decide to initiate insulin in T2DM. The methods employed snowball sampling to recruit a purposive and varied sample of 16 GPs. Interviews were recorded and transcribed, and following initial familiarisation was coded thematically and recorded using QSR International NVivo software. Reflexive thematic analysis was performed across the 16 case transcripts to generate the outcome themes (Braun et al., 2018; Braun and Clarke, 2021). During the later stages of refining codes, tensions became evident. As part of the iterative process of qualitative research, a decision was made to analyse these tensions specifically using the narrative structural analysis methods and thus, provide triangulation to the outcome data.

3.5 Sampling

Sampling in qualitative research aims to gain in-depth and contextual knowledge when exploring a phenomenon (Kirchherr and Charles, 2018). Traditional sampling methods utilise a sampling frame that defines the inclusion criteria for the study population. A second step involves selecting a random sample from that identified group of people. This type of sampling method is suitable for quantitative survey designs (Given, 2008; Kirchherr and Charles, 2018).

Instead, a purposive sample is required where the inclusion criteria depend on the objectives and the research context (Given, 2008). This research aims to understand GP approach to PCC, their experiences, attitudes and activities when initiating insulin in T2DM. The individuals recruited for the sample are of interest because of their different characteristics to supply varied and interesting data. The aim was to seek a purposively diverse set of participants rather than conformity across the group of GPs (Higginbottom, 2004; Given, 2008). Finding the individuals to fulfil the purposive sampling methods required the sampling to consider the characteristics of GPs. Towards this aim, a demographic questionnaire was sent to the GPs

prior to the interview with the research information and consent form. Inclusion criteria were decided upon with the supervisor and advisory panel, who were key expert informants for the topic guide and initial research planning.

3.5.1 Sampling criteria

Variability in age and gender, year of qualification from GP vocational training, year of qualification with medical degree, MRCP, additional diplomas in specialist topics and additional degrees were questions aimed to understand the extent of additional professional qualifications. More years of experience in the GP setting, age and gender were suspected to add to variability. Previous research has sought variability in recruitment by the status of practices as academic and non-academic practice, with an assumption that academic GPs may have differing views to non-academics (Agarwal *et al.*, 2008; Luijks *et al.*, 2012). The intention in this research to seek variability in the GPs' qualifications were sought based on literature that shows that GPs with additional professional qualifications such as Membership of the Royal College of General Practitioners' (MRCP), were significantly less likely to report 'heartsink' patients (Mathers, Jones and Hannay, 1995). The prior assumption for this research was that GPs with varied qualifications may view chronic disease patients differently. Similarly, any special interest in diabetes at the practice was also separately questioned special views on diabetes may directly influence attitudes towards diabetes related decisions and perspectives.

The practice demographics of each GP were additionally sought. Again, the variability in the demographic population may reflect GP experience in chronic disease management and may also reflect additional variability in diabetic population experiences. Fear of hypoglycaemia for older age patients is a known clinician barrier (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021), whilst diversity amongst the GPs population may also related varied opinion on T2DM or chronic disease management (Kutob *et al.*, 2013; Ali *et al.*, 2016). Having a nurse with a special interest in diabetes at the practice may have had implications for how the GPs viewed and delegated care. Finally, principals manage staff and allocate resources, but non-principals may prescribe or lead chronic disease management care at practices without business or management roles.

The size of practice and the number of principal and non-principals at the practice may have impacted the individual GPs experiences of chronic disease management in the various practice sizes.

Although purposive sampling could be argued to be open to selection bias, there were anticipated barriers to recruitment. GPs are a busy and time-poor group of individuals within practices and were not easily approachable through practice or post-graduate educational meetings. Moreover, this research utilises subjective and reflexive methods that do not require theoretical saturation and progressive theoretical sampling, which is expected in grounded theory methods (Higginbottom, 2004; Braun and Clarke, 2019). Consequently, the chosen sampling methods were purposive and snowball sampling. The latter involves identifying ‘seed’ participants who then indicates one or more potential participants for the researcher to approach whilst still aiming for participant diversity (Kirchherr and Charles, 2018).

Snowballing can help identify populations that do not want to be contacted. This is usually said of less empowered population groups such as the homeless, but GPs can be arguably considered elites that present a similar challenge, although from an opposing socio-economic demographic (Blakeley, 2012; Huggins, 2014). There are limitations to the sampling methods and discussed in section 9.13.1, but the main strength of snowballing is the ability to seek a purposive and diverse sample of participants. The following sections explains the study population.

3.6 Study population

This research sought qualified GPs in the South Yorkshire region and included recruitment from Sheffield, Barnsley, and Rotherham. This geographical location for the sampling and recruitment was chosen for pragmatic and logistical reasons because of the researcher’s base in the regional area. As explained in section 3.5.1, a demographic questionnaire was devised to aid the process of recruiting a purposive and varied sample of GPs from the region. GPs did not have to be diabetic leads, and both salaried, sessional or locum GPs and GP partners were sought.

As explained before, the demographic questionnaire asked GPs to specify: age, sex, specialist degrees or diplomas, special interest in diabetes, practice population, number of partners at the practice and non-partners or salaried GPs, year of qualification from GP vocational training and with their medical degree, whether they had the membership of the Royal College of General practitioners (MRCGP) (because it was a voluntary qualification for GP practice at the time), the ethnic minority population size and an indication of types, population over 65y and whether they referred to secondary care or initiated insulin in practice. The next section describes recruitment in further depth.

3.7 Recruitment

Two recruitment methods were employed: firstly, an invitation letter sent through the post directly to the GP practices with a plan for purposive sampling. Secondly, a purposive and snowballing recruitment method was employed after initial interest from GPs, and further participants were introduced through the GP social networks locally (Ingleton, 2004; Kirchherr and Charles, 2018). Snowballing is particularly useful in populations that are difficult to identify or have known barriers to recruitment (Ingleton, 2004).

Initial identification and recruitment of GPs involved sending postal invitations to practices in the region. It was felt this was ethically more appropriate than 'cold-calling' GPs and may achieve some response. The postal recruitment method involved an information letter inviting GPs to participate and contact the researcher directly by email or mobile phone. Over a hundred letters were sent by post in the first recruitment phase. However, this process failed to have any responses, and two weeks later, it was followed up with a telephone call to the practice. Sometimes GPs were available to speak, but often the administration staff took messages. For some GPs, the invitation letter had sat amongst the general post without the GPs being aware, whilst others had been too busy to respond. The follow-up telephone call was helpful to understand why the postal invitation process had failed and highlighted the barriers to accessing GPs for research participation. Eight GPs (Dan, James, Vicky, Jackie, Cath, Charles, Jen and Harry) had agreed to participate after the follow-up telephone call. They were then also asked to suggest other GPs that may be interested in taking part.

As a GP, the researcher was aware of the time pressures of GPs, access difficulties of approaching GPs through practice reception staff and managers, and snowballing helped

overcome these first barriers to GP recruitment. None of the GPs later declined or withdrew. The researcher's contact with the recruited GP may have helped retain the GPs who had agreed to participate.

There are **limitations to snowballing recruitment** related to the potentially limited networks of GP and so diversity of the sample. The limitation of the sampling method is further discussed in subsection 7.2 The sample aimed to be diverse in GP characteristics and utilised the demographic questionnaire to aid the sampling strategy. Although the method cannot fully ensure sample diversity, it was successful to a certain extent and displayed (in chapter 5) by the demographic data of the sixteen GPs recruited (Kirchherr and Charles, 2018).

3.8 Data collection

Data collection involved semi-structured interviews with the sixteen GPs. An interview guide (appendix 12.3) was used to aid the opening questions to the interview, focusing on insulin initiation in the GP practice setting. This section details the interview process further.

3.8.1 Interviews

Qualitative interviews allow exploring participants' experiences and perceptions of the phenomena of interest in an in-depth way. Understanding clinicians' conceptions of working in their environment to achieve insulin initiation required a method to give voice to their subjective experiences. Accordingly, semi-structured interviews were the most appropriate method for the research design.

Specific efforts were made to achieve informed consent from the GPs to participate. GPs were asked to read the participant information sheet, consent form and complete the demographic questionnaire before the interview. These were revisited at the beginning of the interview. Some GPs completed the demographic questionnaires with the researcher at the interview and highlighted how busy the GPs were. All consent forms were signed at the interview. Only approximate numbers of practice population size were required, and so reduced the preparation and search of the practice database that the GPs had to do before the interviews.

3.8.2 Semi-structured interview and guide

This section will explain the interview process and the guide.

The GPs agreed to the time and location, and the length of the interviews was one to two hours each. They took place in the GP practices in a consulting room for most GPs, or a room at the university, and two GPs preferred to have the interview in their home when they were not working. The interview locations were chosen to suit the participants but recognised that the data was confidential to the GP and was expected to be about confidential patient information. Recording equipment had to be thoughtfully purchased with the limited resources from the awarded Claire Wand research funds to allow sound surround recording for the interview and ease of transcribing.

Following initial rapport building, GPs were invited to explain and discuss their insulin initiation experiences with patients and reflect on patient encounters in the practice setting. Involvement of the practice nursing team in T2DM management was anticipated, and the GPs were asked open questions to seek their perspectives of the GP and nurse roles.

The interview guide (appendix 12.3) was purposively semi-structured with an aim to ask the GPs to reflect on their experiences and their practice and have few predetermined questions (McGrath, Palmgren and Liljedahl, 2019). The less structured guide aligned to the research methodology and allowed exploration of issues presented by the participant (DiCicco-Bloom and Crabtree, 2006; McGrath, Palmgren and Liljedahl, 2019). The guide was tested with a pilot focus group of GPs within the University academic unit before submission to the ethics committee. The learning gained from the focus group helped develop interviewer skills and the guide but was not included in the research findings.

The ‘traveller’ and interview questions

To explain the semistructured nature of the interview further, section 3.3.2 introduced the “traveller” concept the applies to the researcher approach, and the appropriate suitability to the chosen constructionist episteme. With reference to Kvale (Kvale, 1996) again, the interview can follow a detailed thematic interview with many structured questions derived from research questions, whilst a looser topic guide requires dynamism in the interview and clarification questions to understand the the actions, attitudes, feelings and characters in the stories told

(Kvale, 1996). The questions were recorded and transcribed and were also held in the NVivo case transcripts for analysis purposes along side the participant comments. In the subsequent chapters the quotes provided may not have the associated questions, and as an example the following example displays the opening questions and part of the response (truncated) and a follow up question to display the narrative style of the interview. The full narrative section has been added to the appendix at section 12.4.

Interviewer

Right. So I just want you to consider any kind of diabetic patients that you've had that you've been involved in their care for and in particular just at this point, any patients that you have referred for or started insulin on that you can remember.

Respondent

We've had a couple of diabetics. I'm talking about my patients from the practice I left in June this year so it's a little bit fuzzy.

Interviewer

Yeah.

Respondent

But there were a couple of patients who I remember well. One of them was referred to the hospital because he had a bad foot and he had neuropathy and he was actually sent to the foot clinic and by the time they'd sorted him he came back to us on insulin so I didn't actually initiate him on insulin but I felt that it was the next step. ...**(truncated narrative- full narrative section at appendix 10.3)**... but there are reasons why people don't respond and you really need to see the person and you really need to be approachable and tell them – it's just the approach to him but he responded so beautifully and really a success story. I don't think he was ever started on insulin because he did well with the medication once he settled down so it's not quite the point but it's just really how you approach people I think is important.

Interviewer

Yeah. I mean that case in point that it's not just about the initiation of insulin, there is a whole load of things that you've talked about.

Respondent

“Yes and that may come and I think it's important to let people realise that it's not because they've failed that they need to go on insulin, if they do need to go on insulin...”

Rapport building was essential, and opening questions and topics helped ease the participant into the interview. The above example highlights the biomedical nature of the opening question and participant response, which was part of the design, and allowed rapport building. The follow up questions allowed clarification but was dynamic enough to allow the participant to

flow on. The open style and long narrative illustrate the freedom and time given to the GPs to openly tell their story (Kvale, 1996).

The participant was reminded of the research question and aimed to seek their perspective through a semi-structured and discursive interview style. They were aware their opinions were welcome alongside descriptive patient encounters and experiences from the GP position. Power dimensions of the interview were anticipated with more experienced and partner GPs. The researcher was also aware that GPs were potentially informing of their professional behaviours. Consequently, GPs may be aware of their wider medical audience and describe what they perceived was expected rather than openly reflecting on their experience. Importantly GPs were also reminded in the interview and through the participant information sheet that their data was confidential and could withdraw at any time.

3.8.3 Insider researcher and interviewing skills

The qualitative interview requires the conceptual and practical preparation of the interviewer (Kvale and Brinkmann, 2015). The researcher was also a practising GP, had no particular interest in diabetes clinically, and had similar regional training, patient and practice experience as the recruited GPs. However, every GP practice can vary, and individual training and patient experience can mould GP development differently. Reflexivity was critical to the process and manifested as a reflection during the interview as field notes, Nvivo journal memos and NVivo annotations during analysis. Discussion with the supervisor allowed additional reflection and feedback on the process, with plans for iterations to the interview questions, development of skills in the facilitation of the interview.

The pilot focus group explained in section 3.7.2 helped the researcher gain insight into how to question experienced GPs to reflect for research in contrast to consulting patients or motivational interviews for students and GPs for appraisal. Active listening was vital to understanding the GP experience, with summarising, clarification, sometimes probing questions at times of interest, whilst aiming to return to the research focus.

The qualitative researcher is recognised as the instrument for data collection and co-constructs the data with the participant (Riessman, 2008; McGrath, Palmgren and Liljedahl, 2019; Braun and Clarke, 2021). In this research, the GP interviewer was an 'insider' with knowledge of the

biomedical language used by the interviewees. The co-construction of interview data also extended into the commonality of understanding of general practice from the perspectives of training, biomedical knowledge, patient care, and the regional experiences of GP. The researcher had the opportunity to reflect and learn from two early interviews with a departmental colleague, a psychologist (and so not a GP), and offered feedback from her perspective on two interviews and the thematic analysis process. A key learning point was to be reflexive and mindful of assumptions during this co-construction of the interviews and analysis of the data. Even silences may be opportunities for ongoing reflection, expressed emotions were valuable and carefully considering the generated coding by taking account of the participant perspective rather than the researcher assumptions (Kvale, 1996; McGrath, Palmgren and Liljedahl, 2019). The co-construction could lead to tacitly assumed opinions and experiences, and the researcher had to be mindful to make individual GP experiences explicit through the active listening process. Further to this awareness of the insider researcher and co-constructed data, strengths and limitations are further discussed relevant to these resultant research findings in subsection 9.13.

3.9 Reflexive thematic analysis

The reflexive thematic approach to the data analysis has been explained in section 3.3.4. Themes organise data that have patterns of shared meaning around a unifying central concept (Braun and Clarke, 2022). The process of coding explores the patterns and meanings in the data and aims to produce labelled codes as an output, that are conceptually meaningful segments of data (p 53 of Braun and Clarke, 2022). In this data means the textual transcribed data, but familiarisation did include the audio-recorded interviews.

The codes were developed with the research question of understanding the person-centeredness of GPs when considering insulin initiation in T2DM in mind:

- 1- The unifying and organising core concept that may have multiple facets.
- 2- There are boundaries around the theme that determine what is included and excluded.
- 3- There is sufficient meaningful data to support and enrich the theme.
- 4- On the other hand, the data in the theme are not overly diverse or broad.
- 5- The theme contains useful and meaningful information about the dataset and research question.

The use of questions during coding can aid coding and applicable across qualitative research disciplines (Saldaña, 2013b). The questions considered in this research were:

- What are the GPs saying they are delivering insulin initiation?
- How do they characterise or understand what is going on?
- What assumptions do the GPs make?
- What assumptions have I made?
- What was surprising or created tensions?
- Were there meanings that were disturbing? Indicating researcher tensions to track attitudes and value systems of the researcher.

Consequently, the thematic generation method employed for this research was an active six-phase process outlined by Braun and Clarke (Braun and Clarke, 2013, 2022):

1. Familiarisation with the data - involving reading and re-reading transcribed interview

data with initial interpretive notes.

2. Generation of initial nodes - systematically coding interesting features of the data across all the interview transcripts.
3. The collection of nodes into potential themes – grouping the data into potential themes relevant to the research question
4. Review and refine themes – verifying that the collated extracts form a coherent pattern and whether each theme reflects the data set.
5. Defining and naming themes – seeking to ensure that the collated data extracts are organised, coherent and internally consistent.
6. Produce a report - providing a coherent account representing the analytic narrative and argument in relation to the research question.

Codes are the basic units of analysis and in NVivo, they are called nodes. Both are labels for concepts or ideas capturing description, interpretation and conceptual information identified during analysis of text. It is an arguably, reductionist process, thus reducing the data. As such, and being mindful of the planned narrative approach, the amount of text was kept broad for some meanings that may lead to narrative structural analysis. For thematic coding, the interview accounts were ‘split’ into smaller lines of text or ‘lumps of text’ (at p22 Saldana, 2013b) or longer lengths were also coded, depending on the meaning identified. Aided by coding labels, code properties (detailing the nodes meaning at the time of creation), annotations and memos recorded in the NVivo journal and linked directly to codes and text. It was then easy to identify the analysis thoughts and ideas along the way.

The quantity of nodes, annotations and memos created was initially overwhelming and is a recognised part of the qualitative researcher journey (Saldaña, 2013b; Braun and Clarke, 2022). Discussion with supervisors, reflection and then later examiner review helped and despite interesting accounts and associated analysis, familiarisation, coding and thematic analysis was an expected difficult reflexive journey.

Braun and Clarke defined key features of the thematic analysis that was employed in this research. Firstly, that themes are generated in reflexive TA methods and not emergent, and as explained earlier in this chapter, theme generation was a conception reinforced in this research because of the accepted ontological and epistemological positions (Braun and Clarke, 2021b).

Secondly, Braun and Clarke (Braun and Clarke, 2006) argue that there are various conventions for describing the prevalence of themes and that this prevalence across the data set can be flexible. Importantly prevalence of a theme is not exactly quantified in qualitative methods and usually will not be present across all the participants. Braun and Clarke reference examples of how other researchers have also described prevalence descriptions:

- “*across the majority of participants*” (Meehan, Vermeer and Windsor, 2000)
- “*many participants*” (Taylor and Ussher, 2001)
- “*a number of participants*” (Braun, Gavey and McPhillips, 2003)

In this research, thematic saturation was conceptualised using the reflexive TA meaning of saturation and applied the definition of thematic saturation as “*a number of participants*” (Braun, Gavey and McPhillips, 2003). Braun and Clarke also question empiricist framings of the concept of saturation. More specifically, in grounded theory methods, there is a link between information redundancy, theoretical sampling size and concurrent data collection (Braun and Clarke, 2019). Significantly, Braun and Clarke also support arguments from qualitative researchers who criticise the definition of data saturation as new information and state that this conception of saturation is logically false (Braun and Clarke, 2019; Low, 2019). In reflexive TA methods, meaning generated by data that requires interpretation by the researcher is embedded in the interpretive research process.

Consequently, new meanings are then possible beyond points of saturation (Braun and Clarke, 2019). They also argue that sampling size is also a pragmatic practice and often connected to normative influences: local context, the topic discipline, the expectations of journals, or financial and time resources of the research (Braun and Clarke, 2019; Low, 2019). Consequently, Braun and Clarke recommend that reflexive TA methods do not seek saturation as a key sign of validity in reflexive methods (Braun and Clarke, 2019).

From the reflexive and interpretive approach taken in this research, important themes are valid if some participants stated them and gave meaningful insight into the influences that theme had on the person-centredness of the GP decisions to initiate insulin in T2DM. Throughout the findings chapter, there will be illustrative quotes and explanations of themes and their hierarchies, aiming to make explicit the research engagement with the data, transparency of the data, internal validity through the reflexive thematic analysis process.

The NVivo software by QSR international provided transcript data storing, recording of annotations and memos for significant researcher reflexive analytical points. The process of analysis involves initial coding and recorded in the software as nodes. Further refinement of these nodes into different hierarchical nodes can be collected and traced using the software file. This tracing back to initial unrefined nodes can be done even after developing final themes as findings outcomes.

After initial familiarisation with the transcripts and the notes accompanying the interviews, the coding process within the NVivo software files was begun. The following paragraphs explain how this research utilised NVivo software to create nodes and themes to add to the transparency of the process.

- In the early phases of analysis, an unrefined node recorded sections of transcribed text within categories and was labelled with descriptive or meaningful concepts. This process of coding in the NVivo software was researcher driven and did not employ the Nvivo software analysis tools such as text or word queries in the early phases. However, the creation of nodes allowed sections of text to be stored under descriptive node headings. The nodes were containers of the data that had been categorised under a concept such as ‘HCP with diabetes’ or ‘QOF’.
- The same text may have been categorised under multiple different nodes because it had different meanings under different descriptive node labels. For example, node labels seemed sensical from the GP insider biomedical perspective, such as EBM and HbA1c targets. The same text also had a meaningful message in relation to another concept, such as the ‘strong’ medication. At other times, nodes were named by reflecting on the interpretation of the text, such as patient refusal of insulin and ‘strong’ medication.
- Codes were then categorised in hierarchies because of meaningful links generated between codes at the same or hierarchical levels. To aid the process of comparison, linking, and refining nodes, the NVivo software allowed visualisation of the coded data in terms of NVivo trees of nodes and allowed sections of data to be seen with associated coding stripes (Bazeley, 2007).

- As cases were analysed, nodes that were created with conceptual titles were reviewed for thematic conceptual consistency. If nodes had been created that represented similar concepts, the review and refinement process led to merging them or even ‘binning’ nodes that were found to be redundant.
- As further interviews were analysed, the iterative reviewing of nodes allowed checking and rechecking associations between cases. Nodes were also generated from cross-comparison of concepts such as ‘insulin as a failure’, which had different meanings from the biomedical and person-centred perspectives, and later generated significant themes.
- The final Nvivo files stored coded data in tree formation and were composed of hierarchical nodes and child nodes that could store quotes or longer sections of the analysed text. This data was held in a password protected ‘cloud’ storage in keeping the Sheffield University ethics and data protection policies. Case GPs were labelled with pseudonyms that had no association with the GPs own names and allowed an understanding of the GPs as male or female for the reader.

With the analysis of later case GP interviews, initial nodes were confirmed and further refined into hierarchical order. This refining process allowed the nodes to be organised into a hierarchical structure that could develop into potential themes and higher-order constructs—subsequently, producing a final report required further hierarchical thematic development.

3.10 Hierarchical thematic development

The final descriptive nodes were held within the NVivo software and allowed representation of the data as descriptive coded concepts once the 16 cases had been analysed. The nodes had developed through the description, comparison and seeking relationships between them (Bazeley, 2013c, 2013a). However, through thematic refinement, further reflection on cases and cross-comparison of cases, further sense-making created an understanding of the meaning beyond descriptive category codes. Braun and Clarke explain that this final process is key to the interpretive process in reflexive TA. There was a transition from interim research text,

coded quotes, and reflexive annotations within the NVivo software files to final research texts. The data was read and re-read multiple times, created engagement, and allowed deeper understanding to make sense of the complexity presented by the varied attitudinal stances presented by the GPs.

Seeking meaningful patterns in the data around the research question generated themes that had central organising concepts. GPs described both memorable patient encounters and reflected on their overall opinions and evaluations about insulin initiation in T2DM. As a result, the coding process also inductively generated themes that influenced GP decisions to initiate insulin beyond the boundaries of the biomedical decision of insulin initiation for individual patients. As part of the iterative and exploratory qualitative research process, these influences were recognised as valuable insight into how GPs decided to initiate insulin in T2DM.

The hierarchical thematic analysis during these later interpretation stages also allowed coherence with the wider literature by indicating the conceptual and theoretical coherence of the generated themes. For example, the hierarchical concepts of biomedical and person-centred constructs were conceptually coherent with the literature review hierarchical themes. Moreover, the literature review themes are explicit prior knowledge and sensitising themes from the conceptual framework. Consequently, the inductively achieved outcome themes from this research were confirmatory of some of the literature review findings and made explicit the position of this research amongst the wider literature. This final level of thematic interpretation required challenging the data to understand the meaning and implications of the themes and categories. Reflecting on the different cases and even groups of cases, such as diabetic leads in practice or GPs displaying empathy, prompted ideas about relationships across cases as part of the cross-comparison process and developed concepts to develop into thematic hierarchies of understanding and possible theory building.

3.11 Tensions

This section explains how a contrasting narrative analysis process was employed to explain tensions identified during the thematic analysis. Tensions were generated when interrogating the data to seek links, relationships and comparisons between identified themes (Bazeley,

2013a; Braun and Clarke, 2021b). Tensions can be inherent in all aspects of life, including education and healthcare.

Tensions can present in different ways and are dependent on the context of the research questions and the theoretical frame of the research. This research recognised main types of tensions:

- **Emotional tensions**, specifically discomfort caused by difficulty, uncertainty and problematic situations (Hong, Falter and Fecho, 2017), and,
- **Contradictory meanings evident when comparing generated themes** (p107 of Braun and Clarke, 2022). Additionally, each theme or node should not contain a interpretations contradictory to the central concept of the theme. For example, the NVivo node ‘confidence gained from past experience’ contained the child node: ‘Negative outcomes for patients reduce GP confidence in GP decision making’. Reviewing the interview text, it was relabelled as ‘Reflective learning from negative patient outcomes’, because of the GP was explaining learning from a negative evident. However, reconsidering the node, revealed an additional internal tension of ‘inevitable risk in patient care’ (below).
- Within the latter theme was a latent thematic message that negative patient outcomes were an inevitable risk and part of the job, constituting an uncomfortable acceptance that such as risk was inevitable: **a tension internal to the theme.**

According to the constructionist epistemological foundation of this thesis, the data does not provide a “*transparent window*” (Braun and Clarke, 2006) to the social construction and reality of the participants' world. However, a constructionist positioned thematic analysis will expose contrasts, links and conflicts between themes that enlighten how participants' experiences of reality result from the social constructions of participants' culture, society, and the world (Braun and Clarke, 2006). The refining and defining of the hierarchical themes involved identifying internal consistencies within themes and then comparing the coherent messages between themes, exposing opposing and contrasting concepts such as lack of knowledge and duty of care, which indicated tensions. Moreover, tensions were significantly evident when interlinking, comparing and contrasting themes between the dominant perspectives of biomedical, person-centred, and GP-centred perspectives (Braun and Clarke, 2006).

Qualitative analysis approaches seek to uncover and deconstruct such tensions to get a deeper understanding of the world's complexity, particularly when they manifest as human encounters within the social environment (Hong, Falter and Fecho, 2017). Arguably, a thematic analysis may not acknowledge dissonance or tensions in the data nor offer deeper interpretations of the co-constructed data between researcher and participant (Hong, Falter and Fecho, 2017). However, narrative methods may reveal such depth further, evaluate and make sense of tensions which are often integral to experience (Mertova and Webster, 2019). Consequently, triangulation with a narrative approach to understanding the tensions evident thematically may credibly strengthen the output findings.

For example, the GPs showed awareness of a patients' perspective of diabetic health – but from the GP position. Consequently, the GPs ability to frame the patient diabetic health in terms of their views of the patient – The GP' perspective of the person. When there was inconsistency or incongruence between biomedical and the patient-centred views, then tension was evident. The concepts that were generated as tensions were also inductively evident during the cross-comparison of case GP narrative accounts and cross-comparison of identified themes. Tensions appeared as links between identified themes and refining nodes to hierarchical NVivo nodes (Bazeley, 2013b, 2013a).

Additionally, tensions were evident when comparing how different cases were represented within the themes. For example, the concept of 'strong medication' emerged from GP accounts of patient perceptions of insulin as a 'strong' medication related to refusal of insulin therapy. However, the GPs also perceived the harmful risk of medication from the biomedical perspective and led to cautious prescribing concepts (section 8.5). Therefore, a further and final analysis of the transcribed data was performed using narrative structural analysis to explore these tensions further. The following section explains the narrative analysis process employed in this thesis.

3.12 Narrative structural analysis

In this thesis, tensions identified following hierarchical refinement and investigating relationships between concepts were explored further using a narrative method. The methodological basis for the narrative approach employed was explained in section 3.3.5 and

has been aligned to the combined thematic and narrative structural analysis work by Robichaux (Robichaux, 2002). In this research, seeking narrative components identified narrative text segments, particularly the orientating features or abstract or summary. The segments were displayed in tables to show how words or lines of text related to the relevant structural component and used the following labelling:

- *AB= the abstract, summary or points of the story,*
- *OR= the orientation in time and place character or situation,*
- *CA= The complicating action, the event sequence or plot.*
- *EV= The evaluation where the narrator steps back and comments on meaning and communicates emotions*
- *RE= The resolution or outcome of the plot*
- *CO= The coda where the narrator ends this story brings the action back to the present.*

A decision was made to explicitly display the narrative segments identified next to the researcher's interpretation in chapter 8. The aim was to provide illustrative text and support the interpretations with an audit trail to aid persuasiveness, transparency, internal validity, and trustworthiness towards the analysis process (Riessman, 2008d). Interpretation is a valuable part of the narrative analysis of any form, and even in structural analysis, the components are only an aid to creating units of analysis (Saldaña, 2013a).

The concept of orientation has a specific function that sets the scene and allows the narrator, the listener, and the audience to negotiate and share understandings of experiences. Orientations may fill gaps in the interviewer about the scenario or highlight knowledge that requires exploring further in interviews (Labov, 1972; Modan and Shuman, 2011). *Embedded* orientations within the narrative account can also suspend the complicating action within the narrative has additional functions to describe and highlight information that narrators want to share in strategic ways. Thereby, embedded orientations provide an additional evaluation of the complicating action, create suspense when narrators withhold information for later in the narrative, clarify details of evaluative opinions, or reinforce known information (Labov, 1972; Modan and Shuman, 2011). These functions of embedded orientations provide the narrator

with tools to frame information in meaningful ways and even achieve aims such as ideological goals or morally differentiate between characters or events in the narrative (Modan and Shuman, 2011). In this research, embedded orientations are displayed in the narrative segments.

Riessman explains narrative analysis approaches with clarity and persuasiveness by describing and explaining how different researchers' use narrative methods and explains their methods by using examples of their work that display the analysed narrative transcripts (Riessman, 2008b). Following Riessman's explanatory technique, the following two examples explain the interpretive process in this research. Firstly, some narrative segments of text were identified by either the abstract or the opening orientation and were similar to Robichaux's nursing examples when GPs began narratives about patient encounters (Robichaux, 2002). Units of text were identified to have meaning and labelled as a relevant structural analysis component. Rather than fracturing the data, the rows represented units of meaning and were assigned structural components of the narrative, creating order and organisation. Then each narrative account was reflected upon to understand the view of the GP and interpret the meaning represented by the segment of text.

The following example is part of a segment of text from Andy. The opening line that introduced the narrative segment was: *"one in particular..."* (Andy). This type of opening was typical of the GP accounts of memorable patients. Andy then provided evaluative comments about the patient's lack of willingness to change his lifestyle. The fifth row reinforces the meaning – that the patient remained unengaged in his health care despite commencing medication:

Table 1 example narrative from Andy.

| | | |
|---|--|----|
| 1 | one in particular, a chap who's late 50s, | OR |
| 2 | very amenable chap but certainly not very keen on injecting himself and starting insulin and | EV |
| 3 | in fact certainly even after the point of diagnosis of diabetes, not very keen on changing his lifestyle | EV |
| 4 | So he was a big drinker, he was a smoker and we'd obviously identified he had diabetes. | OR |

| | | |
|---|--|----|
| 5 | He's commenced on oral medication, he was not very keen on taking that and was very hit and miss with it and I think really it took a long time. | OR |
|---|--|----|

In addition, in this research, these structural components were also identifiable when GPs gave an opinion and reflected on practice, and was in contrast to Robichaux, who chose to apply thematic analysis only to these types of narratives by nurses. In this research, commentary or opinion in the accounts was evident when GPs observed their practice or gave opinions on wider systems and agencies such as authoritative bodies. These narrative accounts also could be generated into extended segments of text that were structurally analysed. In the following example taken from section 8.3.1, Harry provided an account of being unable to prescribe medication. Features of time, setting and varied characters or agents are evident. The first three of the four rows of text below were separated to highlight that the meaning in each row was slightly different, but all represented a complicating action. In a descriptive form- line one- duloxetine had been available for several years, and GPs could not prescribe it. In line two- a different but relevant complicating action: the pain management consultant asked the GP to prescribe it on his behalf. In row three, a third agent, the primary care trust (PCT), created a barrier to the GPs ability to prescribe the medication and a relevant but different aspect of the complicating action. However, the interpretation of the account further elevated by conceptualising the components- that the GP felt thwarted in his objective to prescribe the medication by different agents in the narrative. The fourth row provides the abstract or summary of the GPs message for the audience: that the medicines management authorities locally presented barriers to the GP's ability to prescribe the medication.

Table 2 - example narrative from Harry

| | | |
|---|--|----|
| 1 | one in particular, a chap who's late 50s, | OR |
| 2 | very amenable chap but certainly not very keen on injecting himself and starting insulin and | EV |
| 3 | in fact certainly even after the point of diagnosis of diabetes, not very keen on changing his lifestyle | EV |
| 4 | So he was a big drinker, he was a smoker and we'd obviously identified he had diabetes. | OR |
| 5 | He's commenced on oral medication; he was not very keen on taking that and was very hit and miss with it and I think really it took a long time. | OR |

In summary, this research employed a triangulated reflexive thematic analysis and narrative structural analysis method to analyse audio-recorded and transcribed interviews from sixteen

GPs in South Yorkshire. The analysis methods are complimentary from a methodological perspective yet provide different ways to make qualitative and interpretive meaning from the textual data and were planned to provide new exploratory insights into GP decisions when initiating insulin in T2DM.

3.13 Research ethics and governance approval

Ethical concerns that may arise from this research were considered early in the research process when applying for ethics and governance approval. Ethical approval for the planned research was gained from the National Research Ethics Service (NRES) Committee for South Yorkshire and Humber (REC reference 08/H1300/67, protocol number URMS 121882). The approval included the project design, participant consent forms, participant information sheets, demographic questionnaires, interview guide, and plans to audio-record, transcribe, and analyse the GP interviews. GPs participated as research volunteers. A decision was made to offer no incentivised payments for the GPs' time as it was felt ethically inappropriate after discussion with the ethical review panel. After the progress report submitted in 2010, further approval was given to continue for the duration of the study (appendix 13.5).

Governance approval was gained in July 2008 from the Sheffield Health and Social Research Consortium (SHSRC) after panel review, including lay members feedback (consortium reference ZJ68). There was understandable concern from lay members that the research would benefit from the involvement of lay members in conceptualising the design and implementation or analysis of the research. The panel later accepted that the research design was qualitative and methodologically utilised the researcher as the instrument for qualitative analysis. However, the lay members of the SHSRC raised an important issue, and the research benefited from the inclusion of a patient representative on the advisory panel to inform the further development of data collection and early analysis.

The advisory panel was composed of the research supervisors- Professor Nigel Mathers and Dr Mark Hayter; patient representative and retired nurse, Mrs Mary MacKinnon; psychologist, Mr Tim Norfolk; GP and academic departmental colleague, Dr Chirk Jen Ng. From the beginning, the patient representative, Mary Mackinnon's valuable insight was informed by her diabetes charity work, her experience as a retired diabetic specialist nurse and as a diabetic

patient herself. Mrs MacKinnon was vital to providing important patient representative feedback to the development of the research plan to investigate GP values, behaviours, and management of T2DM and insulin initiation in primary care. She supported the need to understand the GP perspective, identify barriers to primary care insulin initiation and welcomed a criticality toward the interview and analysis process. Mr Tim Norfolk had interests in decision making in primary care and GP training. Dr Ng was investigating the delivery of a patient decision aid (PDA) to help initiate insulin in primary care.

All interview data had been collected by October 2010. In 2011, changes to the NRES procedures meant the study no longer required NHS Research Ethics committee review (appendix 13.5). The qualitative analysis continued under the research governance processes of the University of Sheffield. GPs volunteered to participate in the research as interviewees. A participant information sheet was developed and provided before the interviews to allow participants to consider the research purpose, what would be expected of them, that they were volunteers and could withdraw at any time without giving a reason.

The interviews were an opportunity to reflect on the GPs medical practice, and there may have been an occasion for GPs decisions to be questioned or considered critically. However, the interview was not a process of test of knowledge or judgment of their decision-making processes. Instead, it sought their experience and perspective of how GPs made decisions when initiating insulin in T2DM.

However, ethical concerns specific to this research resulted from GPs' reflections on memorable patient encounters. The anonymity of the GP, patient and any other persons such as family or other health care professionals were considered in the transcription process and the use of text when reporting the findings of analysis and interpretation. If GPs mentioned names of colleagues, these were changed, and GPs were also given anonymous names that conveyed only their gender. Moreover, the presentation of data analysis was also considered and changed from an individual GP case analysis because of concern for anonymity of the participants, patients, and other agents. Importantly, GPs were informed that their confidentiality would be respected but under GMC regulations and governance processes. If there was an evident public interest concern or threat to a specific individual, then the details may be required to be passed to relevant authorities.

3.14 Reflexivity and the insider researcher

Before concluding this methods chapter, it is essential to emphasise the importance of reflexivity throughout. A key aspect of the latter relates to recognising the insider research and considering how this may have affected the research and sampling, data collection, and analysis (Costley, Elliot and Gibbs, 2010; Saidin, 2016). Aside from the shared knowledge of biomedicine, biomedical language, and clinical patient care experience, the participants also knew the dual roles of insider researcher. The interviewees had an expert status as medical professionals but were not experts in diabetes management – relative to secondary care diabetologists. The commonality with the insider GP was anticipated to allow GPs to reflect on their work with T2DM patients with more ease. The interviews created a space for the GPs to tell and provide critical insight into their work that may be taken for granted in the everyday activities of medical practice (Modan and Shuman, 2011). This benefit of the insider researcher is particularly relevant to research with practising expert professional interviewees such as GPs and nurses where tacit shared knowledge may facilitate the co-constructed interviews (Robichaux and Clarke, 2006; Martin, Currie and Finn, 2009).

During the early phases of this research and after data collection, the initial intention was to triangulate a narrative thematic analysis with narrative structural analysis (Robichaux, 2002; Riessman, 2008b, 2008c). To represent the GPs' experiences and life in context appeared to indicate the need to present case analysis. A method was planned to present a narrative structural analysis of five cases and represent the other eleven GP accounts through the thematic analysis. However, the central issue of participant confidentiality and methodological rigour required meant this plan was changed.

After a change of thesis supervision, the design of the method changed to a thematic analysis of all 16 interview transcripts and the narrative structural analysis of identified tensions between and within these generated themes. The narrative analysis allowed the display of informants' accounts, including negative cases and providing an alternative interpretation and triangulation. The GPs' accounts were positioned in a time and place, and their experiences and beliefs had enduring persuasiveness. Unlike historical or journalistic interpretations of facts, narrative methods situate individuals' narratives in social and political, and in this case,

biomedical contexts (Riessman, 2008a). For the GPs accounts, they were also placed in the medical context within generalism. Riessman provided persuasive arguments for the validity achieved using narrative methods and aiming for the trustworthiness of the participants' stories, how they are collected, and analysis performed (Riessman, 2008d). Thus, the claims demonstrated by the findings are documented for the reader to make sense of them and add to the trustworthiness of final interpretations (Riessman, 2008d; Thomas *et al.*, 2009).

Finally, an essential reflexive aspect to note at this point is the impact on the overall timeline of this research. There were periods of absence, which, combined with supervision changes during the doctoral process and necessary writing support, led to the writing up phase becoming a protracted journey. Additional researcher development required self-awareness and language support and is explained further in the reflexivity section of the discussion. Also, a reflexive thematic approach and a focused narrative chapter allowed the generated tensions to be meaningfully elevated to interpretive outputs using the narrative structural analysis. The consequence was further development in researcher skills and added value to the findings. The duration of this research, the additional and significant changes were developmental experiences and insights that have strengthened the research and researcher and will be revisited in the discussion.

3.15 Conclusion

This qualitative research recruited a purposive sample of 16 GPs using a snowball sampling technique. Interviews were recorded and transcribed, with all data collection complete before the end of 2010. All transcript data were analysed using a reflexive thematic analysis method (Braun *et al.*, 2018). Following initial familiarisation, NVivo software recorded coded transcript data and progressed to further coding refinement before hierarchical thematic development. Identified tensions were targeted using a narrative structural analysis method, creating methodological triangulation and adding to the trustworthiness of findings.

4 Analysis

4.1 Introduction

This chapter will report on the findings of the reflexive thematic analysis, presenting the interpreted output themes. The empirical lit review, sensitising conceptual factors, critical realist ontological approach, and constructionist episteme underpin the analysis process.

Tensions identified as relationships, links and emotive or uncomfortable contextual theme, will be identified in different narrative structural analysis of the data as previously described in the methods chapter.

Reporting styles of qualitative research can include models where results and discussion can be combined. In this way, the analysis report connects and contextualises the findings in the wider literature and existing theory (p131 of Braun and Clarke, 2022). A discussion chapter will be included to bring together the interpretations and conclusions from the thematic analysis, identified tensions, and narrative structural analysis.

4.2 The Findings summary

This section will summarise key findings before the subsequent sections discuss the separate reflexive TA and narrative SA respectively.

The reflexive thematic followed the principles as explained in chapter three. Initial familiarisation followed coding with a 'back and forth' (Brauna and Clarke, 2022; Saldana 2005) process of attention to meaning and aiming to seek conceptual coherence towards the aim of theme development when refining codes to themes (as explained in section 3.9, 4.4 and 4.5).

The interviewee demographic profiles are described in section 4.3 to aid the subsequent thematic analysis reported findings (sections 4.6 and 4.7). Notably 12 of the doctors were diabetes leads at the practice and three were delivering insulin initiation (Dan, James, Charles). A further two GPs (Jen and Sally) had attended training with a view to delivering a funded pilot project to deliver insulin in the community and was led by secondary care specialists. However, both GPs had withdrawn.

The audio-recorded and professionally transcribed interview data were analysed considering the research question to understand the person-centredness of GPs in primary care, what the GPs say about their patient-provider relationships and PCC delivery in their setting. The co-produced travelling style semi-structured interviews meant GPs reflected and shared attitudinal opinion and patient encounters beyond insulin initiation. Insulin initiation in T2DM was part of the research design to open conversations about person-centred care and understand the GP perspective at that point of escalation of therapy. This research design will also be revisited as a limitation to the research because, on first analysis of the interview data the biomedical and doctor-centredness of the themes were prominent.

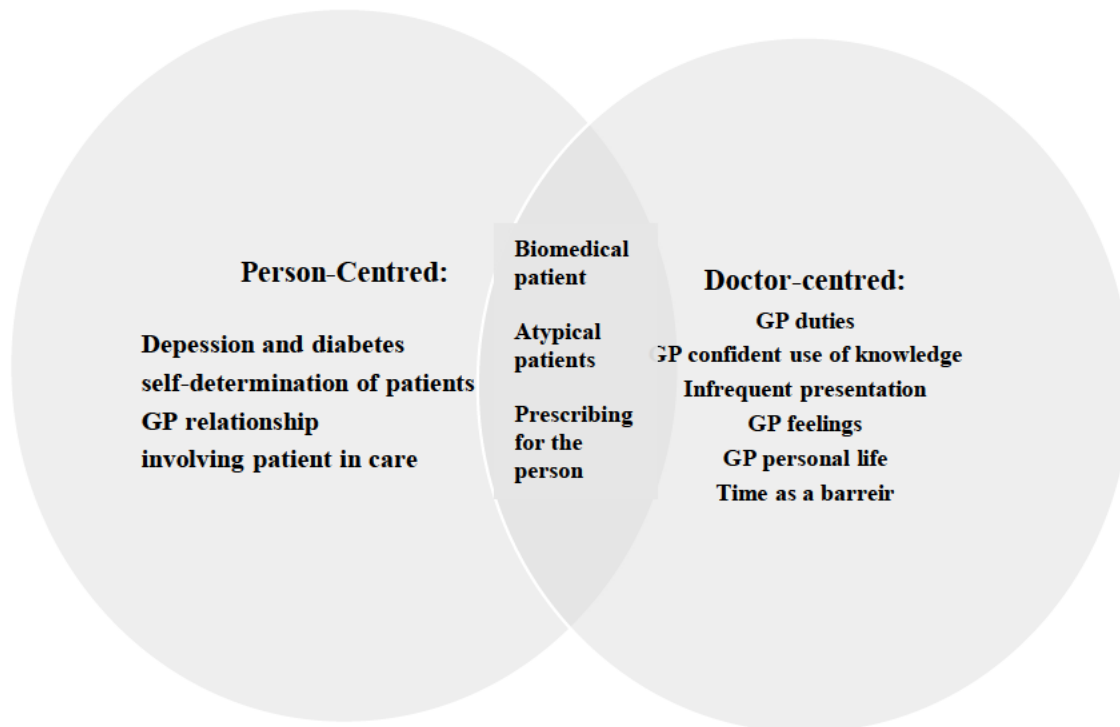
Subsequent re-analysis back to the level of stage 2 and 3 coding, and phase 2 thematic development. Thesis section 3.9 explains the phases as outlined by Braun and Clarke, and sections 4.4.2, 4.4.3 and 4.5 explain the coding process and thematic development.

In keeping with reflexive TA methods and the constructionist episteme, the themes are reported to be generated, rather than revealed or emergent. The researcher subjectivity and explicit travelling style of interview to co-produced the interview is acknowledged and add to the recognised partiality of big Q research (Braun and Clarke, 2022).

The reflexive TA findings are reported in two main sections: the person- and doctor-centred themes.

The biomedical construction of the patient was a previously hierarchical theme also, but with review of the literature, additional sensitising concepts of person-centredness, related constructs of whole person care and patient-centred care (PtCC), the textual data were re-examined. Consequently, the biomedical construction of the patient was generated within a person-centred context when GPs related person-centred (PC) approaches and relationships within memorable patient encounters, or PC attitudes to delivering diabetes care or insulin initiation. The following Venn diagram also shown and explained in section 4.10, shows the main reflexive TA themes.

Venn diagram of the hierarchical themes of the reflexive TA findings:



Tension findings are then reported in 4.8 and 4.9. the generated tension themes were the result of identified emotions or constructed interpretive tensions from linking relationships between reflexive TA output themes. The table in section 4.9 summarises the tensions and their associated thematically derived linking themes.

The findings of thematic analysis are then summarised in section 4.10, before the Narrative structural analysis find are reported in chapter 5.

Chapter 5 presents a contrasting method, and the analytical reports shows tables of structurally labelled textual data (from Abstract (AB) to coda (Co)) these are labelled for different parts of generated text that show conceptual meaning and have been interpreted by the researcher. The narrative structural analysis method was described in section 3.12.

The narrative SA findings are reported as tables of the narrative text and with interpretation before and after.

The interpretive text provides a different perspective to the thematically generated themes. The narrative SA findings are divided into topic areas: Lack of patient engagement, cautious prescribing, insulin as failure, and distal practice. Finally, section 5.6 summarise the narrative SA interpretive finding. Significantly, a table in section 5.6, displays the generated stance of

the GPs analysed narratively in each narrative subsection. This table shows how GPs attitudinal a generated in positions of doctor or person-centred attitudes towards patients and patient care, and how GPs can shift from DC to PC and vice versa on case-by-case basis.

4.3 The interviewees and demographics

This section will provide a contextual understanding of the sixteen GPs' training and its relevance to biomedical knowledge development. There were seven female and nine male GPs, ranging from age 39 to 59 years. For this research, the GPs were given pseudonyms that identified them by gender only. One GP, Alice, had type 1 diabetes and insulin-dependent for many years, and another GP, Cath, had T2DM and was treated with OADs only. Alice was also the only sessional GP, whilst all the other GPs were GP partners. Eleven GPs had a special interest in diabetes at their practice and indicated the self-selecting demographic despite the purposive recruitment method aimed at diversity. This is discussed further in the limitations.

The GPs' practice varied in size from 4000 to 13250 patients. The majority had low numbers of ethnic minority patients, and seven GPs worked in practice with 10 to 25% of their patient population from Ethnic minority groups, including South Asian, Afro-Caribbean, Somali, Thai, Chinese, and East European. These demographics reflect the diverse experience the GPs had. Black, Asian, and minority ethnic groups are more at risk of T2DM and were recorded to provide contextual information for the individual GPs, thereby improving the snowball recruitment of a varied and diverse sample of GPs.

The GPs had similar undergraduate medical training to achieve their Bachelor of Medicine and Bachelor of Surgery (MBBS) qualification and then junior doctor posts to complete registration with the General Medical Council (GMC) as qualified doctors. Further vocational training in General Practice was composed of hospital and general practice placements. At the end of GP speciality training, they passed a vocational training examination called a 'Summative Assessment' that allowed them to practice as GPs in the UK (row 2 in the table below.) In addition, GPs could attain the Membership of the Royal College of General Practitioners (MRCGP), which credited them with a higher level of academic training in general practice.

From 2006, the GP training qualifications were amalgamated into the new MRCGP (nMRCGP). All the interviewed GPs had trained in the older scheme and were not required to gain the MRCGP to practice.

Table 4 shows the GPs all had qualified as doctors before 1999 and had completed the GP vocational training and summative assessment before 2003. Rob and Dan had trained in another speciality before commencing GP training and so had more extended periods from MBBS to qualification from GP vocational training.

Table 3 showing the decade of qualification from medical school (year of MBBS attainment) and GP qualifications across the interviewed GPs.

| | 1970-79 | 1980-89 | 1990-99 | 2000-2010 |
|--|------------------------------------|--|--|-----------|
| 1. Year of MBBS attainment | 5= Harry, Vicky, Cath, James Peter | 8= Jen, Mike, Matt, Charles, Alice, Jackie, Fiona, Dan | 3 = Sally, Rob, Andy. | |
| 2. Attainment of vocational GP qualification | 2= Cath, Vicky | 5 = James, Harry, Pete, Jen, Mike | 8 = Matt, Fiona, Charles, Jackie, Andy, Dan, Sally, Alice. | 1= Rob |

13 of the 16 GPs interviewed had the MRCGP qualification, and, as explained above, at that time, MRCGP attainment was not a requirement for professional practice.

The understanding of diabetes as a disease originated from undergraduate biomedical training. As medical students, understanding biomedical illness and individual care included seeking patient agendas as part of their training. These skills were further developed during the MRCGP and the vocational summative assessment.

As GPs gained experience, they acquired varied skills and knowledge. Later in the findings, it is argued that GPs showed variation in their experience, responsibility for diabetic care in practice, confidence, and their attitude to deliver insulin initiation within their practice settings. Table 5 shows this variation amongst the individual GPs.

Table 4 Characteristics of study participants

| GP | Experience in insulin initiation | Diabetes Lead (DL) and/or practice partner focus | Confident accounts of insulin initiation | Attitude toward insulin initiation in practice |
|------|----------------------------------|--|--|--|
| Rob | no | DL | no | No plan to deliver, uninterested. |
| Andy | no | DL and partner | no | Considering a plan to deliver |

| | | | | |
|---------|-----------------------------|---------------------------|---|---|
| Jen | yes | DL and partner | yes | Planned to increase practice delivery but decided to continue to refer. |
| Alice | no | Sessional GP | No, but aware of insulin Rx through personal experience | Sessional so not involved with plans to consider II services. |
| Matt | no | Used to be DL, GP partner | no | II delivery at the practice but delegated to GP colleague |
| Cath | no | DL and GP partner | no | Refers to start insulin delivered by (diabetes specialist nurse) DSN. |
| Mike | yes | DL and GP partner | no | Had started to initiate insulin, referred to DSN before that. |
| Jackie | no | DL and GP partner | no | Referred to start insulin delivered by DSN. |
| Vicky | no | DL and GP partner | no | Referred to start insulin delivered by DSN. |
| Charles | yes | DL and GP partner | yes | Started to initiate insulin, referred to DSN before that, confidently leading practice nurses to support diabetes and II delivery |
| Dan | yes | DL and GP partner | Yes, notably more biomedically detailed about insulin therapies | Confidently leading practice nurses to support diabetes and II delivery |
| James | yes | DL and GP partner | Yes, notably more biomedically detailed about insulin therapies | Confidently leading practice nurses to support diabetes and II delivery |
| Sally | No, it was delegated to NP. | DL and GP partner | no | Lost funding for pilot scheme locally, no plans to provide, but willing to for an exceptional case. |
| Harry | No | DL and GP partner | no | No plan to deliver, uninterested. |
| Fiona | No | GP partner | no | No plan to deliver, uninterested. |
| Peter | No | GP partner | no | No plan to deliver, uninterested. |

4.4 Thematic Analysis findings

4.4.1 Introduction

4.4.2 Early interviews

This section will explain the early interview process. The research question at the initial design planned to explore the GPs views on insulin initiation in T2DM. The GPs shared narrative accounts of T2DM management as a chronic disease through the co-produced interviews and Kvale's metaphorical 'travelling' style. They also shared scenarios of their experiences with memorable patients, which was part of the planned interview guide and research design.

However, the narrative style also meant GPs did direct the interview agenda too. At times there were interesting, detailed accounts from GPs like Jen who related socio-demographically detailed narratives of her Pakistani population, multi-sensory experiences of home visits (for example, she recounted sensory experiences that formed her person-centred knowledge of her patients such as details of wall paper texture in her description), scenarios of depression, patient lack of engagement in self-care and problematic social issues involving her patients' lack female empowerment. At first sight, her rich account of her population was too detailed and irrelevant to the focused biomedical research question. However, her person-centred approach to her local ethnic population despite her own white Caucasian background revealed a sensitive, empathic, and capable GP, who provided a person-centred service to her population. Because of patient confidentiality concerns, some of her interview was not appropriate to include in the form of quotes, narrative sections, or the appendix, even in truncated form.

Similarly, Alice provided a long narrative section describing memorable patients. One narrative section is included at appendix 10.3 as an example of opening questions, participant-interview interactions and the patient scenario shared by the GP.

In contrast, Pete was another GP analysed early in the process of coding. He made clear that his practice had no plans to initiate insulin in T2DM without the provision of funding resources. As the interview progressed, he provided superficial accounts of patient interactions in the same way. He instead shared opinion, such as applying consultation skills as an experienced GP. The interview was redirected, and he was asked to discuss related chronic diseases, such as patients that required hypertension management, but continued with similar lack of detailed

patient narrative. However, he did provide important views of the chronic disease of CKD management, and his views of controlling person-centred consultations that later directed significant themes on doctor-centredness. After an initial discussion with supervisors at the time (Professor Mathers and Dr Mark Hayter), the interview was retained in the group because he revealed a particular business minded attitude that contrasted with the very person-centred attitudes of Jen. His interview was apparently an outlier at first, with little relevance to insulin intuition or person-centredness, but later became an example that included doctor-centred attitudes about working in the delivery of PCC.

Significantly, Jen's narrative interview alone took weeks to analyse both thematically and then narratively. After a change in supervision when the first PhD supervisor retired, a decision was made with Dr Richard Cooper to thematically analyse all the audio-recorded and transcribed interviews before consideration of further narrative analysis.

The next section explains the code development process in the NVivo software and subsequent thematic analysis process.

4.4.3 Initial code development

This section will explain the process of code development, utilising the NVivo software as the tool to hold and organise the codes (which are called nodes in NVivo). The reflexive thematic analysis coding process is described in the methods section 3.11 and outlined the process of theme generation from familiarisation to the data, initial coding, coding development to theme development. The data recording during analysis was held within NVivo 7, later NVivo 10, 11 and 12 management software. It is important to note the software acted as a storage for the data but was not used to analyse data.

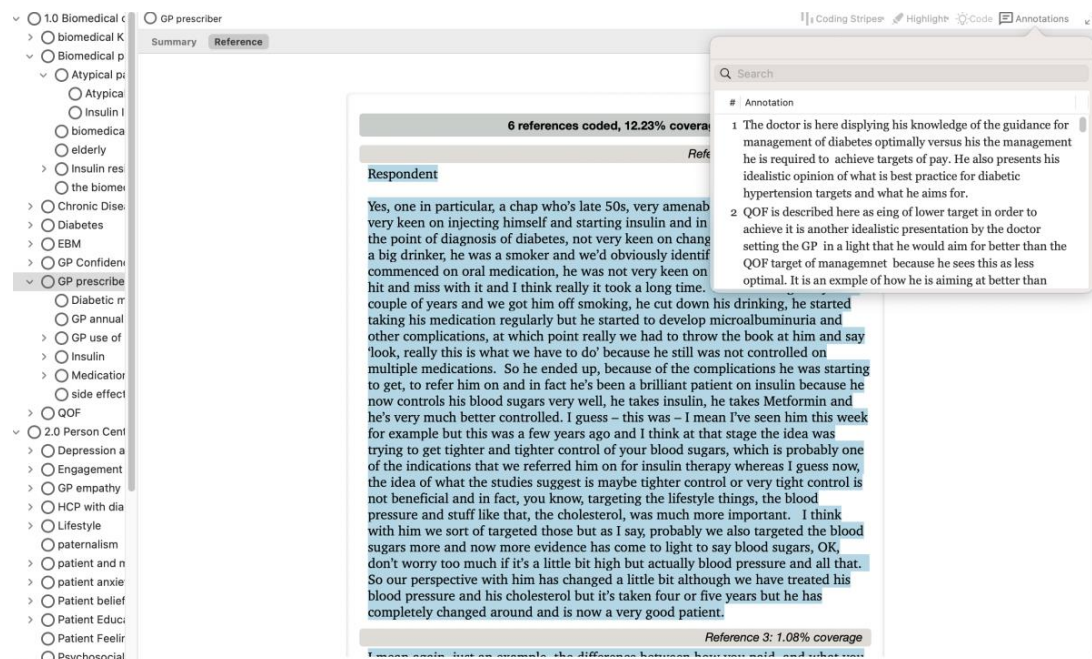
Thematic analysis began during the interviews and was completed after all the interviews were transcribed from audio-recordings by a professional university ethical and governance approved transcribing service. Initial familiarisation meant reading the transcripts of the documents and listening to audio-recordings for depth, clarification, or emphasis. Each transcript was analysed in turn systematically, but pragmatically it was not possible to analyse the transcripts in the short time frames between interviews. All interviews have been recorded

in the space of 12 months, and transcribed. Handwritten field notes during the interviews were a reminder of key points, but audio-recordings were key to any re-familiarisation when the text was later analysed on the NVivo software.

The transcribed interviews were added to the NVivo software as 'files' of whole transcripts which allowed highlighting of text that could be coded to labelled 'nodes'. The longer section of text utilised for coding purposes supports the narrative approach, with the aim to avoid fragmentation of narrative sections that may later form the basis for narrative structural analysis (Riessman, 2008c), and contrasts with the of small line by line coding advocated by Charmaz (Charmaz, 2006). The length of the text is irrelevant in thematic analysis, which focuses on the key messages, patterns, and meaning of shorter or longer lengths of interview text provided by different participants.(Miles, Huberman and Saldana, 2014). As such, thematically coded sections varied in length, but notably, the sections were coded under single or multiple themes depending on the generating concepts observed.

As an example, the 'GP prescriber' node (unrefined) is pictured in **Figure X** and represents an early unrefined node stored in the NVivo software with an associated annotation (1) written at the time of early immersion in the data and first coding as nodes. Topic summaries were avoided as much as possible, but some topics were more appropriate than others and later removed into a categorised 'binned' nodes, or moved, or given a new hierarchy depending on identified associations with 'parent nodes' refined.

Figure X: showing a highlighted section of text, coded at the GP prescriber node and annotations.



Stage one coding resulted in multiple codes even after the first two interviews. Organising of the nodes into a hierarchical parent nodes helped to manage the mounting numbers after reviewing NVivo coding references (Bazeley, 2007, 2013c; Saldaña, 2013b; Miles, Huberman and Saldana, 2014) and discussion with supervisors.

The quantity of nodes, annotations and memos created was initially overwhelming and is a recognised part of the qualitative researcher journey (Saldaña, 2013b; Braun and Clarke, 2022). Discussion with supervisors, reflection and then later examiner review helped and despite interesting accounts and associated analysis, familiarisation, coding and thematic analysis was an expected difficult reflexive journey. However, after five GP transcripts were analysed thematically, then structurally, the process was found to be too laborious for an individual and a change of direction took place with a change of supervisor. All the 16 GP transcripts were thematically analysed and recorded in NVivo.

Appendices 10.7 to 10.10 display iterations of the lists of 'tree' nodes as they developed with the interview transcripts and is recorded in the NVivo journal. Appendix 10.7 shows four pages of nodes that, although they are in hierarchical codes of parent and child nodes, the list lacks

the required refinement, so further analysis sought more commonality in concepts, and removal, merging or relabelling of nodes was required.

Node labels were also re-considered. The research question directed the meaning sought in the text, and the GPs were informing on a wider narrative beyond the issue of insulin initiation. Coding included views, attitudes and patient-centred rich experiences that appeared little to do with insulin initiation, but more about the patient related encounters of the jobbing GP in T2DM as a chronic disease in the primary care setting. Discussion with departmental colleagues, advisory group and supervisor aided the reflective process, and these nodes were retained in the early interviews with awareness that the GP experiences were valuable and may reveal alternative insight.

The process of coding an individual document is shown in **Figure Y** below, capturing a thematically coded section of text from James' interview, which occurred towards the end of the 16 recruited GPs. The longer section of text shows the narrative section used which could be coded once as a new node, or in multiple codes that were already present, if the meaning generated was relevant.

Coding 'stripes' are a feature of NVivo that allows visualisation of the multiple codes that apply to the same narrative section. The multiple coding technique had the advantage to code the same section with different nodes depending on the generated meaning and were visible as different colours if they had been coded separately. The same section of text may contain semantic (explicit) and latent (implicit) meaning. A disadvantage was the multiple NVivo nodes that needed review, and extra work entailed in the need for relabelling if inappropriate or removal. However, the coding journey is expected to provide 100 to 300 codes (p24 of Saldana, 2013b). This journey was difficult at times, required reflection and thought with mindful attention to avoid superficial coding and topic summaries (Saldaña, 2013b; Braun and Clarke, 2022).

Each code may have meaning related to the whole narrative section. This meant that an overarching label may apply to the section. As an example of coding, **Figure Y** shows a descriptive theme of 'GP prescriber', 'GP use of new medication' and 'biomedical construction of the patient'. A meaningful and latent theme of 'cautiousness of new drugs and 'harm' was

part of the initial coding, but equally, emotions may be coded such as frustration and anger, which were indicators of tension. These codes were later refined and the theme of ‘cautious prescribing’ persisted as coding progressed.

With re-organisation of the codes, ‘Biomedical construction of the patient’ became a parent node, and sub-nodes were ‘GP prescriber’, and ‘GP use of new medication’ and ‘harm’. Notably parts of the same narrative section were also coded in smaller ‘lumps’ of text, lines as nodes, as part of the coding of the thematic analysis. The latter two codes were apparently biomedically driven by the research question, but also showed links with person-centred doctor concerns such as harm. The sub-nodes combined a PCC approach for this, and other GPs, that was relevant as a biomedical construction of the patient and the GP prescriber role.

Figure X : part of section of text from James’ narrative section on cautious prescribing.

The screenshot displays the NVivo interface. On the left, a tree view shows a hierarchy of codes, with 'Cautious of NEW drugs' selected. The main window shows a text document with several segments highlighted in yellow. The segments are as follows:

- Interviewer: "And I asked him to show us about this drug. And he brought his usual stuff erm, and it looked wonderful. But I'd read one or two reports from America and I said can you tell me is there any problem with liver functions?"
- Respondent: "Right."
- Interviewer: "In front of my partners, in front of these nurses, he laughed at me."
- Respondent: "Right."
- Interviewer: "He just 'Oh for god's sake Dr A, don't believe everything you read. Oh god, my, listen if you want take an LFT before you put them on it and check it again in a month alright?' And I thought you condescending bastard, sorry. You know, but it looked like such a good drug, you know, I thought I had 2 or 3 patients in mind that we're struggling with that we're thinking oh do they need to be on insulin, but there's nothing else we can do, well now there was. So I said right I've got 2 or 3 patients, Margaret bring them in next week and we'll talk to them about it."
- Respondent: "Yeah."
- Interviewer: "The following day, Thursday, I got, I'm secretary of the BMA, I got a fax from the BMA saying this drug has been withdrawn, 20 people have died of liver failure in America."
- Respondent: "Right ok. That was very up to date."
- Interviewer: "I was looking for his card, I wanted to ring him up and say 'you bastard, I want a word with you'. Because he made me look about that big."

On the right side, a 'CODE STRIPES' panel shows a list of codes with corresponding colored vertical bars indicating their application to the text segments:

- diabetic LEAD in practice
- Diabetic medication
- glizone
- GP Duties
- 3.0 GP - the person
- harm
- GP use of NEW medication
- GP prescriber
- 1.0 Biomedical construction of the patient
- Coding Density

During the process of code generation further iterations for the NVivo node trees developed. So, Figure W above was the example of the NVivo tree at the point of early analysis.

Figure W showing a smaller list of parent and child nodes on the way to theme development under the main headings of biomedical construction of the patient, the ‘person-centred GP perspective’ and the ‘GP person’.

- 1.0 Biomedical construction of the patient
 - > biomedical Knowledge
 - > Biomedical patient
 - > Chronic Disease management
 - > Diabetes
 - > EBM
 - > GP Confidence in decision making
 - > GP prescriber
 - > QOF
 - 2.0 Person Centred GP perspective
 - > Depression and diabetes
 - > Engagement in health
 - > GP empathy
 - > HCP with diabetes
 - > Lifestyle
 - paternalism
 - > patient and medication
 - > patient anxiety
 - > Patient beliefs
 - > Patient Education
 - Patient Feelings_GP Narr
 - Psychosocial problems presenting as organic disease
 - QOF and person centred
 - > Shared Decision Making
 - > TRUST Patient trust in doctor or healthcare system
 - 3.0 GP - the person
 - > distal GP
 - > GP Duties
 - > GP feelings
 - GP personal life
 - > GP's own Personal Values
 - 4.0 Tensions
 - Blame
 - > GP Confidence in decision making
-

A later list of NVivo nodes is shown in figure W (appendix 10.9), which shows a further iteration of the nodes and though a smaller list of parent and child nodes. The list still shows the potential biomedical bias relevant to insulin initiation and lack of the person-centred data that was recorded amongst the child nodes.

An example of this point is the ‘health belief model’ (HBM) code that was directed by the intrinsic researcher knowledge of HBM and represented an assumed sensitising concept for the

GPs (Janz and Becker, 1984; Rosenstock, Strecher and Becker, 1988; Taylor et al., 2006) and presented a topic summary.

To consider the person-centred perspective further a new literature review considered the person-centredness of GP in chronic disease management in primary care, rather than a focus on the initiation of insulin in T2DM in primary care. The resultant research questions were changed and emphasis during coding adapted.

The thesis research question (from section 2.7):

“How do GPs address person-centred care when considering insulin initiation in T2DM?”

Subsidiary questions to seek in the data:

1. What do the GPs say about their relationships between patients and doctors?
2. What do GPs say about delivering PCC when considering insulin initiation in T2DM?

And so, the revised question to consider of the coding data included:

- What are the GPs saying about their person-centredness, relationships with patients and delivering PCC when considering insulin initiation in T2DM?

Further review was made of the coded text and child nodes to reconsider questions above. The node tree was review back to the early stage two levels, which allowed review and writing about the NVivo coding process to add to credibility. To support this iterative change, Braun and Clarke also advocate theme revision at the full dataset stage (p101 of Braun and Clarke, 2022). Going deeper into the analysis back to the level of stage 2 coding, reviewing coding text, nodes, annotations and sometimes, the files of the full interview transcriptions, allowed review for the emphasis towards the person-centredness of the GPs, their relationships with patients and delivery of PCC rather than just insulin initiation. Braun and Clarke provide an example of a similar review of the codes and data set, with a resultant change in the final map of themes. They describe a journey to re-map a cluster of “*patterned and intersecting ideas*”, to find improved explanations for the overall story of the research (p 102 of Braun and Clarke, 2022).

The following table of nodes are examples of later reviewed nodes, relabelled, moved, merged into other nodes, or removed to a separate category of ‘binned’ nodes that still be accessed if needed.

Table of example nodes that were reviewed.

| Node | Review: relabelled or removed | Explanation |
|---|---|---|
| Health Beliefs Model (HBM) | removed | Analysed text and properties of the node were all centrally around the HBM, representing a topic summary about an assumed motivational method to help patients’ self-care. |
| Negotiating with the patient | removed | Lacked depth of meaning and was descriptive, fitting a topic summary relevant to communication skills. |
| Psychosocial problem presenting as organic disease | removed | This node contained one coded text section from one GP only and was already coded under the more appropriate ‘depression and diabetes’ node. |
| Patient lack of compliance node | Relabelled to ‘adherence’ | Adherence represented an appropriate label considering the literature review sensitising concept. |
| Patient coach | removed | Only one GP mentioned the idea of a ‘patient coach’ as part of considerations of motivating patients. |
| Shared decision making (SDM) node – language barrier | Moved to person-centred subcode: information sharing | Although related to Jen only and her ethnic population, the text related a person-centred information sharing behaviour, rather than a shared decision-making behaviour or views. |
| Resources for SDM | removed | Descriptive only, the actual meaning of the text related difficulty in finding time and resources to motivate patients in the appointment time available for one GP, another GPs mentioned supportive resources such as patient education programmes. |
| QOF and the person | Moved to the ‘person-centred elderly’ node | Related the PCC view of GPs to be more relaxed about QOF targets for older patients in relation to diabetes. |
| ‘Negative outcomes for patients reduce GP confidence in GP decision making’ | Relabelled to ‘Reflective learning from negative patient outcomes’ and moved to existing node of acceptance of uncertainty. | The first child node in the first column applied to one GP only, and on reviewing the data, there was already a node relevant to risk labelled ‘uncertainty’ with other participant views coded. The data |

| | | |
|------------------------------------|---------|---|
| | | was added as a child node to 'Acceptance of uncertainty'. |
| Patient responsibility | removed | The node itself was descriptive at a superficial and though GPs use the word responsibility, interpretations of the same coded text had already been appropriately captured under the self-determination and lack of self-determination themes. |
| Engagement in healthcare | removed | The theme behaved as a topic summary and initially appropriate to collate the subthemes. However, the sub-codes were relevant PCC themes in their own right. |
| Guidelines | removed | The theme |
| Opinion on evidence-based medicine | removed | The EBM and most subthemes were not PCC or DCC, but about GP opinions on EBM., subthemes related to use of guidance in PCC ways were retained and moved to the PCC section. A theme on use of EBM to explain to patients was retained and moved to information sharing. |

The final list of nodes that developed the themes are shown in the capture figure V.

Figure V: final stage of coding after revising the thesis literature review and research questions.

The next section describes the process of theme development.

4.5 Theme development

The aim of theme development is to find the most relevant and important patterned meaning that explains the data, the existing empirical data and PCC approaches, and also the wider context of GP.

The developed research question was focused on the person-centredness of GPs when considering the biomedical question of insulin initiation in T2DM. Consequently, the output themes were previously biomedically led by the research question too focused on insulin initiation and directed by the researcher bias towards the medicalised construction of the patient. Consequently, theme development represents the next phase of reflexive TA that was performed on the collated nodes.

Phases four and five of reflexive TA theme development (explained in section 3.9), that is:

- Review and refine themes – verifying the collated lumps or snips of text form a coherent pattern and whether each theme reflects the data set.
- Reviewing the theme names and the extracts are organised, coherent and internally consistent.

Through thematic refinement, further reflection on cases and cross-comparison of cases, sense-making created an understanding of the meaning beyond descriptive category codes. Braun and Clarke explain that this final process is key to the interpretive process in reflexive TA. There was a transition from interim research text, coded quotes, and reflexive annotations within the NVivo software files to final research texts. The data was read and re-read multiple times, created re-engagement, and allowed fresh understanding to make sense of the varied attitudinal stances presented by the GPs.

Seeking meaningful patterns in the data around the research question generated themes that had central organising concepts. GPs described both memorable patient encounters and reflected on their overall opinions and evaluations about insulin initiation in T2DM.

This final level of thematic interpretation required challenging the data to understand the meaning and implications of the themes and categories. Reflecting on the different cases and even groups of cases, such as diabetic leads in practice or GPs displaying empathy, prompted ideas about relationships across cases as part of the cross-comparison process and developed concepts to develop into thematic hierarchies of understanding and possible theory building.

Braun and Clarke describe the process of thematic mapping, whereby visualisation of the thesis story is informed by the theme boundaries, the connections between themes and analysis structure evident through NVivo coding and seeking an overall story (p102 Braun and Clarke).

With a change in research question to focus on the person-centredness of GPs the still relevant biomedical construction of the patient became a subordinate to the person-centred theme. It was possible to deliver PCC with the objectifying mindset of a biomedical construction of the patient, if what was intrinsically at the core of the theme was PCC relevant: to consider and deliver biomedical care to the individual.

Consequently, ongoing review of other themes, the thematic map developed to a dyad of doctor and patient centred hierarchy, with subordinates. In the following sections the person-centred and doctor-centred maps will be shown, with explanation.

4.6 Theme findings

4.6.1 Introduction

This section explains the reflexive thematic analysis findings. As previously explained, the further iteration of coding and thematic analysis followed a change in the research question to focus on understanding the person-centredness of GPs when considering insulin initiation in T2DM.

4.6.2 Person centred themes

This section will explain the person-centred construct which was a key framing theme for the constituent themes that share the central feature of person-centredness.

In the person-centred theme and subthemes, the patient has been considered as an individual person, with autonomy to act and decide on their healthcare, evident in the analysed subthemes when the GP describes or explains their attitudes, opinions, or experiences with patients.

The person-centred theme is argued to have been inductively (data-driven) generated (Braun and Clarke, 2022), despite the prior conceptual framing of the person-centred approaches in chapter one. This thesis has utilised key concepts of personhood to define (see table) the construct of person-centredness, which allows the theme to encompass the various possible approaches explained in chapter one.

The biomedical construction of the patient initially was classified as a disease-centred and oppositional theme to the person-centred approaches. However, after analytical review and consideration for the context within which GP explained the biomedical construct, it was clear, that biomedical constructions of patients by clinicians can be person-centred. It is a positive framing of biomedical constructions and places the theme under the hierarchical heading of person-centred themes.

For example, numerical descriptions were used to understand and explain the biomedical care, across the GPs the figures explained severity or the need for expediency to consider escalation

of therapy. Patient health was described in numerical values such as age, BP, the patient's body mass index (BMI), serum cholesterol level, glycosylated haemoglobin (HbA1c) and blood glucose levels.

“Because her diabetes was just so badly out of control and her erm, you know, BMs (Blood sugar) were sort of in the 30's or 20's and 30's all the time...HbA1c's...About, you know, 10.” Sally

However, the biomedical construction was reframed within person-centred care generated the biomedical construction of patients as a person-centred theme the individual care need was biomedical and related to person-centred explanation or description. Notably, the person-centredness during analysis was also examined and generated by the insider GP and reflexive criticality was required, which is a limitation of this research, but also highlights the thought given to reframing biomedical constructions of patients from the disease centred objectifications, to positively framed GP construction of the biomedical patient within the person-centred context.

For example, when Jackie shared an account about a newly diagnosed diabetic patient who required a breast operation. The context and medical plan involved numerical objectification, but Jackie's account retained the priority to address the patient's biomedical need for glucose control in preparation for planned surgery, to make her feel symptomatically better when oral medications were not helping. The expediency of the biomedical need was a priority due to need for surgery.

“[...] glucose was actually really quite high and it was about- around sort of mid 20's I think [...]really was actually feeling quite unwell[...]we were trying to get her glucose down really quite quickly[...]And we had this pressure of us trying to get her well enough for the operation [...] in the end we did refer her [...]this lady was really quite happy to go on insulin.” Jackie.

In contrast, when biomedical constructions play no role in a person-centred memorable account or attitudinal description, the concepts were analysed as doctor-centred, created tension for the researcher GP during interview and analysis, and are described in section 4.6.3.

As previously explained the review and re-analysis of the data following the focused research question seeking the person-centredness of GPs in chronic disease management, the original transcribed interview data and coded text were reviewed to reflexively check the output codes and their labels. The following table explains the subthemes that were generated from analysis and organisation of the coded nodes in the NVivo software.

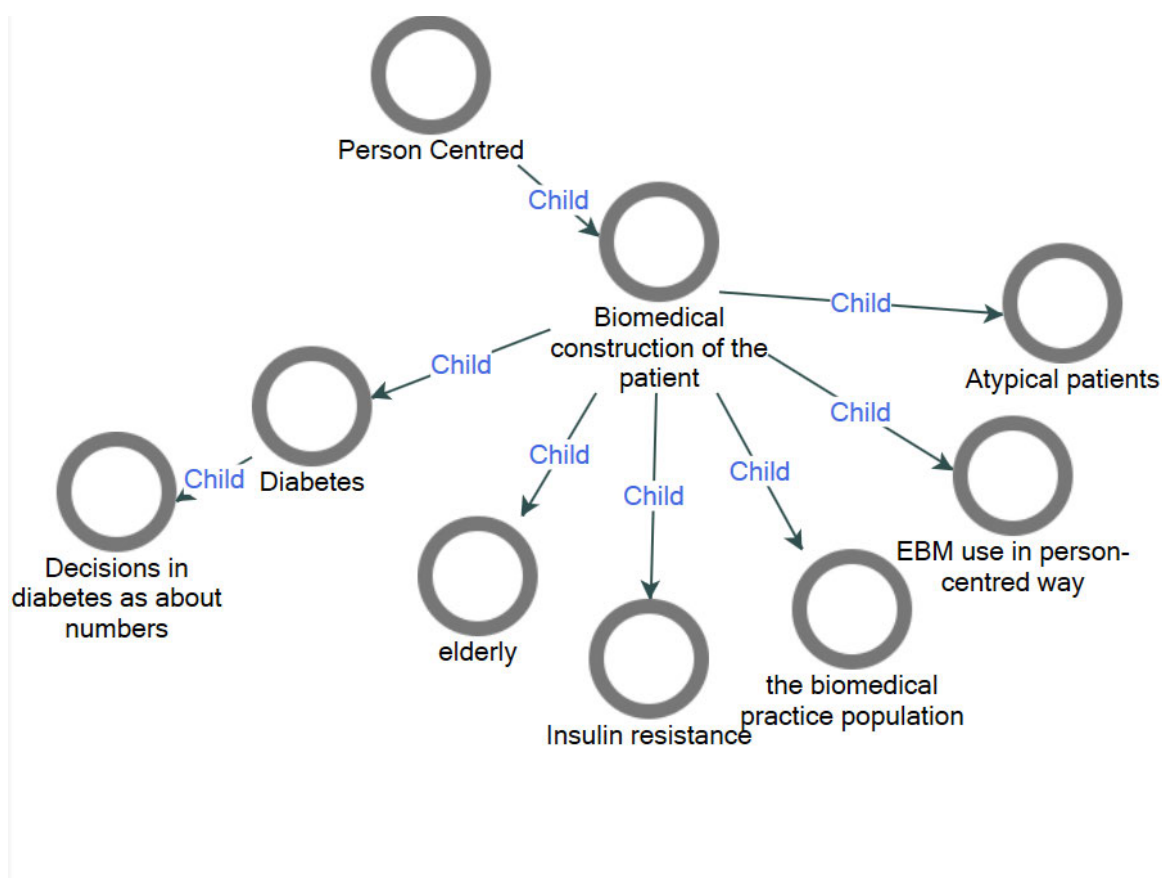
Table of higher order themes, their definitions, and a sub-theme with example quote:

| Theme | Definition | Example quote |
|--|---|--|
| Person-centred | The patient has been considered as an individual person, with autonomy to act and decide on their healthcare, evident in the analysed subthemes when the GP describes or explains their attitudes, opinions, or experiences with patients. | <i>"..I have quite a strong image in my mind of her and her being frustrated and worried and anxious about you know things like a year ago I was fine'." Rob (GP empathy)</i> |
| The biomedical construction of the patient | The objectification of the patient as a described biological entity to be managed medically, but with the clear intention to deliver person-centred care. In contrast, when biomedical constructions play no role in a person-centred memorable account or attitudinal description, the concepts were analysed as doctor-centred. | <i>"...you see someone a diagnosis of HbA1c as 7 or 8, ...you've diagnosed it, and you put them in Metformin. And a year or two later the HbA1c creeps up to 8 or 9." James (biomedical construction of the patient)</i> |
| Depression and diabetes | Depressed patients and the bidirectional influence of diabetes on their mental health. | <i>"...his affect is always quite low...part of the reason he is not, erm, you know, able to comply" Rob(depression and diabetes)</i> |
| GP relationship with patients | The way GPs described their relationship with patients . This is descriptive, as a hierarchical theme, but the various subthemes provide a multifaceted (Braun and Clarke, 2022) view of the overarching relationship theme. | <i>"I think it was perhaps taking an interest in him and not seeing him as a series of diseases..." Andy (patient as a person)</i> |
| Involving patients in care | The way GPs described how they involved patients . This is descriptive as a hierarchical theme, but the various subthemes provide a multifaceted (Braun and Clarke, 2022) view of how GPs viewed how they involved or 'failed' to involve patients in their health. | <i>"I don't know what's going on...it's well documented she has allergies to other medications in the past...she just didn't feel well {with insulin}" Cath (lack of medication adherence)</i> |
| Prescribing for the person | Another multi-faceted theme that contains the varied ways GPs saw prescribing for individual patients. | <i>"I think the generation who we are diagnosing in their 70's or 80's will think that the benefits of getting glycaemic control for them so great..." Vicky</i> |
| Self-determination behaviour | Sub-divides into separate subthemes of positively | <i>"...we'd issued him with a supply and we were concerned because he hadn't collected anymore so he'd</i> |

| | | |
|--|--|---|
| | determining patients and negative, lack of self-determination. | <i>obviously not been taking it..." Mike(depression and diabetes)</i> |
|--|--|---|

4.6.2.1 The biomedical construction of the patient

Map 1. The biomedical construction of the patient.



The biomedical construction of the patient (Map 1) encompassed the various ways GPs described patients in an objectified way, but still retained a sense of person-centred attitude towards the patient when describing the individuals care.

Several biomedical constructs were used explicitly by GPs and confirmed the multimorbid nature of T2DM, with presentation of a cluster of diseases within individuals the GPs encountered (Whitty *et al.*, 2020). These constructs included glycaemic control, blood pressure and chronic kidney disease (CKD) status and had a positivistic and often measurable scientific basis. There were also measurable representations of the practice population health, such as chronic disease monitoring (CDM) across the population and the quality outcome framework

(QOF). These were biomedical numerical markers of patient and practice population health such as glycaemic control and blood pressure. Some constructs represented pathological processes, such as microvascular disease leading to chronic kidney disease (CKD) or urinary ketones indicating keto-acidosis. Other constructs were representations of patient symptoms that were indicators of poorly controlled diabetes, such as urinary ketones (ketonuria), polydipsia and polyuria.

The numerical HbA1c targets for Quality and Outcomes Framework (QOF) achievement were part of the GP contract to incentivise primary care management and indicated quality outcomes for diabetic care for the practice population (Lester and Campbell, 2010).

Despite these apparently recurrent biomedical constructions of patients, when experiences with patients were described, GPs also provided the person-centred context for biomedical disease constructions. This was most apparent when choosing insulin for vulnerable patients, when the risk of hypoglycaemia was a key biochemical factor. As a result, the elderly population were a patient group to avoid aggressive blood sugar control and reconsider insulin therapy when managing T2DM. Although, there was research evidence support for tolerating higher levels of HbA1c in the elderly population, the QOF targets for HbA1c were not in keeping with the available biomedical evidence at the time and were aiming for HbA1c targets lower than GPs felt was safe. Low target HbA1c levels were problematic for individual patients that had compounding associated biomedical complications. Peripheral neuropathy manifested as reduced sensation in the fingers and feet, with a risk of accidental injury. Elderly patients may be “*frail[...]*with not a lot of muscle bulk” (Mike) and so vulnerable to fractures, or could have early memory disturbance. Together these features of elderly patients compounded the risks of hypoglycaemia. The risk of hypoglycaemia with insulin was generated as a GP barrier to insulin initiation for this group of GPs and primarily when concerned for their vulnerable and the elderly and conformed the empirical literature (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Ngassa Piotie *et al.*, 2021).

When GPs considered the individual and practice population management, these different health constructs were sometimes presented as formulaic management plans that informed practice protocols. In the following quote, Charles pursued a biomedical approach when he talked of managing and monitoring the practice’s diabetic population. Thinking of diabetic

management for individual patients from the perspective of a protocol was comfortable and not challenging.

"...fairly obvious protocol that you can follow relatively easily[...] you know, you make sure their blood pressure controlled, [...]The sugar isn't quite right, you'll be putting them on Metformin, you know, those decisions are easy, you know, don't need to think very much about them, you just look at the data and just say 'well yeah, this is what we need to do" Charles.

Guidelines from authoritative bodies such as NICE informed GPs of the current management based on expert and Evidence-Based healthcare recommendations. Guidance offered GPs biomedical and numerical parameters to improve diabetic patient chronic cardiovascular healthcare and glycaemic control. EBM provided the latest research evidence for therapies available but may not be endorsed by authoritative guidelines.

The accepted assumption was that research evidence underpinned guidelines, and so provided access to Evidence-Based practice. Evidence within guidelines was cumulative and systematised research evidence that was endorsed by authoritative bodies such as local PCT guidance or NICE. Consequently, GPs valued guidance as providing authoritative summaries of recommended patient management. They motivated GPs to change their prescribing behaviour and were part of accepted practice across their peers. GPs used varied descriptions when referring to evidence-based recommendations and guidance: "*headlines*" (Mike) and "*synopsis*" (Jackie). These recommendations were credible because authoritative bodies endorsed them. NICE guidelines were frequently mentioned across the GPs when considering glycaemic targets and escalation of therapy, which gave a sense of greater influence on GP decisions, especially their prescribing behaviour, than research evidence across the GPs.

The GP position to provide patient care defensively was another alternative view of a potential GP attitude. If a GP considered an alternative action against the guidance that would be more appropriate to the patient, then there was a sense of greater uncertainty. Peter reflected on this point specifically and warned that a GP would have to justify their actions carefully. It was also a cautious reminder for GPs to be mindful if actively prescribing therapy against guidelines:

"[...]you still don't always do what they (guidelines) say but I think you need to be aware that if you're not doing that then you need to know why....Well, you need - well you need to be aware that you've made a decision consciously." Peter

Evidence from healthcare research that supported the guidelines was also a consideration for GPs. The next section explained the ways GPs viewed evidence-based medicine (EBM).

4.6.2.2 Person-centred use of evidence-based medicine (EBM).

Compared to guidelines, evidence-based practice (EBP) involved the systematic process of seeking the latest research evidence for individual patients' best available management. GPs did not show or explain the use of systematic EBP processes. Instead, GPs described using information they found credible and endorsed by expert and authoritative institutions.

When there was a reference to research evidence or guidance, the GP belief in the scientific research underlying diabetes management reinforced the GPs' biomedical beliefs. Accordingly, GPs understood that glycaemic control targets were supported by NICE guidance and underpinning research evidence. GPs also preferred guidelines to support the recommended patient management of the complications of diabetes. For example, whilst glycaemic control remained important, there was a priority within the evidence-based research and guidance towards blood pressure and cholesterol management as critical areas for clinicians to consider. GPs understood the importance of this change in practice and believed the scientific research to support it.

There was also an opinion that evidence and guidance allowed confident but limited treatment choices. Consultations with patients involved diagnosing the medical problem through patient history and examination and involving the patient by sharing and agreeing with a management plan. In the following quote, Fiona described a rational process to use EBP, which supported her decisions and allowed justification to the patient through an explanation. The choices available to Fiona helped her manage the choices of therapy in a pragmatic way. However, the lack of good quality research evidence-base was a limitation for EBM use in practice.

"I do like Evidence-Based Practice and I do find it simplifies things, for me personally, because actually the treatment choices are far

narrower when you restrict them down to the ones that have been proven to work[...] I think it has its limitations[...] So if the evidence-base is poor, you know, as in there aren't many gold standard RCTs, there aren't good qualitative studies that talk about the process of care or there aren't good descriptions of complex interventions for patients and users of the evidence-base. " Fiona

Apart from the opinion that Evidence-based Practice (EBP) reduced and restricted treatment choices, Fiona and the other GPs did not describe or give an opinion on the stepped process of EBP, nor did they describe decisions they made during patients encounters using EBP. Instead, there were more vague references to knowledge from the internet or practice-based software knowledge tools such as "*web-mentor*" (Mike). In an example with a patient, Jackie described a patient encounter with suspected steroid-induced myositis. She focused her description of seeking knowledge on medical sites on the internet rather than considering steps of EBP. When research studies were named, it was superficially, and the GPs described key messages they retained from the research. The implication was that GPs valued the vital messages that underpinned practice recommendations within guidance but did not value EBP as a detailed process for researching and planning patient management.

In summary, GPs consider the guidelines and had an awareness of the associated evidence-based research. They valued evidence-based research underpinning guidelines, but actively practising EBP and retaining detailed knowledge of research evidence was not valued. Moreover, the generalist role was believed to be to understand the breadth of knowledge required for practice and appreciate the summary knowledge provided by experts. There was an indication that GPs valued the utility of guideline knowledge as recommendations for practice and showed an instrumentality towards guideline use in practice. The resultant attitude shown by the GPs created a stance towards EBM knowledge that was different and distinct from guidelines. However, the mindset shown by the GPs was a reflection of the literature evidence of Gabbay and May who offer 'mindlines' as an alternative view of how GPs manage and interpret biomedical knowledge in practice that is "*collectively reinforced, internalised tacit guidelines*" (Gabbay and May, 2004). Other researchers have since replicated their findings (Wieringa and Greenhalgh, 2015). Wieringa et al. have shown in their systematic review that 'mindlines' have continued parallel to guidelines but not incorporated into recommendations for practice (Wieringa and Greenhalgh, 2015).

4.6.2.3 Atypical patient constructions

Typical biomedical T2DM patients were expected to be overweight, have a poor diet and lifestyle and have pathophysiology of slow deterioration and gradual “insulin resistance”. Insulin resistance was a subtheme that explains a biomedical construction of the typical patient. If a patient did not fit the pattern, then the diagnosis of T2DM was questioned, and the patient was referred to secondary care.

In contrast, atypical presentations contrasted to the frequent descriptions of typical T2DM patients and the usual biomedical model of diabetes they understood. The resultant uncertainty of diagnosis resulted from the patient biomedical “*profile*” (*Rob*) not suiting constructions of type 1 or type 2 diabetic patients that the GP had formulated using their biomedical perspectives.

“This lady is somewhere in between. She's only recently diagnosed, but she's 40. So is she old type 1 or is she a young type 2? If she was a young type 2 I don't think I would have expected her diabetes to have deteriorated so rapidly, so quickly.... she had no ketones, no symptoms funnily enough, no polydypsia or polyuria, just had an HBA1C of 13%.....” James

The GPs tried to formulate decisions, but as the patient condition failed to behave in the manner expected or predicted from their biomedical understanding of T2DM and diabetes remained uncontrolled, then GPs would refer the patients to the diabetic specialist team.

“I think she’s always going to end up needing insulin, which is a bit of a cliché but I think it is true isn’t it, if you don’t have the classic non-insulin dependent diabetic who’s got a BMI of 35 and talk about their diet and start them on Metformin... She was referred pretty soon to a specialist...” Fiona

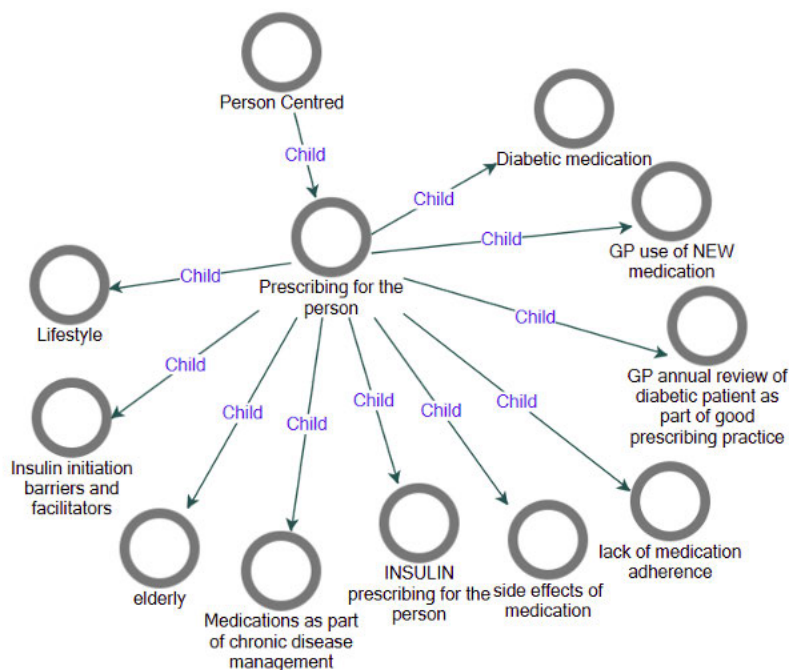
These atypical patient descriptions were infrequent as memorable patients across the GPs and may be due to the infrequent presentation of such primary care cases. However, the atypical

nature and awareness of such cases amongst the GPs highlighted their belief in typical T2DM patient presentation patterns.

GPs confidently moved forward to prescribe or advise patients when their biomedical knowledge supported them and refer patients when they felt they could not act at points of limitation in their knowledge or understanding of the patient problem. The type of consideration of typical and atypical T2DM constituted a ‘mindline’ or an aide-memoire to diagnose and manage diabetic patient types and directed person-centred biomedical care (Gabbay and le May, 2010).

4.6.2.4 Prescribing for the person

The GP prescriber theme acknowledged the GPs’ prescriber role in T2DM management at their practices where GPs were unable to delegate their prescribing role except for Sally, who had nurse practitioner. (Sally’s situation will be explained separately).



Prescribing for the person was a multi-faceted theme that contained the varied ways GPs saw prescribing for individual patients.

GPs showed understanding of diabetic medications and their appropriate prescribing use, according to authoritative guidelines such as NICE T2DM guidance.

The GPs' understanding of the benefits and side-effects of medications benefits directed their prescribing and resulted in decisions that balanced the opposing biomedical effects and constituted person-centred choices. James evaluated oral anti-diabetic drugs (OADs) insightfully and based on knowledge and experience as a junior doctor working in secondary care and his general practice experience as a diabetic lead. He believed the second-line medications after metformin had similar effectiveness to improve HbA1c levels. His belief was informed by experience rather than guidance. As a result, when choosing an OAD, he considered the medication's biomedical side-effect profile and based therapy decisions on his patients' profiles – such as age. He aimed to minimise biomedically anticipated side effects.

“Yeah, but they'll do the same. I mean, if you look at all the drugs they will all reduce your HBA1C by 1%. If there was one of them [medications] that reduced it by 2% they'd all be on that wouldn't they?... it's tailoring your therapy, look at the patient, look at the age,” James

Exenatide prescribing was motivated by its positive biomedical side-effect. The benefits on patient weight motivated GPs to understand the medication, and Vicky complained that they could not because it was not yet classified for primary care prescribing.

The prescribing of diabetic medication remained the GP's responsibility. The practice nurse would liaise with the GP and highlight patients who required escalation of diabetic or cardiovascular (hypertension and ischaemic heart disease) medication. When the nurse was a trained Nurse Practitioner (NP) and able to prescribe medications, the GP still retained overall responsibility for patient care through GMS service contracts. There was implicit awareness across the GPs that overall responsibility for medication prescribing remained the GP's responsibility.

When insulin was considered for individual patients, GPs confirmed the empirical data describing the barriers to insulin initiation. The fear of hypoglycaemia for elderly patients has already been discussed above and was the biomedical construction of an insulin side effect that could be life-threatening to vulnerable patients (Haque *et al.*, 2005; Ngassa Piotie *et al.*, 2021). Similarly, the GPs also confirmed other barriers recognised in the literature such as the fear of needles, weight gain and that commencing insulin meant the patient perceived themselves to be “ill”. Cath noted her practice population composed chiefly of white Caucasian patients feared insulin because of their observations and experiences of patients, and insulin meant they had entered the illness role and patients associated insulin with the deterioration of their diabetes.

“Because I think it’s historical that they as a younger person saw people who needed insulin as being ill.” Cath

Patients also envisaged insulin as harmful because of its side effect profile and experience. Jen also explained these negative views of insulin to be evident amongst the South Asian population. However, Jen also believed her patients blamed insulin and did not understand that their diabetic disease was uncontrolled and deteriorated. In the quote below, Jen explained that patients were not happy to initiate the medicine despite the degree of their disease.

“[...]there’s this concept of strong medicine and medicine being damaging in itself and that insulin’s a strong medicine that will harm them and they see that the medicine is more harmful than the disease [...] They kind of blame the insulin rather than the disease process.”
Jen

GPs recognised that insulin side effects included potentially life-threatening hypoglycaemic effects, and they had to prescribe the medication cautiously in the elderly or other vulnerable patients.

In summary, GP prescriber attitudes indicated that GPs were making person-centred medication choices. Although this research cannot claim the effectiveness and frequency of these person-centred biomedical choices, these GPs accounts confirms the positive patient reported literature that shows that GPs can provide individualised person-centred biomedically

focused care (Millar *et al.*, 2018). However, there was also negative qualitative literature showing how a seemingly patient-care focused clinician may have biomedical and disease centred agendas that cause her to miss person-centred patient agendas and collaborative or partnership opportunities (Bartz and Francisco, 1999).

4.6.2.5 Depression and diabetes

Depression and the associated apathy were mentioned by most GPs. They recognised depression and low mood amongst their patients and the associated lack of motivation to self-help, improve diet and lifestyles and engage with the healthcare or treatments. Empathy and understanding of patient feelings were widespread across the GPs and evidenced in their accounts of memorable patients. For example, in the following quote, Rob described a disengaged and depressed patient referred to the secondary care team for insulin initiation. Rob's frustration in his account reflected his sense of powerlessness to effect change for the patient.

“...when you've sort of given up and[...]self-defeating kind of thing, you know, just can't sort of say 'well, you know, I've tried losing weight and I can't', you know, that sort of slightly frustrating what's the point kind of conversations[...], I guess he's someone who always comes across as quite low in mood.” Rob

Apathy was a recognised diabetic patient behaviour, and GPs associated it with disengagement from self-care and depression. GPs wanted patients to take responsibility for their health and be self-determining and recognised that some patients were not engaged because of depression and an inability to engage. Comfort eating was also a recognised behaviour amongst diabetic patients and was believed to be significantly additive to weight management and diabetes control.

The sense of resignation that GPs and other diabetic specialist teams had done as much as possible was evident in their reflections and reflected the GPs' sadness when a patient's difficult social life confounded their depression. Jen described a patient that disengaged from healthcare. Though the patient said she took her medication and insulin injections, both Jen

and the secondary care specialist team believed she did not. Jen identified with the South Asian woman who had children of a similar age as her own. Jen described her outcome as tragic because the woman's diabetic health deteriorated, resulting in amputations and eventual death from cardiac disease. In Jen's mind, the process took place over many years but was led by the patient's depression.

“[...]woman who'd turned into this depressed, obese, housebound, defeated person[...] and just like nihilistic, [...]” Jen

These findings demonstrated links with GP empathy themes and understanding of the person-centred aspects of diabetes and depression and are a reminder to GPs to be vigilant that diabetes symptoms and low mood symptoms occur together and appear similar. They reinforce the GP ability to be person-centred as recommended in the approaches to PCC and identified in the empirical literature when Scandinavian clinicians reported empathic beliefs as core values for person-centredness (Fagerli et al. 2005).

4.6.2.6 Self-determination behaviour of patients

Patient self-determination was a construct that included competent patients making decisions to self-care and engage in therapy. GPs spoke of memorable patients who showed self-determination by refusing therapy or not involving themselves in self-care and healthy lifestyles. This subchapter will explain how GPs viewed patient self-determination as healthcare providers to individuals and groups of populations. Self-determination was also viewed in a similar dichotomous way as engagement in health, with patients being positively framed when they exercised self-determination and negatively framed when they refused therapy. Consequently, self-determining patients were identified as actively taking responsibility for their health.

Taking responsibility meant taking control of their diabetic health through compliance with advice and medications, and the biomedical GP agenda was fulfilled. Self-determined patients were adaptable to change, and medication use- especially insulin initiation, they had often empowered themselves in some way to use self-care mechanisms such as accessing online education.

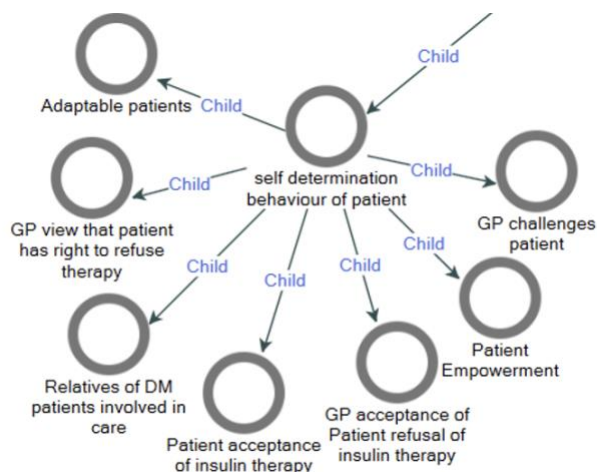
Consequently, when patients were competent to make their own decisions but refused therapy or escalation to insulin initiation, GPs attempted to understand the patient reasoning for refusal. The GPs identified patients who had prioritised social life and other personal agendas over their health. The GPs would then attempt to negotiate with patients or accept the patient refusal with a follow-up plan. Patient agendas exemplified by GPs amongst their memorable patients were varied:

- A Patient that was a Heavy Goods Vehicle (HGV) driver so wanted to avoid insulin therapy because of the potential of losing their job.
- A patient who was a carer for their partner and had a stressful life.
- Patients who were wanting to try harder with diet and refusing insulin therapy against biomedical advice.
- Patients who were refusing to attend secondary care for insulin initiation and follow up.

When patients refused therapy, GPs respected their decisions and their right to refuse therapy. The GPs showed person-centredness; they could transition from their biomedical stance to prioritise the patient agenda. This change in perspective was a move towards a shared decision-making approach with respect for patient autonomy. To reach a decision that included the person-centred approach and accept patient priorities, GPs would compromise their belief in the need for insulin and their biomedical stance. GPs did feel uncomfortable about this biomedical compromise and acceptance of patient self-determination. The following quote demonstrated how a GP was uncomfortable with his compromised biomedical belief that the patient required an escalation in his treatment rather than further diet and lifestyle change efforts.

“...I’m thinking you can try – no matter how hard you try you’re still not going to get it sorted here. This isn’t – all you can do at this stage is tinker with your lifestyle and diet. You’re not going to revolutionise things anymore.” Mike

Map 4: The theme of the GP perspectives of the self-determination behaviour of patients.



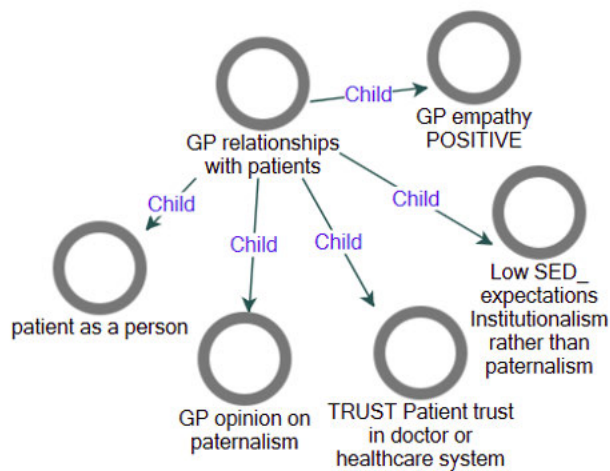
When patients wanted to avoid insulin because of different person-centred agendas, the patient attitude reinforced the negative GP position to leave insulin as a last resort. However, when GPs reached the point of wanting to prescribe insulin and patients refused it, GPs were left with an uncomfortable stance of compromise. When person-centred agendas were more important to patients, GPs respected that they had decided not to prioritise health. Despite feeling the tension, the GP respect for patient autonomy, and so self-determination was evident.

In summary, biomedical construction of patients was described by GPs in the context of person-centred decisions of prescribing T2DM oral medications and insulin initiation.

4.6.2.7 GP relationships with patients

GP relationships with patients was a theme that included multifaceted ways GPs described their relationship with patients. It was inductively generated and evident prior to the change in the RQ seeking person-centeredness of GPs more than the biomedical aspect of insulin initiation in T2DM. This is a hierarchical theme with various subthemes that provide a multifaceted view of GP relationships at a descriptive level. Essentially, this meant seeing the patient as a person, with social lives, jobs, families, and the impact disease had on life. Such rich descriptions came from doctors such as Dan, Jen and Alice, but most doctors related patients they had developed longer term relationships with continuity of care, and trust.

Figure 5 the GP relationships with patient theme and subthemes



GPs recognised the patients as a person through short and long accounts of patient encounters as individuals. The GPs explained relationships with memorable patients and their practice population locally including positively and negatively framing themes. Trust resulted from positively framed relationships and rapport built with patients over time. This does not imply frequency or commonality for all patients. However, there were relationships with T2DM patients that had a cluster of issues that required relationship building and described across the GPs.

Building rapport to gain patient confidence and a positive doctor-patient relationship in general practice, meant follow up and continuity of patients which allowed GPs to understand patients' lives and the impact diabetes had on their lives. In this following quote, Andy described his efforts to achieve rapport with a patient who had failed to attend appointments with the practice nurse. Andy was self-aware that he aimed at building a rapport with the patient to achieve patient engagement with his diabetic health.

“...it was seeing him quite regularly and really sort of building up his confidence that things were going in a direction that he could manage...I think it was perhaps taking an interest in him not just as a

series of disease, not just as a person sitting in front of me, but sort of what he does and everything....” Andy

Dan contrasted the ability of GPs to achieve rapport and trust with patients with his past experience as a doctor in secondary care. Dan had explained his patients' experience attending secondary care appointments and not starting medications prescribed in the clinic in the following quote. Dan believed that patient trust of the GP and mistrust of the secondary care team resulted from the greater trust in his opinion because of his position as a GP.

“...they’ll come in when the doctors in cardiology have made perfectly reasonable suggestions and say ‘I haven’t started the tablets but I wanted to run it past you first’, which is very nice but, you know, partly that must be because they want to speak to somebody that they know and trust [...]” Dan

Challenging patient behaviour and so, the patient-provider relationship was infrequent, and as explained in reflexive TA methods, the salient features of the theme are significant. Cath described such a potential breakdown in patient-provider relationship. Consistency in the message to the patient from her colleague nurse, and so support may have aided the retention of the relationship. Driving with a diabetes diagnosis, particularly if on insulin, required individuals to notify the Driver and Vehicle Licensing Agency (DVLA) of their diabetic status. Cath described how a new practice patient had become angry when she advised him to inform the DVLA that he was on insulin and an HGV driver. He had not declared his situation for several years, so she negotiated a time frame with the patient to inform them. The patient remained angry with her for a time, but eventually, he and his wife did send a letter informing the DVLA, and he did retain his rapport and ongoing relationship with the doctor.

“He was rather angry. He said I don’t think it’s anything to do with me and that was at the end of the consultation [...] he would never see me again but she sort of reiterated that that was the correct procedure and I have seen him again and he was fine....” Cath

Reflexively, such cases of trust, rapport building, challenge and retention of patient relationship made sense as an insider GP, but there were surprising descriptions of paternalism that GPs retained despite also expressing person-centred explanations of patient care. The person-centred construct was generated from GP perspectives, and negative attitudes such as paternalism may appear ironic because the concepts were generated during thematic analysis by an insider GP researcher.

So, for some GPs, the key was maintaining the patient relationship, and GPs showed respect for involving patients in medical decisions. The GPs recognised the shift from paternalism to the recognition toward personhood and autonomy. In the following quote, Matt explained how he valued patient involvement rather than medical paternalism in the past because patients engaged with the doctor, and future follow up care was more comfortable.

“If you go in as the doctor knowing what’s best saying ‘I’m recommending this, you must do this. Anything less than this is irresponsible and you’re being stupid’. That’s very destructive to the relationship of the patient and I think the relationship you have with the patient is a precious commodity and not to be at risk of draining away. I think as time’s gone by[...].” Matt

And few expressed paternalisms towards patients, but when they did, it appeared to be due to their patient characteristics, and indicated the clinician lack of self-awareness. Peter saw his population as less assertive and accepting of biomedical advice, including medication. He identified the characteristics in the population, rather than an arguably alternative view that the patient behaviours may reflect his potentially paternalistic attitude:

“...the area where I work, most of the patients just say ‘thank you, doctor, yes of course I’ll take them’ because I mean we’re in that sort of – well our population is largely unquestioning” Peter

An insider GP exposing paternalism may seem ironic, but reflexively considering low SED populations, GPs may continue paternalistic relationships with patients whether aware or not. Fiona was aware of her low SED population’s lower expectations and less questioning of her decisions:

“ I think it’s partly paternalism[...] we’re obviously in a fairly deprived socio-economic area [...] its almost an institutionalism rather than a paternalism. [...] when they get the doctor’s expert advice then that’s fine.” Fiona

The paternalistic provider relationship with patients of low SED may be a factor in the acknowledge unmet needs of low SED patients (Houle *et al.*, 2012; de Figueiredo, Snoek and Barreto, 2013; Rutten *et al.*, 2018). Rutten et al found clinicians excluded 28% of low SED group patients from a PCC intervention because of social issues and the authors believed these were the very patients that may have benefited (Rutten et al, 2018). Houle et al also reported unmet patient needs from low SED groups with complaints about ‘less talk-time’ (Houle et al., 2012). If paternalism is a factor, then education of clinicians in PCC approaches, and improving self-awareness of such attitudes may improve PCC delivery at the individual level.

So, in summary, GPs frequently were expressing positive patient provider relationships with patients, showing respect for personhood, the social world of patients and the impact disease could have on their lives. Building relationships was about rapport and maintaining relationships through follow-up, despite occasional reports of challenge to the patient-provider relationship. Distal GPs in chronic disease management meant delegation of workload, but obvious impacts on GP-patient relationships with patients problems arose. Despite seeing themselves as problem solvers (see the doctor-centred themes), the distal GP relationship was a barrier to patient management at times that they needed it and providing PCC ‘by proxy’ through the nurses appeared to be the way this group of GPs behaved. However, paternalism may continue for GPs consciously or unconsciously in populations that are accepting of it. However, unlike the Norwegian clinicians reported to feel discomfort over submissive or accepting Pakistani patients, these UK clinicians appeared more accepting and perhaps the tension belonged to the insider GP researcher who may align more Norwegian clinician attitudes (Fagerli *et al.*, 2005).

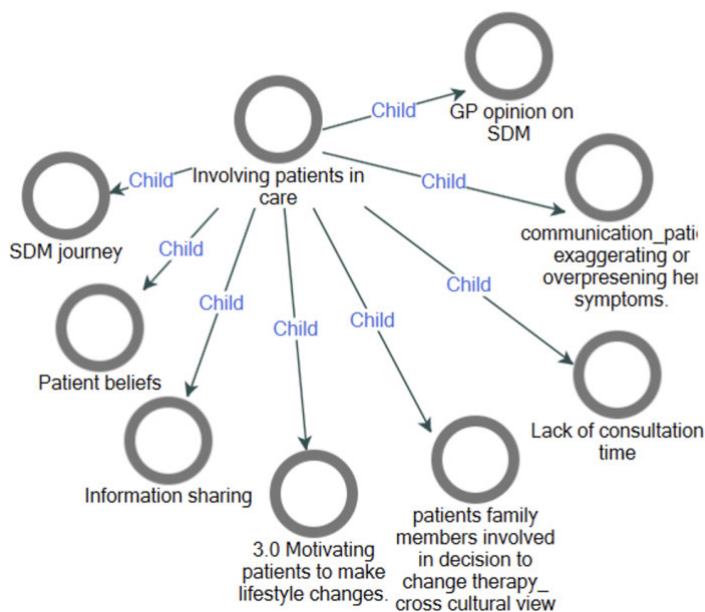
The link between the person-centred self-determination themes, generated tensions about patient engagement in care for GPs, and the patient-GP relationship. and is explored separately in the tensions subsection 4.9.1. However, the distal patient- provider relationship

The next section explores how GPs explained patient involvement in care.

4.6.2.8 Involving patients in care

This theme encompassed the different ways GPs believed they involved patients in care. They were subjective and descriptive at times, and at other times, appeared learnt from training such as shared decision-making knowledge, but evidence of GP involvement of patients in care was through the sharing of memorable patients.

Figure 6 Involving patients in care theme that was deductively organised after the literature review on person-centredness.



GP opinion on shared decision making (SDM) was more akin to person-centred overall approaches and there was no actual description of regular use of SDM tools. However, talk of delivering SDM, being patient-centred and sharing options were common across the GPs. The paternalistic relationship and GP attitude was previously discussed in the way GPs presented relationships. But such paternalism was a barrier to SDM delivery when needed. Moreover, Pete made credible argument for not using SDM methods, and offering ‘control’ of

the consultation in an instrumental way: to maintain control of the consultation and, aiming to manage workloads and time:

“[...]the problem with the stuff we are doing at the college on communication skills assessment [...]I think it’s a control thing because as soon as you say to the patient, “What do you think we should do?”, you’re immediately handing control of the consultation [...] until you’re confident enough to know you can get it back whenever you want, you know new guys don’t know particularly like doing that.” Pete

Awareness of patients varied beliefs about health was expressed in scenarios such as ideas of insulin ‘being strong’ medicine amongst the Pakistani population for Jen, or health literacy issues when patients misunderstood that the numerical dose of one drug did not equate to the same strength or effectiveness of another.

Examples of information sharing included knowledge of education programmes, patient leaflets, and support groups, and varied quantity and depth of the explanations across the GPs may be the result of the interview process as a ‘travelling’ and exploring the participants views rather than questioning their knowledge and detailed explanations to educate patients. However, implicitly, the role of sharing information, educating and motivating patients about diabetes was delegated to the nurse for most GPs. However, GPs did provide scenarios of memorable patients where education was provided and succeeded or failed.

“Heading him the sort of direction of diabetes UK and stuff on the web[...] then he came back to see me and we discussed losing weight and these sorts of life style issues.” Andy

There was talk of influencing patients to make lifestyle changes, engage with and adhere to treatment, and often involved ‘threat’ explanations that may not be considered person-centred as previously discussed. GPs described patient scenarios of normalised explanations of ill-health deterioration when patients did not adhere to medication, that were meant as education,

but appeared blaming. Alice stood out as trying to minimise the fear of needles and used her own T1DM as a source of explanation and align herself to patients.

Sharing uncertainty with patients was infrequently mentioned across the GPs, but the concept of evidence was used by GPs to support arguments and convince patient of the value of medication and disease control. More educated patients asked more questions, and many GPs understood the need to reactively share knowledge with “*demanding*” (Rob) population groups , and the lower expectations of patients from low SED groups has already been discussed.

On the other hand, there were GPs that explicitly believed patients required support during the journey to understand and manage their diabetes as it progressed and changed. It is significant that these ‘journey’ of the diabetic was expressed by Cath and Alice, who had T2DM and T2DM respectively themselves. Their own diabetic experience was implicitly key to their empathy and support to patients. In this following quote, Cath explained her understanding of the patient journey and described helping patients accept biomedical knowledge at the different stages, indicating a supportive and collaborative approach. In addition, the GP showed her empathy towards patients that required time to accept their diagnosis:

“[...] [the diabetes diagnosis] it’s quite a shock to them and you know that you have to start this medication to get them on track and they have to have each one explained and some can take it on board quickly, some it needs several – it’s like a journey really and you start it and you’re with them and it’s no use you going ahead and doing all the correct things if they’re still at base one and have not even accepted the diagnosis. So you’ve both go to progress at the same level. Some will just go nice and smoothly and some are difficult to get off first base aren’t they, ...” Cath

Cath and Alices first-hand experience of living with diabetes provided a person-centred understanding of their patients, and appeared to transcend their diabetes knowledge when they described patient encounters with other problems or diseases. The contrast between these and other GPs' more biomedical and "threat" explanations of how they included patients suggests that practitioner education may increase person-centredness, and may apply to other chronic conditions. Significantly, compared to doctors like Jackie, Sally and Vicky, Cath’s delegation

of diabetic chronic disease management to the nurse still allowed her to be involved with her patients and was able to tell richer narratives of her patients' diabetic journey. Her understanding of her patient's illness narratives, partnership approach and less distal approach indicated a greater degree of person-centredness and arguably, in line with Gothenburg principles.

Involving patients in care did show signs of collaborative and person-centred delivery of patient care, and though self-reported, shows that GPs have person-centred attitudes and behaviours. However, the use of biomedical framed explanations of disease and threat explanations early in disease remained the mainstay of all GPs. However, more empathic and person-centred GPs did show collaborative, continuing care of diabetic patients

Lack of engagement of otherwise self-determining patients are explored later tension sections 4.9. When patients were perceived to be competent and not engaged or involved in therapy- the problem of ongoing poorly managed diabetic health was uncomfortable for the GPs and is explored in [section 4.9.8](#).

4.6.3 Doctor centred themes

The doctor- centred themes were GP constructions of T2DM care and insulin initiation that centred around GP values and agendas. The GP person was a contrasting figure and allowed representation of the GP duties to provide diabetic care beyond biomedical and person-centred care.

The following summary table displays the higher order subthemes, their definitions, and a sub-theme example quote.

Map of the doctor-centred higher order subthemes, their definitions, and a sub-theme example quote.

| | | |
|---------------------|---|--|
| Doctor-centred care | The GP views or values patient care from a doctor-centred values or agendas; subthemes and concepts are not related to person-centred care. | <i>"QOF mean that some of our money comes from doing this well, therefore you employ nurses and you actually, you've improved your</i> |
|---------------------|---|--|

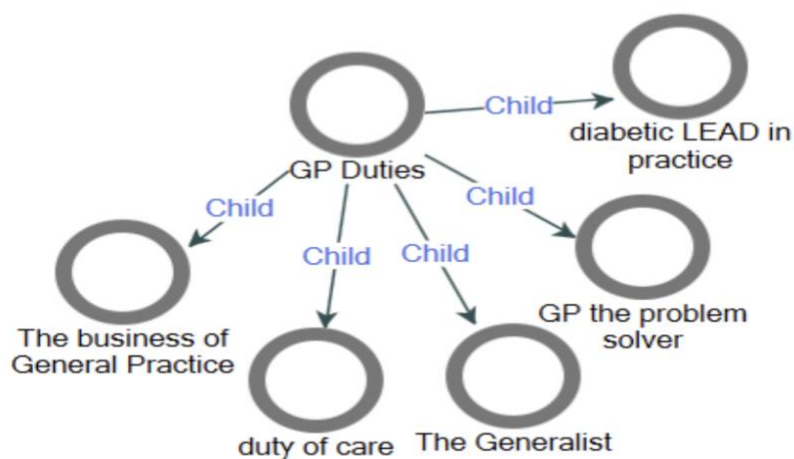
| | | |
|-------------------------------|---|--|
| | | <i>service...” Charles (GP as employer node)</i> |
| GP confident use of knowledge | GP displays or explains confidently using biomedical knowledge. This can include confidently aware of a lack of knowledge or boundary the knowledge they have. | <i>“I’ve come to the conclusion that patients are best served by me referring to secondary care for a decision to be made...”(Matt) (confident decision-making despite uncertainty)</i> |
| GP duties | The combined duties the GPs expressed as their concerns, subthemes included descriptive role and responsibilities, such as diabetic lead or the employer, but the views at their core were doctor-centred agendas. | <i>“...it’s all change because the main, one of the nurses is a month away from retiring, the other one left to work in another part of the country...” Dan (GP problem solver)</i> |
| GP feelings | Expressed feelings – explicit or implicit- during the interview, showing tension and emotion as a result of an opinion or patient experience. | <i>“they come in and say ‘I have given up smoking...I have got this cough’ ...and you xray them and they have go cancer...because you know I have spent years badgering them about stopping” (Andy) (GP frustration)</i> |
| GP personal life | This theme comprised of the impact the GPs own life circumstances had on decisions made to direct care provision. The theme was considered significant because of the context of delegation of care and distal GP, the GPs who described their own journey with diabetes. | <i>“we had all these things going on in our home lives[...]I didn’t really get involved as much as I perhaps could have and our nurse practitioner really took on the, she sees most of the diabetes.” Sally (GP personal life)</i> |
| GPs’ own personal values | The explicit or implicit expression of the GPs own personal values. | <i>Interviewer: “Do you think that that (practicalities) would influence your decision to allow yourself to go on insulin...?” Cath: “I think that would be. Clinical judgement for myself...like I hope it is for them” (personal beliefs node and HCP with diabetes node)</i> |
| Time as a barrier | | <i>“... I basically gave up keeping to ten minutes many years ago and for many years I was endlessly stressed and feeling I should get better, I should improve, that this was a fault of mine and I had issues with time management and as I’ve got older I’ve just become more accepting of it really[...] Jen</i> |
| | | |

4.6.3.1 GP duties

General Practitioner (GP) duties were responsibilities the GP had to provide care towards individual patients and the practice population. A duty of care is a moral and legal obligation

for a doctor to provide patient care and was underpinned by contractual obligations to the Primary Care Trust (PCT) and ethical obligations under the General Medical Council (GMC). GP roles were leadership responsibilities in addition to the general medical service provision to all patients. All the GPs had duties to provide general medical services to patients, maintain competence, ensure patient safety and maintain trust through professional integrity, which constituted the generalist role. If GPs performed additional roles in their practice, the GP-Person interacted with other agents to perform that role. Specifically, the GP roles of diabetic lead and the business manager of general practice had identifiable duties to lead practice teams of doctors, nurses, and administration staff.

The map of GP duties subthemes:



The GPs' duties in practice were dependent on the responsibility they had taken. Some GPs were partners and diabetic leads, while others had been diabetic leads in the past and were no longer so or never had been diabetic leads. As generalists, all the GPs saw diabetic patients when patients booked to see them or at the request of the practice nurse. Only one of the interviewed GPs, Alice, was a sessional GP, not a GP partner, and had no diabetic clinical leadership roles in practice. However, she also experienced managing diabetic patients who booked to see her for clinical issues related to diabetes.

Diabetes workload management and insulin initiation service provision were additional to the GPs' generalist role. The additional workload, the potential for multiple other roles, and the undifferentiated and uncertain daily patient care work as generalists could all be overwhelming for some GPs. This was especially so if the GP perceived that the practice population health needs were high. Consequently, if there were no additional funding and resource allocation for

insulin initiation, GP and nursing care and administration resources were redirected from generalist work. The findings indicated that some GPs were not interested in planning insulin initiation at their practice because of these barriers.

GPs supported nurses in diabetic clinics and were available to make medical therapy decisions about diabetes and related complications, especially cardiovascular complications. There were nurse practitioners able to prescribe, but the GP would be involved with patients if the NP requested a review. The GP's involvement could vary depending on the nurse and NP experience and confidence and the availability of trained nurses. For example, James explained that the NP prescribed limited medications but would not confidently withdraw medications:

“But I think I must see 90% of the patients in the clinic, together with the nurse. They do the clinic, I just advise as it were[...] And with nurse prescribers they can only prescribe certain drugs and then only by advance patient directives[...] But even then, you know, 90% of the patients will be straightforward. We're talking about small numbers.”

James

James' narrative relayed his distal role through delegating chronic disease management, which applied to most diabetic patients. By implication, the person-centred delivery of T2DM care for most patients was the responsibility of the nurse.

James, Dan and Charles delivered insulin therapy, and it was done so as business model, with managed nursing staff for delivering the care. Other GPs had a more collaborative, or even dependent relationship with the nurse. Like Jackie, Vicky and Sally relied on the nurse to deliver diabetic care. However, Sally expressed gratitude over the nurse practitioner's competence and initiative to take the lead in diabetic care of patients, even when difficult and complex patients arose. Consequently, the varied styles of how diabetes was managed at each practice was sometimes the result of the various skills of nurses and doctors. However, as confirmed in the literature, a clear boundary between the nurse and doctor role lay in the prescribing responsibility. Despite the depth of trust and reliance in the NP at her practice, Sally remained aware of her responsibility for prescribing over all:

“I mean there have definitely been times [...] she'll (the practice nurse) come and suggest something [...] normally it'll take me ages to actually think it through and I might have to look it up and some guideline and then, you know, sometimes I will come back and say no, actually because of this or that and I shouldn't do what you suggested [...].” Sally

GP duties also involved awareness of doctor-centred duties around prescribing and the need to avoid harm. This was explicit and implicit amongst the GPs when they discussed the prescribing role, new medications and insulin risks, especially for the vulnerable and elderly. Although an expected finding, the fear of harm proved to be a significant driver across the GPs and is explored through narrative analysis.

In summary, GPs varied in the degree of involvement in diabetic patient care. Some diabetic leads supervised and managed practice nurses who provided the proximal diabetic care to the majority of patients. However, at times prescribing, or complications, GPs were involved to direct biomedical patient care. As a result of their distal role, if patient care required escalation, the distal GP role meant a barrier to GP delivery of person-centred care, such as understanding how to manage the poor medication compliance for patients with mental health issues. When they are proximal and person-centred, they are so as a consequence of involvement in the cluster of other diseases, such as hypertension, kidney disease and cardiovascular issues or other diseases for that individual patient.

This distal finding is arguably expected but is viewed in this thesis as a reframing of the GP problem in person-centred care. As a consequence of delegation of duties, GPs are not person-centred for the majority of chronic disease patients, and this is problematic if the patient requires a PCC approach within the context of that disease and GPs may require strategies to manage this within their practice setting.

4.6.3.2 The GP confident use of knowledge

The confident use of knowledge theme initially appeared biomedical, but as analysis progressed, the theme was firmly linked with GP centred perspectives. GPs spoke about insulin initiation in T2DM, emerging diabetic therapies and the associated attitudes GPs presented. The GPs generally showed their knowledge through their biomedical descriptions of patients and their management encounters.

GPs' description of their knowledge of diabetic management, medication and insulin therapies was linked to their role in planning and supporting diabetic management at their practice. Some GPs were diabetic leads, while others were generalists who could consult diabetic patients when requested. When patients consulted GPs, they made appointments separately to the planned diabetic management and monitoring planned with the nurse. A vital point to make, however, is that lack of knowledge of insulin initiation dominated and was linked to the GP perspective of insulin service delivery. However, a key sub-group considered themselves confident in insulin prescribing. These knowledgeable GPs provided contrasting attitudes and views to the other GPs who lacked knowledge or had varying insulin initiation knowledge.

The subthemes related to the confident use of knowledge were expected findings around GP personal development, consultation skills and ongoing development through various means such as courses, reading guidance, journals or seeking expert advice when decision making to support or defend decisions about drugs or diagnosis. For some access to knowledge had to be convenient and at the point of delivery at appointments with patients, whilst others sought expert advice directly. For example, Harry felt thwarted by medicines management when he was unable to prescribe a medication prescribed in secondary care for his patient, and Jackie sought urgent rheumatology advice when she felt a patient developed a rare condition of myositis as a result of steroid use.

Confident GPs took a positive stance toward insulin initiation in primary care and demonstrated that they had the knowledge and the confidence to develop the practice services. They encouraged practice nurses to train and deliver the insulin initiation at their practice. Dan, James and Mike were diabetic leads and spoke knowledgeably about insulin therapies and processes. James described the patient biomedically in the quote below and displayed his confident knowledge of insulin therapy and administration.

“Whereas insulin initiation we do ourselves. I mean she had no ketones erm, no symptoms funnily enough, no polydipsia or polyuria, just had an HBA1C of 13%.[...] the options were erm, a long acting insulin Levemir or Glargine together with a bolus of a rapid acting insulin 2 or 3 times a day at mealtimes or a mixture.” James

Local PCT diabetes management guidelines directed therapy prescribed in primary care, including insulin initiation and the newer anti-diabetic agents. Dan, found the PCT guidelines relevant to read and assessed that he already followed the latest diabetic guidelines in the main. He considered he was confident to try the newer anti-diabetic agents suggested for use in primary care:

“[...] those are the kind of guidelines that when they come out, I actually read them rather than feeling, you know, this is not enormously relevant to me, I’m conscious of the fact that I sat down and actually read the guidelines and, you know, found myself thinking, yes, I do this, 80%/90% of this I do, this isn’t any change,.” Dan

As a consequence of re-analysis of the knowledge related themes and textual data, an interesting subtheme were generated. The next section considered the issue of insulin initiation, service delivery and knowledge acquisition from the framing of ‘infrequent presentation of insulin initiation’.

4.6.3.3 Infrequent presentation of insulin initiation

Infrequent presentation of insulin initiation was arguably the result of deductive analysis. Empirical data suggested that GPs fail to meet the needs of MS patients because of a lack of skills and experience due to its uncommon presentation (Methley *et al.*, 2017) .

Only three GPs out of 16 actively delivered insulin initiation, and may be the result of GPs attitudes to knowledge and business plans for infrequently presented problems. Directing GP and nurse funding resources, time, and training toward knowledge and skill acquisition of infrequently presenting problems may be argued to make poor normative sense when prioritising care delivery. This attitude presented a doctor-centred mind-set.

The GPs varied in how explicit they were about the decision to avoid initiation. For Pete, insulin initiation in practice was an explicit frustration and tension and he was irritated that there was no consideration for the funding and resources for such a service by the local health authority. Sally and Jen had planned to deliver insulin initiation services at her practice,

attended training with the practice nurse practitioner and nurse. The funding was withdrawn and the delivery was not initiated for both GPs.

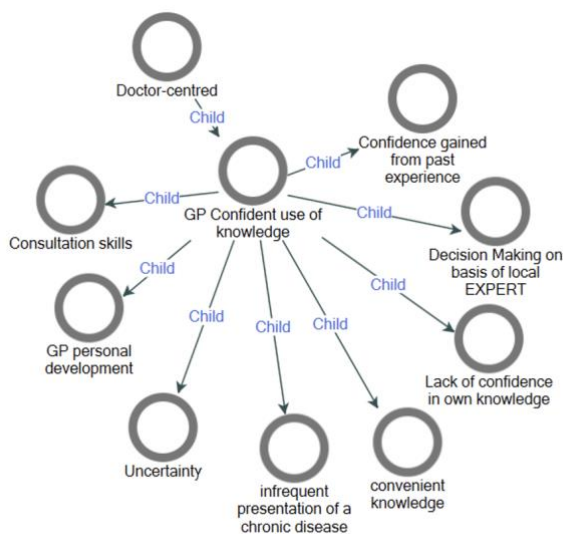
Sally explicitly believed the staff and appointment resources required to deliver the service made it untenable and appeared dismissive over the primary need to offer the service. The lack of time and resources and the issue was not a priority:

“[...]the reality is we don't really have time, you know these patients weren't going to be particularly special or different in any way[...]”
Sally

In comparison, Charles made plans and started a service to deliver insulin initiation, with full awareness that no extra funding was available, but with the plan that it may result in improved QOF results and so, increase practice funding. However, even Charles admitted the low numbers involved meant the service was financially untenable.

“[...] we did an audit [...] I don't think we have a massive problem with, you know, a lack of compliance [...] we ended up identifying 5 or 6 patients of whom 2 really didn't want to get involved[...]”
Charles.

Thus, the infrequent presentation of insulin initiation indicates a doctor-centredness and instrumentality to PCC- to not deliver person-centred care when it was not to the GP or GP practice benefit. This is explained further in section 4.8



Map 5: The Map of subthemes generated around the GP confident use of knowledge.

4.6.3.4 GP feelings

GP feelings was a subtheme generated from the stage of interviews onwards. As GP shared views, expressed attitudes and patient encounters, emotions were evident in their tone, expression and textual data. Although the audio-recordings are not shared as output, the textual data related the GPs' implicit and explicit feelings evidently. The travelling approach to the data in the interview with a colleague may have helped some GPs express more freely.

Significant feelings had been noted as tensions and acted as indicators of what was important and valued. All GPs were expressive of feelings in encounters such sadness shared in empathic situations of patient hardship.

However, fear of harm, frustration, anger and guilt were emotions associated with tensions and the will be addressed alongside corresponding tensions and narrative analyses in 4.7.

For example, the generalist workload was described as intense by some GPs, involving multiple pathological problems and correlated this with their high proportion of patients from lower socio-economic groups. For example, Harry's practice provided services for patients

suffering from mental health problems, drug and alcohol addiction, and smoking-related diseases. He compared his patients to other populations in southern England and described in the following quote that he believed his work also required awareness of complex diagnoses. He provided a vivid picture of the challenges of managing acute and chronic health amongst his practice population. He used “*sharpness*” (Harry) to describe his work implying feelings of working at the edge of challenging medicine:

“[...]the intensity of the work is far too high in this practice[...] sharpness of the work and the repeatedness of the work[...]It is like a treasure trove of pathologies here[...]And typical presentations, those which you don't expect you have to seek out for it, it would be there[...]” Harry

4.6.3.5 GP personal life

This theme was generated from infrequent sharing of personal life history by the GPs, such as their own story of diabetes. GPs only and is listed because of the implication the comment had on the delegation of workload to the nurse. Sally worked with a Nurse practitioner she trusted and delegated the diabetes chronic disease management lead role to. Although Sally was overall responsible for prescribing. Sally explained this was a decision made after her own personal time off work at the time the diabetes lead role was developing.

“we had all these things going on in our home lives[...]I didn't really get involved as much as I perhaps could have and our nurse practitioner really took on the, she sees most of the diabetes.” Sally

Few GPs related their personal life, and it was not the agenda of the interview guide. Sally's interview was one of later interviews in the group and as such the potential to iterative add to the interview guide and ask other GPs about the influence of their personal lives did not arise. However, GP personal life is arguably the aspect that provides the human dimension to the views of GPs. Reviewing the themes from the view of person-centredness, exploring GPs agendas and personal values and attitudes may cause reflection differently on aspects of person-centred delivery. It is a limitation of this research that focused views and questions

around insulin initiation delivery meant seeking further person-centred individual GPs values was unable to construct further dimensions of the GP to explain the later issues of instrumentality.

4.6.3.6 *Time as a barrier*

The difficulty of time management for patient consultations was a frequent complaint from the interviewed GPs. It was also the case for nurses' time in diabetic review appointments, GPs' clinic, and insulin initiation consultations.

There were implicit and explicit indications of GPs feeling undermined when they were unable to manage time. When it was mentioned, the GPs were concerned with time pressure in GP clinics and the effect of managing decisions in the 10 minutes allocated for a consultation. Some of the GPs mentioned the strategies to manage time, but there were no specific strategies to manage time across the GPs. Interestingly, GPs (Jen and Alice) who explicitly accepted the cost for their more empathic approach were to run late in their clinics, which created a negative tension in their narratives and the implication of stress.

“... I basically gave up keeping to ten minutes many years ago and for many years I was endlessly stressed and feeling I should get better, I should improve, that this was a fault of mine and I had issues with time management and as I've got older I've just become more accepting of it really and I just know that my surgeries will go on from ten to nine to gone one and then I space my appointments out much more so that people aren't waiting.” Jen

Across the GPs, there was also concern about time management for chronic disease management because of the complexity associated. GPs had delegated diabetic review services to nurses, and there was an understanding that the diabetic reviews themselves were time-consuming for nurses. The GP agenda may be to consider and plan escalation of therapy with a patient. As part of the chronic disease six-monthly follow-up review, the nurse had “*a lot to fit into a twenty-minute appointment*” (Matt).

Time was also a perceived barrier to insulin initiation in the practice setting for some GPs. The insulin initiation protocols set by the pilot service that Jen and Sally were involved with had planned thirty-minute appointments with many associated administration tasks. After initial

training, Sally and Jen's practice did not continue with the pilot scheme but decided to refer for insulin initiation.

There appeared to be a mismatch between the expectations of the pilot scheme organisers and the GPs and indicated the value of recognising the available GP systems of service delivery and being clear to GPs what resources would be required. Sally found the appointments were inappropriately long for her practice. In the quote below, Sally bemoans the time taken for administration was additive to the insulin initiation consultations already perceived to be time-consuming. The following quote also displayed Sally's belief that the nurses' appointment was a practice resource to be used efficiently.

“... And just the sort of irritation of having so many bits, you know, there's so many things in a patients notes to look at already with the consultation and then all the results and then maybe hospital letters and then to have to go and look at their hand-held notes and I mean I think their expectations were unrealistic and I think they thought that, you know, it would have to be a nurse appointment in like 30 minutes...”Sally

Sally's negativity may be exceptional and related to the pilot service organisation because her attitude was not shared by Jen and across the GPs that were referring to secondary care for the service. Significantly, the GPs that did provide insulin initiation services at their practice (i.e. James, Charles and Dan) did not complain of the time as a barrier in their appointments. Decisions could be taken over multiple appointments and benefited patients in primary care compared to secondary care. Moreover, Dan was explicit in stating he did have time to review and follow up with patients. He compared primary care and secondary care diabetic care, and he believed the continuity offered in his clinics benefited patients because the GP was able to review patients more frequently than secondary care:

“[...] I mean, the sum total of time I can spend with them, you know, maybe only 10 minutes but, you know, times twelve is still two hours of chatting.[...] but I can see what's been going on, up to secondary care, and they're going 'right, well, I'm going to suggest that they do

this and this with their insulin and I'll see them in six month's time', you know, that's, they have to do that because their clinics are too full."

Dan

In summary, there was an acknowledgement that short consultations were a barrier to GPs managing the patient and doctor agendas, but was also identified as an issue for the multiple tasks in practice nurse appointments. Time was an identified barrier to insulin initiation and but not across the GPs and may have been particularly so for GPs that were not fully committed to delivering insulin initiation.

4.7 Instrumentality – thematic finding

Instrumentality is the activity of one entity or agent utilising another entity or agent as a means to an end. Evidence of instrumentality activities could be constructed wherever they were doctor-centred. If the intention was to provide care for the patient, person-centredness was evident when GPs planned and considered the biomedical *within* the construct of person-centredness. Hence the reframing of biomedical patient constructions under person-centeredness, and were positive patient orientated activities.

However, instrumentality was evident when delegated the delivery of chronic disease management and even insulin initiation to nurses. This activity may neutral, and nether positive or negative/good or bad, because the nurses were employed to deliver a service that GPs delegated to.

Insulin initiation as an infrequent presentation was discussed previously in section 4.6.3.3. Arguably, the research design to seek views on this topic led a biomedical agenda. However, because of the narrative open style of the interviews and the travelling approach to the participants, the analysis from the person-centred framing of the data generated an important negative finding – that insulin initiation was not being delivered. The finding of infrequent presentation of insulin initiation indicated GPs placed priority of staff, funding and time resources elsewhere. A limitation of the research was not identifying this earlier and returning to the GPs to find out more of their agenda when avoiding the service delivery.

In view of the issue of diabetic inertia, for GPs the issue of insulin initiation remained minor and almost irrelevant even in 2009 to 2010 when the interviews took place and options for diabetic medications were fewer compared to recent guidance (Seidu *et al.*, 2022b). The GPs were not bound contractually and the majority were actively maintaining a stance to avoid delivery. The GPs had an instrumental attitude to avoid the delivery of insulin initiation in T2DM. Notably, the attitude reflects the literature describing primary care clinicians' negative opinions towards the delivery of person-centred interventions in primary care (Houle *et al.*, 2012). This instrumental attitude to avoid a service delivery because of the lack of benefit to the doctor or practice in itself presents a barrier to service delivery and PCC. Such instrumentality may indicate that time and resources are significantly in the balance of priorities for primary care clinicians when considering care delivery. Arguably, this theme has been generated by the insider GP, and required criticality to generate the concept of instrumentality as the driving force behind such doctor-centred attitudes. Self-awareness for all clinicians, funding authorities and policy makers may help improve decisions made to balance instrumental attitudes with those of meeting person-centred care needs.

The GP-centred perspectives and practice-centredness findings in this research resonate with the recognised views in the wider literature about medico-centrism (Gallagher, 1976). From this sociological understanding of healthcare, the GP appears to utilise resources to achieve biomedical patient care. Arguably, instrumentality exists in GP behaviours to manage the workload of caring for their practice populations. This GP-centred activity utilises resources to achieve biomedical patient care and manages that care within a system of various resources: time, financial and human resources.

On the other hand, within this Parsonian perspective of medico-centrism, the patient is constructed as a biomedical entity. This view is supported by Loewe and Freeman, who similarly showed physicians classify patients as a pathophysiological entity, whilst patients view diabetes through their social lives and their self-identity (Loewe and Freeman, 2000). However, this thesis has tried to argue that when GPs contextualise and construct the person-centred view within the frame of the person-centred perspective of the patient, the patient is objectified and the patient is seen as a person.

However, the GP, who is unable to deliver complete care, delegates patient care to the practice nurses. The practice nurse is an instrumental agent operating under the authority of the GP and manages patients' routine and regular care.

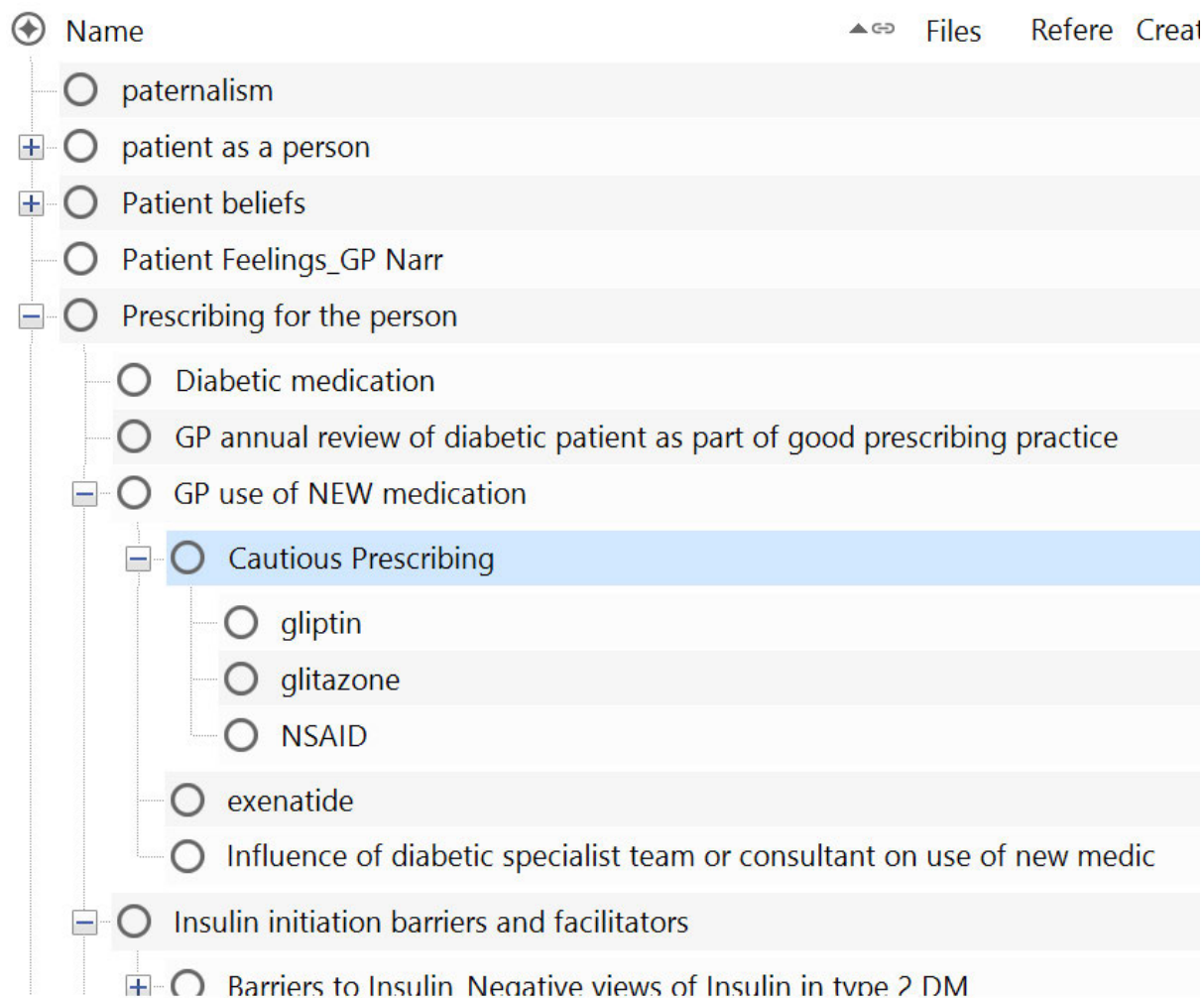
Additionally, GPs also are instrumental in delivering a healthcare provision- namely diabetic care and chronic disease management under the authority of NHSE. Their work in providing generalist care and clinical leadership in the practice setting p(Reeve *et al.*, 2013)tervention (Reeve *et al.*, 2013).

Furthermore, instrumentality was demonstrated throughout the thesis, from utilising biological HbA1c values to meet patient care to trust, rapport building, and SDM to accomplish person-centred care. The dominant biomedical belief was the drive to direct the GPs to use all resources and means to achieve patient care. However, and most significantly, when compromise and balance were needed between GP-centred biomedical and patients person-centred agendas, it was in the act of trying to be person-centred that GPs showed their generalist behaviour. Instrumentality was less evident, and GPs placed their biomedical goals in lower priority to person-centred objectives such as patients' psychosocial priorities and lifestyle choices.

4.8 Tension development

Previously in section 3.11, the methods to identify tensions were explained and related ways tensions were sought and constructed from the themes, links between themes and their relationships. This subchapter will explain the key tensions identified as relevant to person-centredness of GPs.

To example the development this subsection will explain the process of development of the cautious prescribing tension theme. The following screen snip captures the cautious prescribing code that was placed as a child of the GP use of new medication. At a descriptive level the theme was appropriately generated in the 'biomedical construction of the patient' and 'the use of new medication' parent nodes.



However, it was clear that ‘cautious prescribing’ was also linked to fear of hypoglycaemia and the cautiousness around the elderly. It was a concept that was intrinsically full of tension, and a particular narrative with section from James about prescribing a new diabetic drug and meeting with a pharmaceutical representative included apparent of emotions: anger and frustration. However, it also cross-linked with themes of the ‘elderly’, and ‘fear of hypoglycaemia’, both of which involved cautiousness in prescribing implicitly and generated from several GPs; but also resonated as themes from the literature review, and prior concepts. It is also significant to note that the literature review was searched and written after all three themes were generated, and so they were arguably inductively generated, although influenced by other researcher sensitising concepts that were explained in section 3.2. However, as an insider GP, reflexively, there was an alignment with the participants that felt this cautiousness to prescribing medications overall. As a result of listening to the GP accounts, emotions, and tension, the issues concerning the elderly, new medications, and insulin reinforced the insider GPs' own views.

In summary, this theme was about a fear of harm, and duty of care that was intrinsic to the tension of prescribing. But another aspect was linked to this fear and related the issue of collaboration and involving patients in decisions as advocated in PCC by approaches such as the Gothenburg principles.

In addition, the issue of ‘prescribing for the person’, and ‘patient responsibility’ were linked themes that generated tensions in GP reflections when patients were perceived to not engage with self-care, medication or diet and lifestyle change.

4.9 Tension themes

This section will explain the generated tensions from relationships identified between themes, the emotions expressed by participant GPs. The method of identification of tensions was explained in section 3.11 and above, 4.8 explains the process for one of the tensions.

As noted in chapter 3, the narrative structural analysis offers an alternative lens and depth of analysis to understand the tensions inherent to stories told by participants, which are argued to be apparent in GPs’ accounts relating to insulin initiation.

The resultant tensions were generated as additional constructs, such as the tension created between themes of service delivery, a duty of care, and lack of patient of patient engagement (of self-determining patients). Following the critical realist and constructionist methodology underpinning this thesis, generated tensions provide insight into how the participants' experiences resulted from the social constructions within their medical culture. It is hoped that the ensuing thematic tensions provide some insight into the doctor -centric culture and oppositions to PCC care as identified in the literature (Russell et al, 2008).

Table of tension subthemes

| Section title | Tensions | Associated themes |
|----------------------------|---|--|
| Lack of self-determination | When patients had the capacity to make decisions and were refusing therapy, GPs retained a discomfort, and so, a tension, that patients may not understand the implications of their decisions on their long-term health. | patient subthemes (capacity, social support, significant/complex mental health issues, fear, belief in a supreme being); were related GP feeling of uncertainty and fear of ongoing deterioration in |

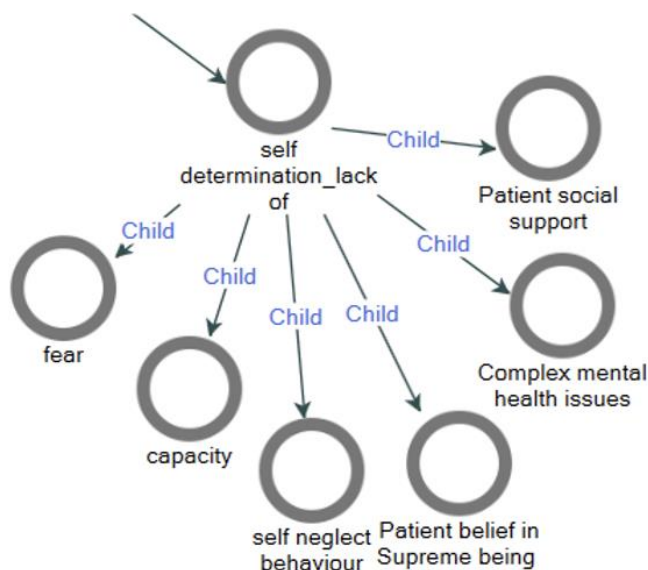
| | | health |
|----------------------------|--|--|
| Insulin as a failure | Biomedical ideal DM management and patient lack of engagement | Insulin as a biomedical failure, lack of patient engagement, blame and person-centred insulin as a failure |
| Lack of patient engagement | Lack of patient engagement <u>versus</u> ideal biomedical management, that which will optimise glycaemic or other chronic health issue such as blood pressure. | Three subcategories were containing the same tension but different resolutions or lack of resolution and associated resultant GP emotions. Themes of lack of engagement, GP-centred CDM and QOF, patient trust, GP feelings and empathy. |
| Cautious prescribing | Patient harm prevention <u>versus</u> recommended or new medications prescribing | Duty of care, harm prevention, new medications, insulin-negative views of insulin |
| Distal practice | Distal practice versus idealistic person-centred proximal practice | Distal practice, delegated DM care, person-centred construct and GP empathy, diabetic lead, a duty of care. |

The table of tension subthemes summarises the tension subthemes and the associated linking or relationships that were generated and rechecked from reviewed the thematic coding in the NVivo software, and back to the coded interviews and textual data.

4.9.1 Tension theme lack of self-determination

Previously the theme of self-determination was described in the person-centred section 4.6.2.6. Self-determination was a theme generation from GP descriptions of how patients would engage in their own self-care.

The oppositional theme of lack of self-determination became a tension theme and is described in this section. When patients had the capacity to make decisions and were refusing therapy, GPs retained a discomfort, and so, a tension, that patients may not understand the implications of their decisions on their long-term health. GPs described the gradual deterioration of diabetic health and the importance of self-care.



Lack of self-determination included GP constructs when GPs believed patients lacked the capacity to self-care because they self-neglected, refused therapy or engagement with a diabetic specialists' appointments, and recommendations for diet and lifestyle changes. There was a 'cluster' (Witty et al, 2020) of patient ill-health that could occur with mental health diagnoses such as schizophrenia involving multiple biomedical disease pathologies, such as obesity and cardiovascular disease, and unhealthy behaviours such as smoking or excess alcohol consumption.

GPs described patients with significant mental health problems less frequently (Alice, Jen, Sally, Mike), and there were valuable insights from GPs' experiences of mental health disorders in the community ranging from severe depression to agoraphobia and psychosis that impacted on the GP relationship and was a barrier to patient involvement in care.

Patients may be at risk of psychosis, their mental health could fluctuate, and patients may lack insight into their mental and physical health. As a result, patients were vulnerable, and GPs worried about the individual patient's ability to understand, manage, and engage with diabetic therapy. They were particularly concerned about managing a diet while on insulin and the need to recognise and act on symptoms of hypoglycaemia. The GPs person-centred and individual

care was apparent and neglect of the diabetic health priorities was part of this individual approach.

Consequently, if the patient lacked insight and understanding, there was a concern over their ability to manage insulin therapy and awareness that patients required protection from harm. The risk of insulin harm to the patient had to be balanced with the benefits of glycaemic control. Rather than a situation where insulin was not needed, biomedically, insulin was the best medication, but insulin was not appropriate or safe for the individual.

For example, Alice described a patient with depression who failed to attend appointments with the diabetic nurse and take anti-diabetic medication resulting in poor diabetic control. Her memorable and she reflected on the lack of support the patient had had from other doctors for his diabetes. Alice explained that she had engaged him in a conversation about his mental health, developed a relationship with him. Her rich account of his depression impressed her appreciation of the impact his depression had on him, his wife and family, with the result that the mental health was priority, whilst diabetes was secondary. Jackie's patient provides evidence that managing the patient's mental health need resulted in positive diabetic and physical health outcome, and adds to the literature claiming that patients prioritise their mental health over their physical (Kristensen, 2018a). Following further review appointments, she described a positive outcome in his mood resulting in health engagement because of more awareness of managing his diet, lifestyle, and medication.

“He was depressed, and I'd been seeing his wife for something else and she'd mentioned that he wasn't taking his medication and he came to me, basically because he hadn't come. [...] I'd seen him for the first time, and he responded really well because when he first came he was not relating to the family, the marriage was very strained, he wasn't talking to his daughter, Christmas came and he didn't even come downstairs.” Alice.

Another construction of the patients that showed a lack of self-determination and a barrier to patient engagement with healthcare involved religious beliefs and the belief that another ‘**supreme being**’ determined health outcomes. Jen described the belief as a patient barrier to insulin initiation and engagement in diabetic self-care. Although only one of the GPs explicitly

explained the concept and represented an outlier, the cultural and person-centred view of patient beliefs of health and determinants of health is relevant. The concept of health determination by external power contrasted and frustrated the GP's belief in biomedical healthcare. In the quote below, Jen was frustrated that her South Asian population could abandon their control over their health by not engaging with healthcare advice because of their fatalistic view of their health outcome. Previously, Jen was described as confident in her rapport with South Asian patients, but the concept of a 'supreme being' was a barrier to that valued trust, and she felt like she was imposing herself on them:

“I would sell it very strongly that you're taking control of your illness, you're prolonging your own life, you're looking after your own health. The patients will say 'well I will die when I die, it's not up to me, it's orchestrated by God' so they're not quite so convinced as I am that insulin's going to make any difference [...]. So, I often feel like I'm imposing my will upon an unwilling patient.” Jen

Jen's frustrations as white Caucasian doctor in the Pakistani community resonate with the findings of Fagerli et al who found clinicians frustrated at patients passive lack of engagement and autonomy (Fagerli et al., 2005). Additionally, there are resonances with the American Caucasian doctor who reflected on her consultations with Native America beliefs, and despite no actual language barrier, realised her biomedical cultural background was an additional barrier to the rapport and partnership with patients she had otherwise great empathy for (Bartz and Francisco, 1999).

A memorable patient with significant mental health needs was described by Mike and relayed the specific issue of lack of self-determination, and so lack of patient involvement in decisions about care. Reflexively, both issues of lack of patient self-determination and the lack of information sharing generated tension from the insider GP perspective. The patient lived alone with no family but had been assigned a community psychiatric nurse and psychiatrist. The patient lived independently, had the capacity to make decisions, and refused mental health team reviews. His mental health could vary unpredictably, and his diabetes was uncontrolled at times of relapse of his mental health. The patient also had an unhealthy diet that was not regular enough to manage his diabetes whilst on insulin therapy. As a result, Mike was keen to avoid

insulin therapy-related hypoglycaemic episodes and decided to undertreat the patient's diabetes using lower doses of once-daily regimes. Undertreating meant future diabetic complications, while hypoglycaemic episodes posed a more immediate danger to the patient. Mike also explained that these patients were disengaged from healthcare professionals and therapy, so conversations about healthcare decisions were also difficult. Mike explicitly believed the memorable patient he had described would not understand the possible insulin regimes and diabetic health implications, displayed a paternalism that Mike did not defend and but implicitly believed was justified in the patient's interests. Involving the patient in the decision was not on Mike's agenda.

“...you know, if he's on a complicated insulin regime I mean one, he wouldn't take it probably and two, you wouldn't be sure if he was eating enough regularly to cause that, to cope with that [...] [Hypoglycaemia] - Is a more immediate harm [...] So you're also making that (*decision*) on his behalf really. I haven't formally discussed with him 'you could have insulin two or three times a day but I don't think you're up to it'. I haven't done that but that's what's been going on in my head.” Mike

Consequently, the capacity to understand how to self-care and manage insulin therapy was perceived as a barrier to its initiation by GPs. When there were examples of insulin initiation in primary care, GPs made choices to reduce the risk of patient harm whilst compromising glycaemic control. Alternatively, there were descriptions of exceptional person-centred care whereby patients were managed in the patient's home, utilising district or practice nursing care instrumentally. Shared decision making was challenging if the GP perceived a patient lacked self-determination because of fluctuating lack of capacity or insight into their diabetic physical health or mental health. If the patient was disengaged from healthcare professionals, shared-decision making was a further challenge, and GPs behaved arguably more paternalistically.

In conclusion, the patient's lack of self-determination was constructed by GPs to conceive the person-centred views of how patients engaged with their diabetic health. The GPs would use the concept to understand their patients' reasons for lack of engagement and understand if patients actively refused therapy for person-centred agendas or could not decide to engage in therapy because of lack of ability and capacity. When patients lacked capacity, GPs had to

make challenging decisions to consider patients' best interests, balance insulin benefits and harms, and person-centred of sharing information became less of a priority.

The following section explores the GPs' opinions and the concept of patient responsibility and GP blame towards patients for the perceived lack of responsibility.

4.9.2 Blame and lack of engagement

When patients who had the capacity to make decisions refused therapy, there was evidence that even GPs who were broadly person centred shifted away from a person-centred view when met with refusal of therapy; they would be frustrated and expressed a tension created by patient lack of engagement. However, the GPs respected the overriding principle of patient autonomy and accepted patient refusal of insulin while knowing the patient would continue with inadequately controlled diabetes. This section explores GP perspectives of how the GPs viewed that patient lack of engagement in self-care negatively.

From a constructionist view, the research design at interview used insulin initiation as the point of escalation in therapy to explore the GP views of T2DM management. Arguably, this leading may have influenced GPs to consider the biomedical issues or the disease-centred view as a priority over person-centred views. However, after reviewing the thematic data and code development, the theme was generated and persisted because of the doctors' person-centred beliefs of the individual biomedical benefit of gaining glycaemic control. As explained in section 4.6.2.1, the biomedical construction of the patient is positively framed under the person-centred theme. Moreover, it has also been explained in section 4.9.1 that GPs also reflected in person-centred ways on patients they felt would potentially be harmed if insulin was initiated. It is hoped that the reviewed thematic analysis and regeneration of similar tension themes supports the credibility of the blame theme.

When not engaging in self-care, patient behaviour was constructed as not taking responsibility for their health and resulted in GPs taking a position of blame towards the patient. GPs expected patient diabetic health to deteriorate over time from the biomedical perspective; the same GPs would negatively construct the person-centred diabetic patient when patients were perceived

not to be engaging with diabetic diet, lifestyle, and medication. For example, Vicky did not believe the patient was at “*fault*” (Vicky) biomedically (quoted in subchapter 5.4.3) as diabetes deteriorated but expressed frustration when patients did not engage in therapy and indicated blame. Similarly, in the next quote, Mike blames the patient for deteriorating diabetic control.

“[...] she’s a lady we’ve been trying to persuade to improve her control for a while. She’s on maximum treatment and she usually has plenty of excuses as to why she’s not managed it this time.” Mike

Some GPs expressed initial concern that the explanations and motivation they provided were inadequate and would show self-blame and guilt for not engaging the patient. However, a consistent logical approach across the GPs was that patients had the capacity to self-determine their health, had a right to refuse therapy, and that adequate explanation had been provided by involving multiple healthcare professionals. GPs cited themselves, primary care nurses and the secondary diabetic specialist team supporting and motivating patients. Therefore, there was nothing more that could be done. GPs believed patients were responsible at that point for making their own decision to refuse therapy. However, GPs retained a tension that patients continued to deteriorate. In this quote below, Cath’s frustration was evident and showed the challenge posed by the patient refusal of therapy to the GP beliefs in biomedical medication. Moreover, Cath still believed the patient did not understand despite the efforts of the healthcare team- showing Cath’s persistent frustration and tension.

“Firstly, you think well I mustn’t have explained it properly, that why can’t they see this and why can’t they see that I’m not just wanting to give them more medications for some perverse reason? We’re actually trying to guide them to an ultimate satisfactory end sort of thing really[...]I would be surprised if she didn’t [understand] because after the nurses didn’t have success with the insulin she went to the secondary care team to try and – they had the same frustrating outcome! [laughing] So I don’t think, it’s not through lack of explanation.” Cath

A view of patient responsibility for self-care in diabetes and blame was presented from a more empathic position. GPs recognised that patients blamed themselves and felt blamed by clinicians for deteriorating diabetes to the point of requiring insulin. Other healthcare professionals, GPs or diabetic specialists may have made patients feel blamed by using threat explanations early in the diabetes journey. In this next quote, Alice explained her experience with a memorable patient and her belief that other doctors had used such threat explanations in the past.

“...I think the difference is that the other partners didn’t really listen and they just sort of told him ‘you have to do this or else you’ll end up on insulin for not taking care of yourself’.” Alice

Patients that took self-responsibility attended appointments, took their medication as prescribed and followed diet advice. They were self-determining and engaged with biomedical advice. This attitude went beyond respect for patient autonomy, expected patients to believe in biomedical advice and take responsibility for outcomes. When patients did engage, they took responsibility for their health; they exercised and made lifestyle changes earlier in the diabetic journey. Patients were believed not to be taking responsibility if they failed to change their lifestyle and diet but accepted antidiabetic medication. In the quote below, James explained that some of his diabetic patients engaged with diet and lifestyle change whilst others would only use diabetic medication, indicating a lack of responsibility for their health. James implied a dependency on medication and a patient apathy towards their self-care.

“And to be fair some of them go oh right I’ll lose the weight, I’ll take exercise and all the rest of it and some of them, “just give me the tablet love”. You do it for me.” James

Increased awareness and acceptance of patient autonomy was a change that occurred during their careers. This shift towards patient autonomy meant patient responsibility to be involved in their care. When GPs perceived that the patient was not taking responsibility, the GPs saw themselves as responsible, and the patient was also perceived as showing dependency. This patient behaviour challenged the GP view of patient self-determination and their respect for

patient autonomy. In the quote below, Vicky believed that patients sometimes blamed the GP for not improving their diabetes. However, her quote also indicated blame towards the patient who has not followed healthcare advice.

“So the most frustrating diabetics from my point of view are the ones who always seem to think ‘this is not my fault’ – meaning the patient’s fault – ‘this is happening to me because you are not sorting it out for me’.” Vicky

Patients’ self-neglect behaviours were another GP perception associated with depression and mental health problems, and the question of the patient's lack of capacity needed to be considered. Having explored the issue of capacity, both the GP and other HCPs concluded that patient’s self-neglect as a purposeful act, and so there appeared to be a collective professional patient blame. Jen described a patient who had osteomyelitis of his foot and repeated hospital admissions with diabetic ketoacidosis - which displayed the severity of his poor diabetic control. He then began to self-neglect and not use his insulin correctly or miss doses. When he was discharged from an in-patient admission, the patient had insulin injections at home daily administered by the district nursing service. There was an indication of patient depression, but Jen and the community nursing teams were frustrated because they believed he could manage his insulin injections but had refused to. The resultant tension across Jen and the nurses showed how healthcare professionals might blame the patient for not taking responsibility for their health.

“So the district nurse is saying ‘this is ridiculous, we’re not supposed to be his servant, making his meals and phoning him up to make sure he’s eaten and everything’ so we got the CART team in and they’ve been completely manipulated in the same way and of course.” Jen

This collective blame across and Jen, reinforced Jen's attitude. However, Jen was previously constructed as an otherwise empathic and person-centred GP and showed how she shifted towards a negative doctor-centred attitude. The demand on primary care services placed by one individual patient was overwhelming, and the frustration caused the GP to blame, and showed the point at which she may shift from person-centred to doctor-centredness.

A patient who refused to go to secondary care for insulin introduction had a similar lack of self-determination. This memorable patient had agoraphobia, and so her refusal of the hospital initiation of insulin was related to her mental health. Exceptional services had to be considered, and in this, the GP, Sally, explained that the nurse practitioner (NP) confidently delivered the service at the patient's home. This exceptional case showed person-centred care that the NP delivered on behalf of the practice. It also exhibited the GP's continuing delegation of diabetic care and displayed an instrumentality towards the NP role at the practice.

Conversely, GPs explicitly said they accepted the patient refusal for therapy and believed patients had taken responsibility and exercised their right to refuse. GPs accepted that they had done as much as possible through their explanation. In the quote below, the doctor shifted responsibility to the patient. He implied the patient was to blame for any anticipated future adverse outcomes and does not convincingly resolve the tension of his ongoing responsibility of care towards patients.

“And, you know, a poor blood sugar control like that will make you feel symptomatic. It will make you feel unwell and ultimately it may lead to serious consequences. If I've told you that and you still really don't want to then I'll mention it every time but I'm not going to get personally involved or hooked up on it.” Mike

The GPs highlighted an apparent conflict between respecting patients' freedom to reject treatment and acknowledging that patient ill-health and diabetes deterioration was unavoidable from a biological standpoint. For example, Vicky was explicit in her view that patients blamed GPs for their ongoing deterioration and felt she wanted patients to take responsibility for their health. However, she also felt that diabetes deteriorated gradually, and the patient was not to blame for that biomedical failure. This contradiction created an unresolved tension amongst the themes of patient responsibility and blame for the deterioration in diabetic control.

In conclusion, GPs did accept patient self-determination and respected patient autonomy to direct their health decisions. For example, when a patient refused therapy and GPs could not

understand the person-centred barriers underlying such refusal, but GPs were aware they could revisit the decision with patients in the future. GPs also expected patients to accept responsibility for their choices, and thus, the burden of potential adverse effects moved to patients, but with a retained GP discomfort. There was also an indication of blame towards patients for not taking responsibility for refusal or therapy earlier in the diabetic journey, even if patients took medication to control diabetes. Significantly, the shifts in responsibility to patients and the blame towards patients for not engaging were associated with GP frustration.

4.9.3 Insulin as failure

This section explains the generation of the theme of insulin as failure from identified tension themes and subthemes.

Previously in section 4.6.2.4, insulin was framed negatively by GPs first and foremost, and the GPs' accounts re-enforced the literature on seeing insulin as a last resort, using 'threat explanations' early in the disease progression, and adding to patient perceptions of fear of insulin and blame. This section highlights the concept of threat explanations, which are used by clinicians to educate patients on health and lifestyle change, often early in disease processes, but amount to the threat of health and disease deterioration if patients did not self-care (Peyrot *et al.*, 2006).

Insulin was framed as a "*last resort*" (Matt) by many GPs in this group explicitly and implicitly in their descriptive attitudes and memorable patient scenarios. From a biomedical position, beginning insulin was a biomedical failure related to diabetic disease progression. When counselling patients early in disease GPs frequently described threat explanations. For example, Harry was particularly explicit in his threat explanations and described himself as "*blunt*" (Harry) and embellishes his account with dramatic imagery, showing his frustration and reinforcing attitudes of blame:

“[...] advised him to lose weight; otherwise you are, um, at risk of developing all the complications of obesity, like diabetes, stroke and heart attack, osteoarthritis of the knees and gallstones and that kind of thing, and not only that, erm, erm, I had, like the politicians, I repeated three times, so that it will imprint on the memory, um, firstly, what you want to say, say what you decided to say, and then repeat what you just said, so that kind of thing, so that, um, er, it will go and stick in the

memory and be flashing like neon lights every time they think about me, but, um, it's, um, a few people, that's what is frustrating, that in spite of your repeated hard work and things what you wanted to proven, finally they end up having it!" Harry

Across the GPs, patients were told of that progression early in the disease process as part of threat explanations and motivation to self- through diet and lifestyle change. These motivational 'threat explanations' (Peyrot *et al.*, 2006) to patients earlier in their diabetic journey indicated blame towards patients.

GPs also reflected on how diabetes and the need for escalation to insulin therapy made some patients feel like they had failed. In the next quote, by stating the patient "*ended-up*" (Cath) on insulin, Cath framed insulin as the final available treatment and reinforced the negative biomedical attitude. Cath also identified patient self-blame, and in her experience, self-blame for failure also manifested as patients' fear of insulin. That fear began earlier in the diabetes journey and was apparent at insulin initiation.

"And I think there's a fear of insulin isn't there, or there seems to be[...]They see it as a failure, that somehow if they end up on insulin they've failed[...]They've failed in so far as either the disease is more serious than they thought or they've not followed the instructions[...]Or something's – it definitely is an expression of failure, you know, 'that's the last thing I thought I'd end up having'. They do say that." Cath

When GPs constructed patients as having failed in their self-care, they framed patients' identity negatively as a result. On the other hand, some GPs recognised that patients felt they had or were made to feel blamed by healthcare professionals, which showed empathic understanding. Furthermore, there was evidence of some GPs blaming patients for not taking responsibility for their health (see subchapter 6.2.4). These differing perspectives created a consequent negative framing of patients. The GP view of insulin initiation as failure was a construction generated from both the biomedical and the person-centred perspective and resulted in blame towards patients.

Compared to other GPs, Alice appeared more empathic to diabetic person-centred views, and she used insulin with confidence to manage her T1DM, yet she still described delaying insulin prescribing for a competent and otherwise self-caring elderly patient.

“[...] I think, comes down to the situation you’re in because if your sight is threatened or your kidneys are threatened or your general wellbeing is threatened by having really rubbish controlled diabetes then you need to do something, but I think you would use insulin for the last sort of resort, which I think it is for most people.” Alice

Moreover, patients were described by GPs to fear insulin, but GPs also perceived insulin as a harmful medication. GPs led these negative beliefs with conservative and cautious prescribing of insulin and their biomedical concerns. Additionally, patients could also focus on insulin being the harmful factor in their illness and not uncontrolled deteriorated diabetes.

Significantly, when GPs constructed patients as having failed in their self-care, they framed patients’ identity negatively as a result. On the other hand, some GPs recognised that patients felt they had or were made to feel blamed by healthcare professionals, which showed empathic understanding too. Mike recalled a consultant at the local hospital had overused such ‘fright tactics’ and wondered if his patient did not believe him:

“She’d had experience of with a hospital consultant who was in the habit of using fright tactics on patients. [...] And maybe she didn’t take him seriously.” Mike

Furthermore, there was evidence of some GPs blaming patients for not taking responsibility for their health, and indicating contradictory opinions in the same GP, shifting from empathy and person-centred understanding and alignment to paternalism and blame. This shifting is, and is explored further in the tension theme ‘blame’ and the narrative analysis. These differing perspectives created a consequent negative framing of patients. The GP view of insulin initiation as failure was a construction generated from both the biomedical and the person-centred perspective and resulted in blame towards patients.

From the GP prescriber theme, insulin was already coded as a ‘last resort’. This was a common belief among GPs in diabetes management and appeared to be driven by a fear or avoidance of harm, specifically the risk of hypoglycaemia, but the other named main side effect of weight gain. Even the biomedical guidance placed insulin after possible oral medications. Despite the previously explained cautiousness about new medications and GP experience with Rosiglitazone in recent years, insulin remains the last resort as a biomedical option in GP minds. The combination of authoritative guidelines and GP biomedical belief negatively framed insulin as a ‘**last resort**’.

Figure 1 Representing the negative framing of insulin as a failure. The negative framing thematically connects several themes that interconnect and promote the perception of insulin as a patient failure. The biomedical construction of insulin used as a last resort supported the concept of insulin as a biomedical failure. Threat explanations added to patient self-blame and reinforced GP blame towards patients.

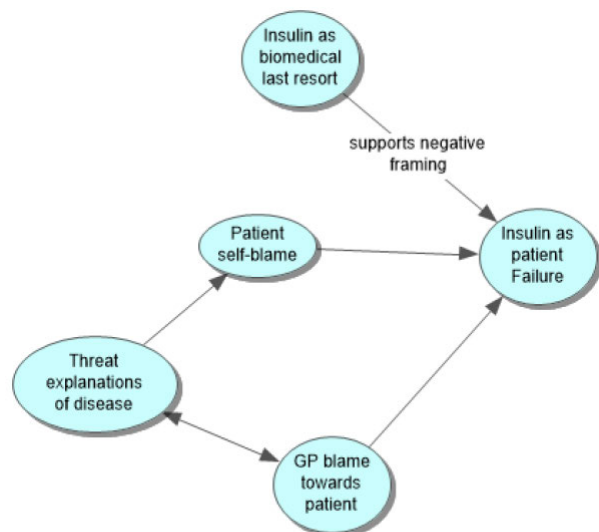


Figure 2 Representing the negative framing of insulin as a failure.

Cautiousness in prescribing insulin (section 4.6.2.4) and other diabetic medications indicated fears and tensions around medication side-effects. The risk of harm to patients was a tension

to be later explored narratively. When person-centred agendas were more important to patients and they refused therapy, GPs respected that patients had decided not to prioritise health and confirmed the literature showing how patients prioritise self-care and mental health over the medical recommendations (Kristensen *et al.*, 2018b). Moreover, the empirical research also shows that clinicians and patients may prioritise mild to moderate mental health problems differently- with patients prioritising chronic anxiety significantly higher than clinicians (Sidorkiewicz *et al.*, 2019). In this research, GPs could and did recognise the mental health issues, and did not discuss mild mental health problems and their impact on self-care, although there was understanding of the link between depression, patient apathy and diabetes. For these GPs, apathy may be the equivalent of the chronic low mood, anxiety and depression more widely known in the literature (Luijks *et al.*, 2012; Ratanawongsa *et al.*, 2012; Sidorkiewicz *et al.*, 2019).

However, amongst their memorable cases it was the patients with highly significant mental health problems that caused these GPs to shift their mindset from biomedical priorities to mental health priorities (Mike, Sally, Jen and Alice). This finding also reinforces the literature which finds that clinicians will avoid insulin when they do not recognise significant mental health disease and patient inability to self-care. Despite feeling the tension, the GPs showed respect for person-centred biomedical care, taking consideration of the patient life circumstances and social environment and avoiding harm. This was a mindset displayed across the countries, for patients with very low SEDs such as South Africa and western countries (Haque *et al.*, 2005; Ratanawongsa *et al.*, 2012; Trachtenberg *et al.*, 2014; Ngassa Piotie *et al.*, 2021). However, what was not clear in the literature was whether patients were informed or in collaborative partnerships during the explained insulin avoidance in the literature. Similarly, the GPs in this research did not explain shared decisions, alignment or collaborative partnerships that indicated patient involvement in person-centred ways.

4.9.4 Tension theme Cautious prescribing

Another aspect of person-centred prescribing was GP cautiousness when prescribing newly introduced medications. The theme was generated from GP reflections on their experiences of antidiabetic medications and changes in diabetes management over their careers. GPs reflected on negative experiences of medications, and remarkably, their experience of the introduction

and withdrawal rosiglitazone was memorable and impact their attitudes towards new drugs. There was explicit resultant suspiciousness and avoidance of prescribing newly introduced medications until GPs felt reassured by guidance. Although GPs did not relate evidence-based or guidance information to support their cautiousness towards new medications, GPs believed experience guided them to feel cautious and was justified by the drugs they recalled. In this following quote, Mike concludes that from his experience, it was wise to avoid the use of new medications when they are first introduced:

“And the glitazones, you know, the first one that was withdrawn with hepatic [effects] [...]I thought at the time what a good drug, that sounds like a good idea but I hadn’t used it[...]But some people had. [...]You don’t jump straight on new drugs.” Mike

GPs were willing to consider Exenatide, a new medication at the time, because of the weight loss benefit of the medication. However, they awaited approval from local prescribing guidance to be able to initiate the medication in primary care. Some drugs were initiated in secondary care and then further managed through agreed shared-care protocols of patients between primary and secondary. In the following quote, Vicky explained that she was reassured if the secondary care specialist initiated a medication. She also explained her negative experience with Glitazones and how she had learned to be cautious towards new antidiabetic medications:

“I am happier when new medications are tried in the Secondary Care for a little while. And I can see they have the effect on the patients. I am thinking particularly of Glitazones because when they came out they were the greatest thing since sliced bread and everybody should be on them ...” Vicky

The withdrawal of rosiglitazone was related to cardiovascular side effects and caused a cautiousness over future antidiabetic prescribing across the GPs. Although it was indicated for use as a third-line medication, it was an alternative to insulin, so it was used by GPs when patients were not interested in initiating insulin. Charles recalled its introduction and later found he had to change patients to an alternative medication- naming Pioglitazone and

Sitagliptin as alternatives. He recalled a seven-year period from introduction to withdrawal of Rosiglitazone, which arguably was a long period time and implied his patients might have been affected. His embarrassment at having to write letters to patients represented his feelings of responsibility and resignation because he had initiated it.

“Rosiglitazone was fantastic, it came along, there was very, there was lots of publicity for it, there was a lot of education around it, [...] then, of course, about 6 or 7 years down the line, out of the woodwork comes this thing about fluid retention, heart failure and increasing heart disease and, all of a sudden, you have to write these embarrassing letters to patients to say well actually you’ve got to change these things.” Charles

Most GPs did not specify how long they would wait before they felt confident to initiate new medications. An attitude of cautiousness generated the theme, and there was no associated strength of feeling for most GPs, except for James. In the following quote, James explained he had learnt to be cautious of new medications during his training and specified that he would avoid prescribing them for two years. His fundamental concern was preventing harm to his patients, a responsibility he held both ethically and medico-legally. However, if harm did occur, his feelings as the doctor that initiated the medication required recognition. That negative feeling was a barrier to prescribing new medications:

“Well early on in my training, one of my trainers told me never use a new drug for the first 2 years[...] I’m very conservative, very wary of using new drugs.” James

In summary, cautiousness when prescribing new medications soon after their introduction was based on the experience of medications, and specifically included antidiabetic medications that had later been withdrawn because of significant associated side effects and fatalities.

This cautiousness constituted another mindset toward prescribing. GPs would consider medications begun by the secondary care teams and were reassured to continue them. The cautiousness was based on beliefs in their duty to prevent harm to their patients and heightened by palpable feelings of fear of harm and personal responsibility during the co-produced interviews, when listening to audio-recordings and the analysing the transcriptions. James’ had

angrily told the story of how he was cautious of new medications and the strength of his opinion is explored in a narrative structural analysis.

4.9.5 Tension theme Distal GP

The distal role of GPs was a pattern across all the GPs and the result of the service design the UK and locally to have delivery of chronic disease management by nurses. Although the nurse role is beyond the boundary of this research, the GP views and experiences of delegating and working with nurses to deliver T2DM and chronic disease management was significant. The theme of distal GP was the result of analysis of the GP-centred themes.

At Jackie's practice, the nurse saw and followed up all the patients with diabetes, and the two lead GPs would review the blood results with 'distal' involvement in diabetic patient care. The GP would see results and discussing patients with the nurse, but only occasionally seeing patients after the nurse had seen them in the diabetic clinic, or if the patient was acutely unwell. Jackie described a patient with significant mental health issues, whose BP and diabetes was uncontrolled, and who she suspected was not taking her medications. The patient who was on a nomad system of medication, and the GP show apprehension as the situation was recent to the interview date and unresolved. The bad snowy weather on the day of the clinic meant the patient and the nurse left, and Jackie described plans to follow up. It was clear the GP felt discomfort about how she would proceed:

“well for a start she had absolutely no idea what medication she was on at all anyway, [...]she sort of didn't know what she had previously been tried on in the past and this sort of thing. [...] I could liaise with Claire who knew her, knew what she was like, so I got sort of a bit more background and [...] because of the weather and everything, erm, that erm, because I had a small time – had a small time with Claire to start off with [...]” Jackie

Moreover, the account was more filled with how Jackie struggled to liaise with the nurse about the patient, and displayed her distal relationship to the patient, discomfort and the person-

centred lack of knowledge of how to proceed. It was clear, the system of delegation was working overall, but for patients with multiple or more complex needs even Jackie felt overwhelmed about how to proceed. Although the situation was unresolved, Jackie's reliance on the nurse for the next steps reinforced her distal role and the acceptance of the less satisfactory patient management. Jackie's distal role confirms the contrasting positive empirical research in Canada and Singapore (Houle et al, 2012, Mathew et al., 2022) which show that positive patient-provider relationships, continuity, and patient involvement in decisions created person-centred care that satisfied patient needs. Arguably, the nurse's ongoing role may fulfil the PCC role, but then the way the individual team members acted in difficult or complex cases needed review and remains a gap to research in the future.

In summary, Key tension's themes were generated through thematic analysis, highlighting the difficulty in GP attempts to provide person-centred care, which created trepidation, fear of injury, caution about overprescribing, and sentiments of blame toward patients.

These tensions are explored further in a triangulated method to use narrative structural analysis to understand them further

4.10 Summary of Reflexive TA themes

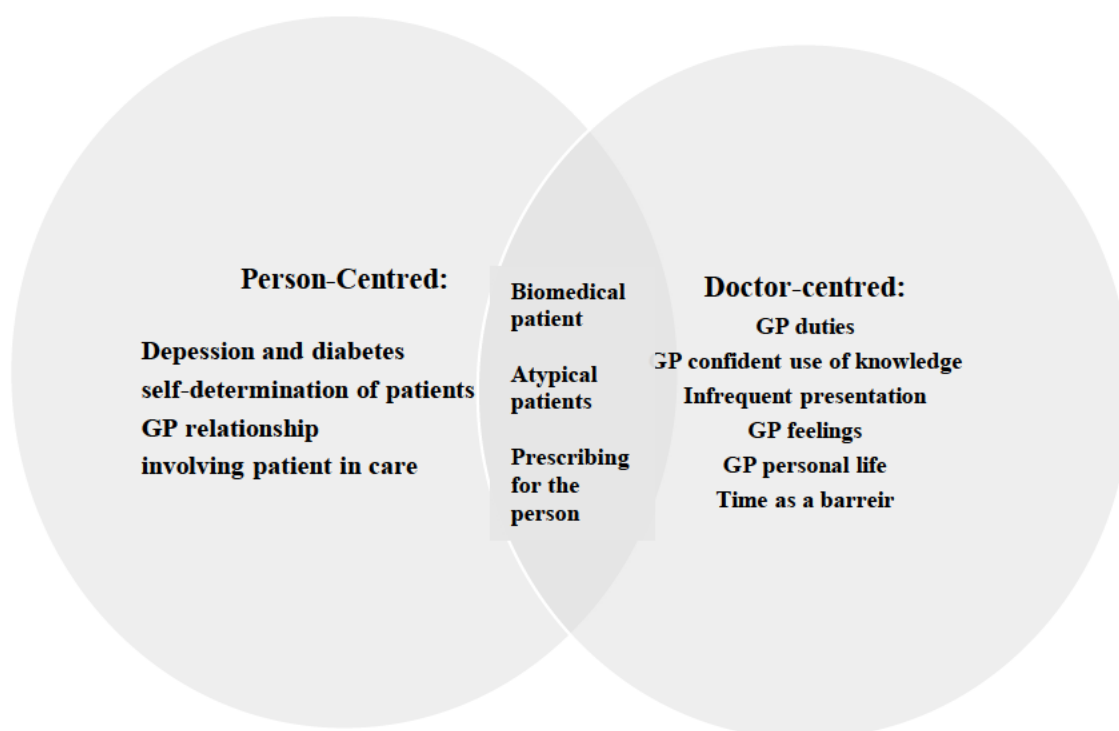
In summary, the reflexive thematic analysis (TA) has generated a number of key themes the separate into person-centred and doctor-centred themes, and generated tension themes.

Previously biomedical was a separate hierarchical theme, but on thematic review, iterative change of the RQ to focus on PCC, and returning to the coded data, biomedical construction of the patient has been re-classified. Biomedical construction of the patient, when contextualised in person-centred care has been constructed under the hierarchic person-centred themes.

The Venn diagram of the reflexive TA findings is presented below, showing the meaningful intersection of the biomedically linked themes with PC themes. Recognition of the biomedical construction in this way allows the PC agenda to understand when GPs have attitudinally considered the patients biomedical needs and aligned with the patients biomedical needs. Unmet biomedical care is failing the person. However, when the biomedical is out of context

of the person, this is doctor-centred biomedical focus and so, prescribing (or not prescribing) for the patient, but to meet the biomedical expectations of the GP/clinician is doctor-centric. This is most recognisably typified by Alice in the narrative structural analysis in section 5.1.3 and will be later shown to shift from a position of person-centredness to a position of doctor-centredness.

Venn diagram of the reflexive TA findings:



The tensions present additional generated themes and construct the GPs in different positions or stance with which they approach PC. Following the critical realist and constructionist methodology underpinning this thesis, generated tensions provide insight into how the participants' experiences resulted from the social constructions within their medical culture.

The following table aligns the summarised and thematically reviewed tensions to GP stances:

| Section title | Tensions | Associated themes | PC or DC stance |
|---------------|----------|-------------------|-----------------|
|---------------|----------|-------------------|-----------------|

| | | | |
|----------------------------|---|--|--|
| Lack of self-determination | When patients had the capacity to make decisions and were refusing therapy, GPs retained a discomfort, and so, a tension, that patients may not understand the implications of their decisions on their long-term health. | Patent social support, complex mental health issues, patient belief in the supreme, self-neglect, capacity, fear (of the patient), negative GP relationship; linked with the fear of harm, barrier to insulin initiation. | DC- duty of care Doctor centred position to avoid escalation of therapy. |
| Insulin as a failure | Biomedical ideal DM management and patient lack of engagement | Insulin as a biomedical failure, lack of patient engagement, blame and person-centred insulin as a failure, GP- feelings of guilt, sadness, frustration. | DC -Blame toward the patient, biomedical failure, patient failure |
| Lack of patient engagement | Lack of patient engagement (of self-determining patients) <u>versus</u> ideal biomedical management, that which will optimise glycaemic or other chronic health issue such as blood pressure. | Three subcategories were containing the same tension but different resolutions or lack of resolution and associated resultant GP emotions. Themes of lack of engagement, GP-centred CDM and QOF, patient trust, GP feelings and empathy. | DC- biomedical stance, and patient personal context is not prioritised. |
| Cautious prescribing | Patient harm prevention <u>versus</u> recommended or new medications prescribing | Duty of care, harm prevention, new medications, insulin-negative views of insulin | DC- when patient context is not prioritised. PC if the person has been prioritised, their life circumstance into the account and their involvement in the decision. |
| Distal practice | Distal practice versus idealistic person-centred proximal practice | Distal practice, delegated DM care, person-centred construct and GP empathy, diabetic lead, a duty of care. | DC stance |

In summary, the reflexive TA findings and cross-linked tension themes generated present the GPs in person-centred or doctor-centred stances. When GPs consider T2DM care and insulin initiation, they will consider patients as individuals, with autonomy and say they respect and involve them in care. However, when GPs are presented with tensions, they withdraw into doctor-centric behaviours such as prescribing to prevent harm and seeing insulin as patient failure and so, blame and guilt. These findings conform the literature and add an alternative framing of biomedical as a person-centred activity when framed in the person-centred context. GPs reflected on positive relationship and collaborative care of patients when they involved them care. Although the latter is self-reported GP opinion, they are welcome and positive which may encourage reflective practitioners to consider how to incorporate PCC approaches into practice.

The next chapter will move the analysis forward into the planned triangulation or ‘crystallisation’, to analyse the identified tensions in a number of narrative interview texts to find alternative perceptive, and meanings through the different ‘lens’ of narrative structural analysis (Denzin and Lincoln, 1998; Ellingson, 2014; Braun and Clarke, 2022). As stated previously, Robichaux (Robichaux, 2002; Robichaux and Clarke, 2006; Riessman, 2008b) exemplified the use of narrative SA in combination with TA to understand intensive care nurse accounts of critical care and sets a precedent for the triangulated method.

5 Narrative structural analysis

This section will report on the narrative structural analyses performed to explore the thematically generated tensions in a different qualitative method to see the data through a different lens of analysis: a process called crystallisation by academic qualitative researchers (Denzin, 2012; Ellingson, 2014) and was explained in section 3.3.3.

5.1 Lack of patient engagement

This tension represented GPs' perceptions when patients did not engage with diabetic diet, lifestyle and therapy advice, including refusal of insulin therapies. The tension was created by the GP belief in the biomedical benefit of diabetic control and patients' lack of engagement. These tensions were generated from the GP self-reported experiences, and presented different types of tensions related to GP perceptions of person-centred diabetic self-care, practice-centred attitudes and GP beliefs in biomedical care. These tensions resulted in various negative GP feelings and indicated the empathy required to achieve person-centred care.

GPs negatively framed chronic disease monitoring (CDM) of diabetic patients when they perceived a lack of engagement. There were financial consequences for GPs because chronic disease management and monitoring of the practice population of health was part of the quality of performance outcomes at a population level through QOF reporting to NHSE. Some GPs expressed frustrations at the efforts required to engage patients and an implied conflict with GP-centred payment awards. Also, there was a person-centred tension for individual patients that failed to engage with self-care or diabetic therapies. Consequently, there were opposing person-centred and GP-centred forces creating conflict that presented as tension. The following sections explain four different types of resolved and unresolved tensions analysed using the narrative method.

5.1.1 Chronic disease management delivery

This first part of this subsection explores tensions exposed by links between chronic disease monitoring (CDM) theme, QOF, and GP perceptions of lack of patient engagement. The

themes were linked by opposing patient and GP biomedical agendas exposing conflict when GPs reflected on patient health deterioration due to poor diabetic control. At other times, GPs expressed emotions of discomfort, conflict, and tension, such as frustration.

CDM meant the regular review and monitoring of diabetic biomedical health twice-yearly according to NICE guidelines of management. GP concerns about individual patients' lack of engagement with health care were compounded by the difficulty of achieving quality indicator targets at a practice population level. There was an awareness that chronic disease monitoring for QOF purposes was a GP-centred activity and that the process of chronic disease monitoring made patients feel bothered or harassed. Three GP extracts were chosen to expose further insights into how the resulting tension was resolved.

The first GP explained an audit performed by the practice team to review the patients with significantly uncontrolled diabetes. Table 15 shows the narrative structural analysis of Harry's experience of the audit. During the interview, Harry offered repeated frustrated narratives around patient engagement in self-care, monitoring, and healthy lifestyle initiatives such as smoking cessation clinics. He talked calmly but decidedly of his frustrations. He initially orientated the narrative to the patient group with HbA1cs over ten and so significantly poorly controlled. The GP reviewed the patient cases with the practice team of health care assistants, nurses and practice manager. They concluded that everything biomedically and pharmacologically had been done. The secondary care team were involved with these patients, as was the diabetic patient education specialist. Charles is generated and embeds as the GP leader involved in the business management of practice, and doctor-centred.

Table 5 Harry's extract - patient lack of engagement in chronic disease monitoring.

| | |
|--|----|
| we did an audit last year, particularly looking at people whose HBA1C is about 10 [...] | OR |
| And, er, we wanted to identify any weaknesses or any gaps in the management to see whether we can identify them and risk them. [...] | OR |
| We have identified a lot of weaknesses, not within the practice, but within the patient, but we looked at the management to see whether there are, anything that we can improve, | CA |
| , there isn't any, each individual we identified, went through them in depth but everything that can be done has been done [...] | RE |
| So we have, even though, er, we are failing in such patients and the QOF management, QOF figures, | EV |

| | |
|---|-----------------|
| but, um, that's the way we have to accept the diabetic management has not been improved and still remains, um, below par. [...] | AB |
| And, um, quite a few of them have been, er, shared care including hospital diabetic clinic, yeah.[...] | OR |
| And, um, we do, er, make use of the secondary care services, we have community, er, diabetic nurse who, um, er, come and do Desmond programmes in our health education room. [...] | OR |
| and, um, so patients, nearly diagnosed diabetics and those whose, um, understanding of the diabetes is poor and those whose, er, management is poor we direct them to a Desmond programme and there is DNA, defaulting quite a few of them. | CA and CO |

The narrative extract exposed that driving forces for the tension from the GP perspective were patient lack of engagement, and the GP blamed patients for it. Harry used provocative words such as “*defaulting*” (Harry), which emphasised his negative attitude. The tension of patient lack of engagement remained unresolved, with Harry’s blame towards the patients and the poor QOF outcomes showing his unsatisfactory and persisting discomfort.

The next GP had a similar view of her patient population with persistent and unresolved tension. Jen explained her experience of patient lack of engagement while working with her local ethnic population. Jen understood her practice population using detailed narratives of social and psychosocial issues within a background of the cultural context she experienced. The long narratives detailed patient encounters, family relationships, experiences from home visits, and sometimes tragic complications of poorly controlled diabetes.

The following extract (Table 16) was chosen to highlight the juxtaposition of Jen’s GP-centred perspective with patient lack of engagement and an additional tension that Jen felt of the broader NHS service provision agenda to reduce referrals from primary to secondary care. Jen leads with an abstract of the narrative with her belief in the biomedical glycaemic control and promoting insulin therapy to the local population of patients. However, the lack of engagement in diabetic self-care amongst the population meant that patients often wanted to delay insulin despite poor glycaemic control. Jen explained that she would insist on insulin when patients were on maximal therapy but, she appeared to collude with patient refusal and lack of engagement unwillingly.

This tension of patients refusing therapy and continuing to deteriorate in their diabetic control was compounded by the GPs biomedical beliefs in glycaemic control and the anticipated

lowering of QOF targets. The juxtaposition of patients' stubborn refusals, the GP's unwilling collusion, the demands of lowering QOF targets and trying to prevent patient referrals to secondary care appeared climactic to the point of futility. Jen resolved to use alternative antidiabetic drugs and seek the diabetologist's support. In doing so, there remained an indication of ongoing implied tension from the overarching negativity that triple therapy may not be enough to control diabetes and insulin was still indicated. Furthermore, Jen retained the ongoing background tension of the South Asian population's lack of engagement in diabetic self-care.

On the other hand, in the reflexive TA analyses of depressive patients, Jen described efforts to understand her populations' cultural orientation and engaged in significant person-centred relationships with her patients e.g. 4.6.2.5. Her patient-GP relationships showed trust, empathy and alignment in person-centred ways, creating positive patient-GP relationships. In this narrative SA, Jen has also retreated to the biomedical stance of frustration and description of powerlessness in the face of multiple demands to improve population health. Jen has shifted from the person-centred empathic GP to the biomedical orientated, doctor centred QOF seeking, but not person-centred GP.

Table 6 Jen's extract - patient lack of engagement

| | |
|--|----|
| I think I've got no doubt, I feel very comfortable about giving them that advice because I do believe that it's in their interests | AB |
| and I do think that they're going to get thirty years of life which for most people is a good thing. | EV |
| So I don't have any problems selling it to them really[...] | AB |
| Um, I suppose you know, 7.5 is the limit when they're on maximum treatment and everything and then sometimes you let people go to sort of 8 but I'd start nagging, really. | OR |
| I mean often they'll be saying 'oh, can we leave it a bit longer?' and so at 9, definitely if they're not on maximum treatment I would. | CA |
| And of course the requirements of QOF as well but I think 7.5 is reasonable and next year it's changing to 7 so that's getting quite strict really[...] | CA |
| I assume it's evidence-based. I think its the NICE guidelines aren't they? They're always very strict. | OR |
| And it is hard for our patients to get down to that level, you know, for the insulin people it's very hard for them to get down to that. | EV |

| | |
|--|----|
| [...] then at that point – of late I've been using triple therapy but that wasn't accepted for GPs was it for a long time? You had to refer them to the diabetic clinic but now you're in this sort of two | OR |
| – the other thing is they want us to reduce referrals so these are my agendas of change as well as, you know, the interests of the patients, you know, there's also the practical side of QOF of having to achieve a certain level and also keeping referrals down | CA |
| so there are people that sometimes I might phone Dr H and say 'do you think it's reasonable just to put this person on glitazones because they're really, really anti going onto insulin?' | RE |

The next narrative analysis (Table 17) will contrast the previous two extracts with additional insight into the GP motivation. The account details the GP's perspective of a memorable patient's lack of engagement in diabetic monitoring services and allows insight into the GP's attitude towards patients who do not engage with the diabetic services.

Compared to Jen and Harry, Charles' local practice population was from a higher sociodemographic group. Consequently, Charles' perceived his practice population as relatively more engaged in healthcare and claimed high QOF target achievements. He also believed his patient population preferred insulin initiated locally rather than in secondary care and made plans to initiate insulin at the practice. So, Charles presented a contrasting figure because he experienced less tension from CDM and QOF achievement processes.

Despite Charles's overall positive perception of patient engagement in CDM and QOF at his practice, he also had the experience of patients who did not engage in diabetic self-care. Charles reflected on such a memorable patient and described his perception of why he failed to engage. Charles' attitude was informative of his leadership and management role at the practice. He began the extract with the abstract, aiming to inform how his practice identified patients who did not engage with practice chronic disease monitoring systems. He orientated the narrative to view that the patient did not want to engage in lifestyle change and self-care to manage his diabetes. Charles accepted the patient attitude to refuse to attend. He explained how he challenged the patient to attend the regular diabetic monitoring service—the tension centres on Charles' feelings of duty and responsibility towards patients that do not engage.

When the patient developed a transient ischaemic attack, a biomedical complication of diabetes, Charles believed the patient attitude changed, and he once again engaged with the

practice healthcare service. The abstract aimed to inform how the practice had picked up a practice systems issue: they did not have a recall system and only captured the patient through the patient prescription system. The tension in the narrative encapsulates the GP's feelings of guilt that the systems could have been better. However, Charles resolved this tension and blamed the patient for refusing to engage in diabetic self-care. He had performed his duty to recall and counsel the patient to self-care, and arguably, he had absolved himself of his feelings of guilt.

Charles reflected on the patient's attitude and believed the patient did not trust biomedical agendas and healthcare systems like many at his practice. Charles evaluated patient attitudes to the wider practice population. He believed some patients felt harassed by CDM practice systems and lacked trust in the GP. So, this negative patient attitude was a barrier to patient engagement in chronic disease monitoring and diabetes follow-up appointments. Charles also evaluated that patients were suspicious of the medical and pharmaceutical agendas. He further resolved the tension of patient lack of engagement in chronic disease monitoring by rationalising patient negative beliefs and trust in biomedical care in his mind. Charles appeared to empathise with the patients' suspicion of healthcare. In his mind, Charles had justified their negative attitude and lack of engagement. Consequently, Charles accepted that patients were self-determining and declined diabetic monitoring and self-care. He accepted an ongoing tension between patient lack of engagement in diabetic care and his duty to provide that care.

Table 7 Charles' narrative extract and reflection on patient lack of engagement

| | |
|--|----|
| the other thing we do is identify patients where the compliance is poor, this person has been ordering prescriptions for nine months but hasn't been reviewed. | AB |
| And there was a good example, a guy, he came about three years ago and, um, sixty, and I diagnosed diabetes, | OR |
| I got him to see the practice nurse, he went to the practice nurse, she told him to do quite a lot of things that he didn't really want to do, change your diet, stop smoking, don't drink so much, lose weight, get a bit fitter, you know, | CA |
| if you're not made like that, that's a pretty intense agenda. | EV |
| And he didn't bother to turn up and, | CA |
| in fact, I spotted him when he ordered a prescription for something like hay fever and I nagged him, and he came back once | RE |
| and I spoke to him and I said 'you're being, you know, you need to come in more' and again he didn't come in for another year and | OR |

| | |
|---|----|
| <i>then he gets a TIA</i> and then suddenly he starts thinking a bit more carefully about this agenda, do you know what I mean? | CA |
| But, but, but you know, so I suppose, some of our role is actually making sure, you know | AB |
| , we don't have a card based, or computer based recall, | OR |
| so if he hadn't turned up, if he wasn't ordering any prescriptions, he could have fallen through the net, do you know? | RE |
| Yeah, that's a pers-, and actually, funnily enough, I think, it surprises me how few people have that view, | EV |
| you know, when you think about MMR, how many millions of people decided they didn't like the idea of MMR after Doctor Wakefield's stuff, you know, you think about this agenda, | CA |
| One- it's naggy | EV |
| Two- it involves poly-pharmacy, which people, you know, people might assume there is a tie up between us and drug companies, you know, | EV |
| with all the research came from drug companies and that's why we're doing this stuff and we get paid based on | CA |
| you're only doing it for the money and, you know, these things are well known, aren't they, do you know? | RE |

Summary

Lack of engagement, QOF and CDM were often juxtaposed in GP accounts. When analysed using narrative analysis methods, there was evidence of tensions for all three GPs related to patient lack of engagement and evidence of GPs blaming patients for their detrimental outcomes due to patient lack of engagement. Arguably, GPs lacked further understanding of the person-centred agendas of patients. They accepted a degree of patient lack of engagement amongst their practice population and, as a result, accepted that the practice might not achieve QOF targets and so, practice payments from NHSE.

At the crux of this tension presented by the linked themes of patient lack of engagement, CDM and the GP-centred QOF targets was a GP sense of a duty of care to diabetic patients as individuals and as a practice population. If patients failed to attend monitoring, GPs were aware that they had a duty to be sure they had provided medical care and did as much as possible to engage patients in diabetic care. However, despite appearing to resolve their tension through acceptance that patients were self-determining and had a right to refuse self-care and therapy, all three GPs had an ongoing unresolved tension between the duty to provide care and patient refusal of that care.

The following subsection explores two further GP extracts that link lack of engagement with the individual patient refusal of therapy and explore other GP expressions of guilt and frustration.

5.1.2 Patient lack of engagement- memorable patients

This second category of lack of engagement and group of extracts will focus on GP accounts of memorable patients which related different GP feelings of discomfort and specifically negative emotions such as frustration, sadness and guilt. As will be shown, these often occurred when patients had not engaged with diabetic care.

The first narrative used to illustrate GP feelings is a narrative account of a memorable patient from Cath (Table 18). The patient declined and refused all therapies, including insulin. The patient believed she was allergic to the medications and complained of documented side effects of oral antidiabetic medications. As a result, there were fewer alternatives to metformin to

choose from, and insulin therapy was advised. The patient complained again of side effects, and Cath appeared frustrated in telling the sequence of events as the patient rejected medication after medication. Cath implied she did not believe the patient had true allergies to all the medications, including insulin, and explained that multiple primary and secondary care professionals had explained the importance of the medication to achieve glycaemic control. Notably, however, **Cath also indicated that the patient was unreasonable and “extreme”, indicating patient blame** to complicate the GP’s acceptance of the patient’s self-determination.

Cath concluded that the patient had accepted her considerable risk of complications of diabetes and reduced life expectancy because she had received the message from so many different HCPs. Cath also believed the patient had a right to refuse therapy, was self-determining and that she understood all the explanations provided. The ongoing tension is summarised within the abstract of the narrative. The conflict between the GP’s biomedical belief in the benefits of diabetic control and the patient’s lack of engagement created the GP’s tension. The belief that the patients’ health would ultimately deteriorate created negative GP feelings of sadness and frustration. Cath felt powerless to effect any change in a situation that she believed was a significant and predictable biomedical risk to the patient. This feeling of powerlessness was accompanied by self-doubt, that perhaps the GP could have done more. However, ultimately Cath resolved her tension only partly because the patient received care from multiple specialists who came to the same conclusion as Cath. Unfortunately, Cath believed there was nothing more they could do. There was no relationship breakdown to the point of complete patient withdrawal, but the indication was the patient was withdrawn from HCPs and their biomedical agenda. From thematic reflexive reviews, Cath appeared empathic, able to engage with diabetic patients and she empathised with the diabetic journey (section 4.6.2.8). She aligns herself to patients, possibly because of her own insights as a diabetic and explains how she involves them in care. She holds a contrastingly positive stance to Harry, who remains negative and frustrated about his population’s engagement even when describing individual patient scenarios related to other diseases. He describes no positive person-centred encounters involving relationship building, alignment or collaboration. His stance is firmly in the doctor centred position and delivers biomedical threat explanations.

The patient persisted with a significantly poor glycaemic control (HbA1c of 12), and despite the predicted steady decline in the patient's health, Cath moved forward to continue managing the patient but anticipated feelings of sadness when significant preventable complications would occur and frustration that the patient's health could have improved. The account provided an example of how negative behaviours and feelings such as blame and frustration display GPs as human and socially reactive, with a sense of normalising their responses in light of their duty of care as professionals.

In terms of Cath's person-centredness however, Cath has also displayed a shift towards blame to the patient. With feelings of guilt, and negativity towards the patient's poor outcome, there is an associate negative blame to the patient that signifies Cath's shift from empathic and PC GP to doctor-centred blame.

Table 8: Cath' extract- GP sadness and frustration

| | |
|---|----|
| I had a lady once who we started off, who presented with new diagnosis, started off with Metformin. She came back and her HbA1c had gone up and she said she'd stopped taking the Metformin. | OR |
| She came back two months later, she'd taken the Metformin for a week and stopped it because she had side effects but left it for the two months. [laughing] So we started the gliclazide because we didn't have the glitazones then. She did exactly the same. | OR |
| And then she had to start insulin because at that time there was no glitazone and she then said she was allergic to insulin and she wouldn't take it. | CA |
| And she was left on, I think, one Gliclazide and her HbA1c runs at 12. | OR |
| And we didn't get very far at all with her and she still presents and has her bloods done regularly and we had the nurse involvement with the insulin and no way[...] | EV |
| I don't know. I really don't know what's going on that. She has – it's well documented allergies to other medications in the past and she said she is sensitive to lots of medications. She said that before her diagnosis and that may indeed prove to be for her. | CA |
| [...] I think she was having fainting, sort of not feeling well, feeling dizzy, unsteady [...] Every time she comes. She still attends for annual checks. Why? I don't know in some ways but we still do her eyes and feet and all the rest of it [...] | EV |
| 'Would you try this?', 'no'. Sometimes she will and then she'll come back say 'I tried it for a week and it's no good' [...] | OR |
| I feel very sorry for her really because she's quite a healthy – she was – quite a healthy woman and fit and well and I know at some point she's not going to be [...] | AB |
| [...] So from her point of view I think she accepts a shorter time of feeling well than a prolonged, as she sees it, feeling poorly with other medications than insulin [...] | EV |
| Do you know what I mean? I suppose she's an intelligent woman, I think she's accepted | RE |

| | |
|--|-----------|
| that she'd rather have a shorter life that she can function at than one that's prolonged but she can't function, she can't do what she wants to do. | |
| [...] She's the extreme. She's the most extreme person we have! [laughing] | EV |
| Yeah, I am, because they're a nice couple, I know her husband and he has a lot of health problems and he's just retired so they should be enjoying themselves shouldn't they?" [laughing] [...] | OR |
| Yes, you can't do anything [...] And it will be – it's when she starts running into problems with her vision or her feet or infections etc that you'll think we could have stopped this, we could have prevented this. | EV |
| The frustration of it really, isn't it? [...] Yes, it's the frustration that if we could have somehow found a way around this earlier on then this could have been prevented. We know they're going to happen but, err - [...] | AB |
| Well firstly you think well I mustn't have explained it properly, that why can't they see this and why can't they see that I'm not just wanting to give them more medications for some perverse reason? We're actually trying to guide them to an ultimate satisfactory end sort of thing really. | EV |
| But you can only do so much and then it's the patient's responsibility isn't it? You can only guide but when you've explained it, and I think she does understand it, then that's her choice then. | AB |
| Well I think she's had now, she does come for her reviews and she sees enough people who tell her the same story each time, so I think she must understand [...] I would be surprised if she didn't because after the nurses didn't have success with the insulin she went to the secondary care team to try and – they had the same frustrating outcome! [laughing] | OR and CO |
| So I don't think, it's not through lack of explanation. | CO |

The following narrative extract (Table 19) exposed similar GP feelings from a GP who also experienced a memorable patient who refused insulin therapy, resulting in a poor patient outcome. The memorable patient was introduced as part of the theme of fear of insulin in subsection 6.2.7. In addition to the description of patient regret, the narrative account also indicated the doctor feelings of sadness, disappointment and guilt.

The extract opens with an abstract meaningfully indicating the GP's reason for telling the account. Mike wondered if the patient did understand the consequences of refusing insulin therapy and uncontrolled diabetes. He orientated the audience and interviewer to a memorable patient who had refused insulin therapy despite repeated discussions with the GP and other professionals. In Mike's mind, her refusal was based on a fear of insulin and her experiences whilst working as a cleaner. She had witnessed a consultant diabetologist using threat

explanations when advising patients to manage their diabetes, and he believed she did not take the threat of diabetic complications seriously. Unfortunately, her diabetes deteriorated to the point of serious complications, including vision loss, and she initiated insulin.

Mike reported that she found insulin use easy, so the patient regretted not starting insulin sooner. However, this was his interpretation of the patient's feelings. The GP tension was based on *his* worry that the patient may have understood the medical advice but did not believe it. Specifically, Mike thought the patient did not believe the biomedical recommendations of glycaemic control and diabetic complications. Her outcome was poor, and he implied that he shared the regret that insulin was not started sooner. He implied uncertainty and self-doubt that more could have been done to explain the risks and indicated guilt feelings. These feelings together comprised an ongoing tension, and there was no resolution component in the extract's narrative structure, and the GP's tension remained unresolved. Mike does show himself to be person-centred, he has tried to understand the patient's perspective where her negative belief has come from. There is no obvious movement or shifting in Mike's narrative, he remains empathic, and any counselling or partnership type engagement with the patient's health beliefs are not described. The absence of such description is the fault of the researcher not recognising the need then or after the interview. Alternatively, the absence of such description may also indicate that although Mike empathises with the patient, He has not built a relationship, does not align or counsel her to move her forward earlier. Self-awareness, reflective practice and education on how to challenge and motivate patients may help GPs like Harry Cath, Jen and Mike who find disengaged patients so frustrating.

Table 9 Mike's extract- GP sadness, regret, and guilt.

| | |
|---|----|
| I suppose you wonder whether they really do understand the consequences of it because I always remember a lady who was, um, um, a cleaner at the hospital[...] | AB |
| Who was absolutely terrified of insulin and refused it | CA |
| and had appalling control and by the time she eventually did accept insulin – this was quite a few years ago now – but by that time she was blind and had renal failure [...] | OR |
| And she did regret it [...] | CA |
| Well because she found it so easy. The insulin treatment she found easy [...] | CA |
| Erm, and wished she hadn't but we had talked to her many times about the consequences of poor control and she was just too frightened to even contemplate it | CA |

| | |
|---|----|
| and wouldn't accept it[...] | |
| Well she had { <i>understood the complications of uncontrolled diabetes</i> } but made – well, maybe she had [...] | CA |
| But maybe she didn't quite believe it [...] | CA |
| Because I, I, she had, um, I think she'd had an experience with a hospital consultant who was in the habit of using fright tactics on patients [...] | OR |
| And maybe she didn't take him seriously [...]. He says that to everyone [...]. So maybe there was an element of that [...] | EV |
| 'If you don't do this you'll go blind', you know, I think he was fairly blunt and direct and, I don't think she took it seriously. | OR |
| and, and, I suppose sometimes if you say something as a blanket scare and don't reserve it for the ones who really are at risk of that, it loses a bit of value and I think she worked at the hospital and I think she knew that he did that a lot[...] | EV |
| I don't think she took it seriously. | CO |

The third extract in this group involves a GP's recollection of a memorable patient who had depression and poor engagement in their health, which resulted in the patient's eventual death and resulting in GP feelings of frustration and loss. This memorable patient was previously referred to in subsection 6.2.3, and some details will not be repeated here for brevity.

The account (Table 20) was about a patient the GP had described as depressed, disengaged from her diabetic management and not self-determining, even powerless. The GP was contrasting the patient with another male patient whom she believed was self-determining. This female patient was perceived to be powerless in many aspects of her social and family life. Jen believed that the patient manipulated healthcare professionals and told them she was injecting insulin when she was not. The patient's interactions with healthcare professionals were positive, and Jen believed she also had a good rapport with the patient. She believed the patient wanted to please those in authority and make them believe that she was taking the prescribed medication.

Jen believed the patient's behaviour resulted from disengagement and a lack of self-awareness rather than manipulation. Jen described her as “*a poor thing*” and “*nihilistic*” and created an image of a powerless woman with low social standing in her community and family. Motherhood formed part of the narrative, and Jen identified with the patient because they were

of a similar age and had children of a similar age. She contrasted herself with the patient and found the patient's lack of empowerment to be pitiful.

The patient's tragic outcome and death resulting from biomedical complications of diabetes were in Jen's mind due to the patient's lack of engagement and nihilistic attitude to life. The patient's disengagement meant she was not trying to improve her situation and was a symptom of her depression. Jen was saddened and appeared to have a sense of loss with a patient she had developed a rapport with over time.

The tension in the narrative lay in the complicating action within the narrative structure. The tension was composed of the patient's disengagement and Jen's feelings of loss and ineffectiveness. The GP appeared frustrated and saddened by the patient's diabetic journey and outcome. She partially resolved the tension by understanding the patient's lack of motivation and behaviour to pretend to inject insulin. She did not appear to blame the patient but felt sad. There was a sense of the GP's own powerlessness in the patient's management, which implied the GP had feelings of failure as a doctor. The ongoing GP tension appeared a combination of sadness and pity for the patient and a retained sense of failure.

Jen previously appeared DC in the narrative SA when she discussed patient population LoE. When explaining her memorable patient, Jen is constructed as empathic, sympathetic often, aligns with the patient as a mother, but finds their relationship dysfunctional, blaming the patient's nihilism, and so, unable to involve her in PCC. Jen appears person centred, in many ways, but stuck and unable to progress beyond the alignment to the patient's nihilism, and so, does shift to DC blame. From the perspective of the insider GP, Jen's attitude and feelings are understandable, and draws to question if Jen may have been helped to move beyond her own feelings about the patient in reflective or therapeutic ways.

Table 10 Jen's extract - patient lack of engagement and GP sadness and loss.

| | |
|--|----|
| But the opposite of that was a woman... | AB |
| who died about eighteen months ago | OR |
| and she was a poor, poor thing. | EV |
| She was an Asian lady in her fifties and, um, she had, um, very poorly controlled diabetes and as the years went by she had a son. She had several children but one child was terribly disabled, he was born with some kind of spinal deformity and he had no bladder control and he was a poor little boy really and she sort of doted on him but that was because of her diabetes, uncontrolled during the | OR |

| | |
|--|----|
| pregnancy. | |
| [...]And she had so many complications and I think in the last year of her life, although she wasn't much older than me, | OR |
| she had a leg amputated but the diabetic nurses – and she was on massive doses of insulin – and the diabetic nurses were convinced that she wasn't injecting herself at all and they were looking for injection sites because the doses that she was on, it should have been – I've forgotten the word for it now – lipo something{ <i>lipo-dystrophy</i> }, you know, around the injection sites. | CA |
| [...] There was no evidence that she was injecting herself and this was for like twenty years, she'd kind of not – whilst swearing blind that she was – | CA |
| and yet the consequences for her were so immediate, you know, these weren't like future complications, she was actually having the most dreadful consequences. | EV |
| So you couldn't really approach that because she would just say 'oh I am, doctor. Yes, I am taking my insulin' and yet her HbA1c was ridiculous, they were about 18, they were higher than anything I've ever seen on these huge doses. | CA |
| And then she died of a heart attack, as you would with basically untreated diabetes for twenty five years.[...] | OR |
| So that was a – so she wasn't sort of manipulating anything and she was just trying to keep you out, you know, it was almost like she didn't want any attention | EV |
| and I couldn't find out what her fears were because she was completely refusing to admit that she wasn't taking any treatment. | CA |
| So that was all a bit sad. She was a poor thing... | EV |
| who was like very housebound really and she had a big, chaotic, dysfunctional family with things going on in the family and that was always difficult | OR |
| because I knew what other members of the family, for example the 15 year old girl..."[...] | CO |
| {Further narrative extract later in the transcript about the same patient:} | |
| [...] I don't know. I mean I suppose it might partly be she might have had more awareness about just how dysfunctional this family was than she was letting on and it's like keeping people out, you know, I think doctors are sometimes seen as sort of officials aren't they?[...] | EV |
| Or representing the outside authorities and maybe the less input she had from doctors, the better[...] Less sort of engagement the better. | EV |
| But she did seem to like me and we talked a lot but not about important things really. | EV |
| So – or whether she just saw herself as completely powerless in this household and very rarely going out... | EV |
| , so it must have been very overwhelming and just like nihilistic, not going to do anything. | AB |

| | |
|--|----|
| But she never came across like that. She never came across as 'I don't care what happens to me', it was very much she seemed to want to please you and do the right things but she just wasn't. | EV |
| I suppose in a way she's keeping control of it, she's doing the opposite of what people say and she's controlling things in a rather strange and self-destructive way. | EV |
| [...]Mmm and she said 'oh no, no, I do doctor, I do' and I'd say 'well where?' and she'd say 'oh here, I put it here' and of course she'd learnt, she'd had all the education, she knew what she was supposed to be doing. [...]And collecting the medication. | OR |
| [...] She was under the diabetic clinic as well, you know, and they were terribly baffled really about this. That's why they couldn't make any inroads with her HbA1c. | OR |

Summary

This section showed further insight into tensions of discomfort when GPs encountered patient lack of engagement in diabetic self-care. Common to the three extracts analysed were descriptions of poor biomedical outcomes that the GPs anticipated. The patients had received medical care from different health care professionals providing the same biomedical advice. They continued to refuse therapy and declined in health. The resultant poor outcomes for patients left GPs with similar negative feelings: frustration, sadness, loss, and guilt.

The narrative extracts showed that GPs were able to evaluate and reflect on the person-centred patient perspective. These evaluations showed GPs empathising with patient mindset and feelings, such as fear, and making efforts to understand actions such as pretending to inject insulin. Moreover, GPs felt powerless to effect change when self-determining patients refused therapy despite multiple professionals' explanations. The GPs accepted patient refusal but were left uncertain as to whether they could have done more. This uncertainty presented feelings of self-doubt and failure in their duty of care that persisted as ongoing tension. Moreover, the section illuminates GP feelings as manifestations of reactive emotional responses that arguably present the GP identity as human in contrast to the normalised role as professionals with a duty of care and service providers.

In these narratives, GPs appeared person-centred and empathic, but blame outwards the patient led by the GPs biomedical beliefs of what was best to maintain the patient physical health drove their narratives to an arguably distracted blame. As a result the doctors are doctor-centred and blaming, and shifting from previous DC or PC positions.

5.1.3 Patient transition: disengaged to engaged

This third section will explain the narrative structural analysis of extracts that focus on GP accounts of memorable patients who had transitioned from lack of engagement to engagement with healthcare and had improved health outcomes. Two narrative extracts show empathic GP understanding of the patient and the GPs' self-reported interactions with the patient.

The following extract (Table 21) from Alice's transcript opens with an orientation of a depressed patient deteriorating his diabetic health and not engaging with diabetic appointments and medication. The narrative has an optimistic tone contrasting previous extracts in this section. The GP described the patient's transformation from a depressed and poignantly sad individual whose life was spiralling out of control. He was a man not engaged in his social and working life, as well as his health. The GP believed that recognising the patient's depression was the critical turning point in resolving the tension created by his lack of engagement. In the GP's mind, the patient's journey and outcome created a straightforward and optimistic narrative account.

The GP appeared as a protagonist, effecting change in a subtle, empathic way. Her role in engaging the patient to manage his psychological well-being was vital to the outcome. She described his outcome with pleasure, and the resolution was complete and free of any ongoing tension. Alice has thematically been generated as a PC doctor and she appears her to remain. Still driven by her biomedical agenda, but in the context of the person-centred management of mood and his lifestyle, and significant contextual features such as family life, which are all important to Alice's agenda.

Table 11: Alice's narrative extract- patient lack of engagement, GP empathic understanding and positive outcome.

| | |
|---|----|
| There was another one who was a man who was being followed by the diabetic nurse at our practice and he hadn't come for his reviews twice and she'd sent a recall letter and the second time around he hadn't responded and she came to me and said 'what shall we do with this man?' and we brought him in and | OR |
| it turned out that he was diabetic, he was suffering from depression and the depression was the reason that he hadn't come for the diabetic reviews. | CA |
| He was depressed and I'd been seeing his wife for something else and she'd mentioned that he wasn't taking his medication and he came to me, basically because he hadn't come. | CA |
| We wrote him a letter to say that he needed to come and see the doctor and | OR |

| | |
|---|-------------|
| I'd seen him for the first time and he responded really well | RE |
| because when he first came he was not relating to the family, the marriage was very strained, he wasn't talking to his daughter, Christmas came and he didn't even come downstairs, that sort of picture. | CA |
| Really down in the dumps and nothing to live for and not performing at work and threats of redundancy and lots of problems | CA |
| and he actually, when I left the practice, he had gone back to work, his marriage was good and he was so turned around | RE |
| but to get him to face up to the diabetes we had to treat the depression and I think this was where it helped him to get there. | AB |
| He was just so fed up but I think when everything's coming at you all together you don't see the wood for the trees | EV |
| and he was brilliant, his Hba1C came down to something like 7 after being double figures and he'd done really well but he just needed time | RE |
| and the nurse was saying to him 'maybe we should, you know, if you don't respond, you don't respond, what can you do?' | OR |
| but there are reasons why people don't respond and you really need to see the person and you really need to be approachable and tell them – it's just the approach to him but he responded so beautifully and really a success story. | EV |
| I don't think he was ever started on insulin because he did well with the medication once he settled down | EV |
| so it's not quite the point but it's just really how you approach people I think is important. | CO Moral |

The next extract also resulted in a positive resolution to the GP's experience of tension toward the patient lack of engagement in diabetic self-care (Table 22). The narrative account opens with an orientation of a patient whose diabetes was deteriorating despite taking her medication correctly. Her husband had Alzheimer's disease, and Dan believed her lifestyle as a carer was causing her to be depressed. Consequently, she was not caring for herself and had a poor diet. The GP and nurses believed that advising the patient to change her lifestyle was making her more miserable. This belief appeared to conspire with the patient to continue her unhealthy diet.

However, Dan explained that the practice team persisted with the messages to encourage lifestyle change to allay this concern. Her diet, in particular, was poor, and he believed the healthcare diet advice added negatively to her low mood. In Dan's mind, patient engagement

was achieved by using shared decision-making processes and understanding that patients will choose to take advice and be motivated when they are ready to. Dan was specific to avoid being aggressive in his explanations and imposing his decisions on patients, believing that patients may lose trust and disagree with management, leading to a lack of engagement.

The patient's health improved with her family's help after a prolonged respite period from her carer role and a holiday. Her mood improved, and she also made efforts to change her diet. The outcome was favourable with improved glycaemic control, and the patient herself believed this resulted from her changed diet.

On the other hand, Dan believed that she engaged in lifestyle changes because of her improved depression. Unlike Alice, Dan did not mention specific management of her mental health by the health care team and psychological services, which arguably was an option to relieve the tension created by her depression and lack of engagement. However, another aspect of this narrative was the patient's underlying background social tension as a carer. Dan believed the patient's own stress and social tension was relieved when she stopped feeling guilty about being away from her husband and allowed herself to follow the path of self-care. Dan created an image of a woman caged in her social circumstance and whose mind was also entrapped, unable to think clearly to manage her own health, leading to her depression. In Dan's mind, the narrative was resolved – firstly from the social context and then the patient's psychological context, which led to lifestyle and diet change, engagement with medication, and ultimately a biomedical resolution.

Dan has shifted from the thematically constructed GP managing the diabetes delivery at the practice, trying to employ more nurses to replace a retiring nurse and deliver the insulin initiation service. He from Dc to Pc with empathy, trust, arguably patience, and appears to collaboratively involve the patient when she is ready to change.

Dan presented a contrasting figure to Harry's frustrated doctor centred blame towards patients for disengagement. He shows understanding of the individual person, her social hardship as a carer and self-neglect that he to others were unable to help or change until she was ready to. Arguably, he and other HCPs could have motivated her to understand social care provision differently. Significantly, unlike Harry, Jen or Cath, Dan shows no blame toward the patient, and has not been constructed and less person-centred, despite being unable to engage the

patient. He evaluates the moral of the narrative well: forcibly imposing the biomedical agenda will cause the patient to retreat (Murdoch et al., 2020).

“If only because, er, if you do try and, sort of, impose stuff upon them, um, they will find opportunities to disagree with what you’ve done[...].” Dan’s MORAL

Table 12 Dan’s narrative extract- patient lack of engagement, GP empathy and positive

| | |
|--|----|
| but, interestingly enough, we, the three, that is myself, the nurse and the patient, sort of, came to a consensus view after a year and a half that, actually she had to start on insulin, | OR |
| but up until that point, it had been very much a, sort of, um, a shared approach to the care, um, and, um | OR |
| , you know, it was interestingly, to have me coming in and having the nurse saying ‘I’m not quite sure what to do with this particular lady’ and me, sort of, talking her through the options in front of the patient, | RE |
| actually interestingly enough, became educational for the patient as well...You know, they can then follow the logic of what’s going on, they can see that there’s some, you know, some proper medical rational behind it all... | EV |
| I mean, you know, you’re really onto a hiding to nothing if you impose treatment in diabetics by and large, you know, because it’s all down to compliance and compliance with everything, er, lifestyle, drug taking, um, you know, yeah. | EV |
| , yeah it seemed to work quite well[...] | EV |
| I’ll use that same woman, um, because her HBA1C dropped from, sort of, being in double figures and it’s now, sort of, 7.1[...] | OR |
| You know, and she just feels re-energised, um. | OR |
| You know, whether that’s entirely down to the diabetes or whether or not it also coincides with the fact that her husband is now so demented he doesn’t even know his wife is anymore and, in a way, it’s almost been liberating to her because she now has lost that sense of guilt when she’s not there... Because she has now become a stranger to him. | RE |
| I think with her, um, you know, I’m not, I will certainly share my impressions with the patients and say ‘this is my sense as to what is going on, you know, do you disagree’, um, | EV |
| and um, you know, er, it’s certainly a very helpful thing from the consultation side of things | EV |
| but, equally, um, they can then understand with some clarity, why I may not be in a terrible rush to do things with them, | EV |

| | |
|--|-------------------|
| that they, it almost gives them permission to, um, er, choose a time and a place when they're going to make these changes in their lives, OK? [...] | RE |
| If only because, er, if you do try and, sort of, impose stuff upon them, um, they will find opportunities to disagree with what you've done [...] | EV AB moral |
| Yeah, yeah, yeah, I mean, she was compliant with her tablets before but, basically, it just wasn't working, you know, um, and by her own admission, she was eating too much. | EV |
| Because at the end of a long day of, you know, looking after her husband, she wanted to have a bit of pie and cake. | CA |
| And I would sit there going 'I can hardly blame you but it's not doing your health any good, is it', um, and she would agree. | CA |
| Yes, with her, in fact, the thing that really made the difference was she was persuaded by her family to go and spend a couple of months with a relative out in Spain. | OR |
| Um, she had two months away from her husband, began, I imagine after about two or three weeks to really relax and then thought, do you know, there's lots of nice salad here, started complying with diet, lost a few pounds, noticed her sugars were improving, um, | OR |
| and then I guess all the months and years of chatting that we'd had about it, sort of, paid dividends because she could make the connection with everything that was going on. | EV |
| Now, for her, she perceives that her life feels better because her diabetes is better controlled, | EV |
| I actually feel that it's, she's just got less depressed and a happy product of that is that she now feels she can comply, alright, and she thinks she's better because her diabetes is better controlled, I think she's better because her depression is lifting. | AB CO |

In summary, both GPs in this subsection showed person-centred empathic understanding of their patients, leading to valuable insights into their patients' lack of engagement. When comparing them, Alice led her narrative with mental health diagnosis and management, whilst Dan believed the social pressures and stress causing the mental health led to the patient's lack of engagement. Both GPs' management was arguably correct, but Alice directly managed the depression. In contrast, Dan believed the patient had to be supported, encouraged. However, ultimately, when her social circumstance changed, the medical advice and patient engagement in self-care resulted in diabetic control.

The narrative extracts indicated that medication and its escalation contributed to glycaemic control, whilst the person-centred and collaborative involvement of the patient in health was

critical. To achieve patient engagement, both GPs looked beyond patient education and explanations, and empathic person-centred relationship building approaches in chronic care were evident.

5.1.4 Summary

This section looked at unresolved tensions felt by GPs when diabetic patients failed to engage with chronic disease monitoring, self-care, and therapy. There were indications of frustration and blame towards patients for their lack of engagement, and GPs were aware that diabetic health monitoring was a GP-centred activity.

At an individual level, GPs accepted that patients were self-determining and had a right to refuse therapy. Despite this, the GPs' awareness of their duty of care and the patient refusal of care created ongoing tension.

When patients had poor outcomes, the narrative analysis revealed GP feelings of frustration, sadness, guilt, loss and failure. They made efforts to understand patients' feelings and mindset but felt powerless to effect change when self-determining patients refused therapy.

GPs were sometimes uncertain that they could have done more to engage patients and that self-doubt was associated with GP feelings of failure and unresolved tension.

There was also indication of negative patient-GP relationships presented by Harry's particularly negative stance about his patient demographic and the narrative confirms the literature findings that show the GP retreat to a biomedical stance, results in authoritative and paternalistic relationships with patients (Murdoch et al., 2020). Qualitative evidence from Murdoch et al. (2020) show that doctors may become more biomedical in their stance when GPs biomedically reframed patient goals, and disregard patient goals- thereby, become less patient centred. Moreover, patients shifted from the passive to active withdrawal from engagement with practitioners when the authoritative expert became more biomedical: indicating failed relationships, power differential and paternalism (Murdoch et al., 2020).

In this research, a contrasting position was held by more empathic GPs, Dan and Alice, who understood patient adverse social and psychological experiences and was linked with narratives of positive patient outcomes and resolution of GP tension. Patients were transformed from

unengaged to individuals participating in healthcare and diabetic self-care. Even though GPs had to accept the tension of poor diabetic control until patients were ready to engage, these narratives of patient transformation provided resolution from ongoing tension. The positive patient shift is the opposite of Murdoch et al.'s patient experiences of withdrawal from biomedical stances and reinforce the positive person-centred attitudes of Dan and Alice.

The differing presentation and alignment presented by Cath's narrative SA (table 18) appeared to be related to the patient's intrinsic disengagement with healthcare and HCPs and Cath retains a blame towards the patient. Compared to the reflexive TA findings, Cath has shifted from the empathic GP, who also has diabetes, aligns herself to patient diabetic journeys, with positive description of relationships. The cause of her shift from person-centred (PC) and empathetic GP to doctor centred appears to be the patients frustrating disengagement with all therapies and Cath's inability to find an avenue to explain the value of medication and diabetic glycaemic control. Despite the possible patient issues present, this research is aiming to understand the GP perspective, and Cath's retreat to the biomedical stance of blame toward the patient from an otherwise positively person-centred GP is significant.

Finally, GPs' honest and open descriptive and emotional reactions related to the human side of professional care when patients are perceived to be disengaged, and GPs felt powerless, which was a contrasting manifestation to the expected norms of professionals with a duty of care.

5.2 Cautious prescribing and the 'pharma-sceptic' GP

This subchapter will explore narrative extracts to enlighten the concepts of cautiousness when prescribing further. GPs described concerns for patient harm when prescribing new medications or even recommended medications, such as insulin. Thematically GPs were cautious of new medications, and some GPs explicitly stated they would delay the use of new medications. GPs had learnt this caution through the experience of medications that were initially presented by the research evidence and guidance as beneficial and then later found to be harmful (see subsection 7.3.2).

Insulin was also treated with caution by GPs from the thematically generated theme from the person-centred GP prescriber doctor centred themes. These negative framings of insulin

aligned with patient's negative framing of insulin: which aligned with how patients perceived insulin as a "strong" (Jen) medication and also their own failure.

The first narrative extract (Table 23) is from Alice describing her cautious view of insulin when prescribing for an elderly patient who had been advised to commence insulin by the diabetologist. The patient attended to see Alice with her daughter, and both were worried about the hypoglycaemic risks of insulin. The patient lived alone, had early memory problems, and her daughter worried about how the patient may manage insulin therapy, especially at night when she would be alone. Alice was a GP living with type 1 diabetes and had the first-hand experience of daily use of insulin and its side-effects. Later in the interview, she provided an insightful and in-depth personal experience of hypoglycaemia at night. Insulin had caused dramatic hypoglycaemia symptoms for her, and Alice feared the elderly patient did not have the cardiovascular stamina to cope physically if that should occur. She had previously explained the value of using insulin to control diabetes, and it was instrumental to her approach to reassuring and counselling patients when planning to initiate insulin. However, this pragmatic attitude masked how she balanced insulin with caution and feared the impact of the hypoglycaemic risk both personally and for vulnerable elderly patients.

Her personal background experience provided the context for her advice and, arguably, collusion with the patient and daughter to delay insulin initiation and advise an alternative medication. Alice's appears person-centred in choosing to avoid insulin for the patient, when the hospital doctor felt the patient would manage and was appropriate for the insulin initiation. Alice's negative and fear of harm of insulin shifted her to considering the biomedical fear of medication- her own cautiousness may arguably be her personal and doctor-centred agenda.

Table 13 Alice Narrative extract: cautiousness of insulin when prescribing for an elderly patient

| | |
|---|----|
| But there was another patient I was going to tell you about, a little old lady called H who's diabetic | OR |
| and her consultant at the hospital wanted to put her on insulin because her A1C I think was about 11 or something | OR |
| and she was about 90 but she was the most frisky 90 year old you'd ever met. | OR |
| She was like a little turbo on her Zimmer and unstoppable and he wanted to put her on it because she was so full of life, you know, and her daughter came with her and her daughter didn't want her to go on it because she lived on her own, | EV |

| | |
|---|----------|
| she was worried about her getting hypo in the night and they came and said 'what do you think?' and we talked about it and it was a good discussion because H started the discussion, she could say how she felt and | CA |
| I think in the end, unfortunately I left the surgery at the time that all of this was happening | OR |
| but, erm, her daughter and I both agreed that insulin probably wasn't the way to go for her because again, she was on her own | RE |
| and if she'd forgotten that she did it and she did it again, you know, it would be worse | CA |
| and I think I already mentioned putting her on Januvia, one of the gliptins | RE |
| But I never knew what happened after that. But she was very amenable, even given her age, you know, she was so amenable to advise and to taking things on board | OR |
| and it wasn't so much the 'I'm telling you to do this therefore you do it', | EV |
| but just to discuss it and with her daughter and herself and she would get more say than anybody else | EV |
| but we took that on board and this is what it will achieve and this is what, you know, and yeah, she responded really well too but again, I don't know what happened. [...] | EV |
| She didn't want to go on it. | RE |
| Her daughter was D and H was the mum and H didn't want her to go on it and H said 'I'm in your hands, doctor, what do you think?' and Dorothy said 'what do you think?' | OR |
| and we talked about it, what it, what it would gain her and what the risks were to it and in the end the three of us decided that we did not do what Dr S wanted to do.[...] | OR |
| Mmm, I said 'I don't think it's a good idea for her', in the sense that we hadn't exhausted all the oral treatments. [...] | EV |
| but basically it's just that you want to, given her age and her lifestyle, | EV |
| she was quite bubbly and you want to keep her like that and a more moderate approach I thought was better for her. | EV |
| I used to say that nothing is carved in stone, you can change things, you can change if you're not happy with this treatment, we can change it and it's just worth a try because if it looks good and it seems to work, it's worth a try. | RE |
| Yes, she lived alone, she was on her own at night. Her daughter looked in on her but, you know, | CA |
| she was basically living on her own and a bit forgetful but not, you know, not too much and yeah, it is her lifestyle. | CA |
| You wouldn't want to put her at risk of going hypo in the night on her own.[...] | AB CO |
| I think if you're on insulin you will have a hypo. It's inevitable that you will and it's important to know what to expect because it's hard to just get it right. | CA |

| | |
|--|----------|
| It's inevitable that you will and it's important to know what to expect because it's hard to just get it right. We don't have a pancreas for the brain and you can't – you just have to sort of see how you go, make it up as you go along, | OR |
| I think if you're on insulin you will have a hypo. but there a lot of people who are very scared of having hypos, especially if it happens to you on your own at night and it can really knock you for six. | EV |
| They're also dangerous because if you have a hypo, a really bad one can get your heart beating really fast and very forcefully and a lot of elderly people who have other comorbidities where they've got heart problems and hypertension, whose hearts could not withstand the physical effect of a hypo because there's a massive tachycardia and massive forceful palpitations that you get | OR |
| – because I get those – and what wakes me up at night is a crashing thud of my heart hitting my ribs and it just goes bang, bang, bang, bang, bang but it's a thud that wakes you up.[...] | OR |
| And it really scares you | CA |
| because then when you get up you kind of don't know what's going on and you know something needs doing but you can't quite figure out what and you can't make your way down the stairs in the night to get a drink and | OR |
| it's just the basic practicalities of it. | CA CO |

The second GP extract (Table 24) chosen shows how a Mike initially opened the narrative describing his cautiousness over new medications. His narrative extract showed his experiential journey with two medications that were withdrawn after safety concerns and his subsequent mistrust of new medications.

He then discussed a new antidiabetic drug type, gliptins and disagreed with the medication recommendations. He thought it should be prescribed early in the diabetic patient journey because of its mechanism. Despite reasoning that he would wait for a patient that the drug would suit biomedically, he had not prescribed the medication. The drug's cost and whether it was prescribed by secondary care were not an influence on him.

The GP resolved this tension between wanting to appear willing to accept change and his mistrust of new medications by saying he would individualise patient care. He would continue using older, trusted medications if his patients continued to benefit from them. The narrative indicated a persistent ongoing mistrust of new medications.

Table 14 Mike's narrative extract- tension of cautious prescribing and mistrust of new medications.

| | |
|--|----|
| Experience comes into it. | AB |
| I mean I think things – I can't remember the name of the drug but the non-steroidal that was withdrawn that was quite a popular one and a lot of people used it quite early[...] | OR |
| Erm, and then it was stopped so it makes you cautious about adopting new things. And the glitazones, you know, the first one that was withdrawn with hepatic failure – I can't remember the name of that one – I think it was thiozolidinedione wasn't it?[...] | CA |
| And that was withdrawn and again, I thought at the time what a good drug, that sounds like a good idea but I hadn't used it [...] | EV |
| You don't jump straight on new drugs[...] | RE |
| I haven't used it { <i>gliptin</i> }, um, largely because it's mechanism of action I can't see what it's going to add to most patients. | OR |
| Because it's stimulating insulin secretion and a lot of the people that you'd be considering using it on I think are those who are moving into insulin failure rather than insulin resistance. Well, sorry, not insulin failure, they will be having a lot of insulin resistance. | OR |
| So actually stimulating more insulin production isn't usually going to make much difference to their HbA1c level. | EV |
| So I'm not that excited by the new one { <i>gliptin</i> }[...] | RE |
| [pause] I think it's – no, I probably wouldn't { <i>wait for secondary care to be using it before I started using it</i> }. | RE |
| Erm, I think it's more likely to be useful early on in the process as an alternative to early treatment but that's not where it's being recommended at the moment. It's more logical to use it early on because its theoretical advantage is that because it's a more tailored response it doesn't produce weight gain, promote weight gain. | EV |
| So you might use it as an alternative Metformin early on[...]. Instead of a sulphonylurea | EV |
| But I'm not mad keen on adding it to existing treatment late on in the process because I don't think it will help[...] | EV |
| So I think maybe it's more like waiting for the right patient to come along than waiting for the hospitals to start to use it[...] | EV |
| I think it would be someone after Metformin or somebody who didn't tolerate Metformin where you were thinking about sulphonylureas but felt well they put weight on[...] | EV |
| But the other consideration is that they're expensive drugs[...] | OR |
| So you would – if a sulphonylurea was adequate and would work for them then you would still use that I think[...]. So there's more than just whether it's suitable comes into it. Is the original drug equally effective and it's obviously more cost effective. | |
| No, you don't think of that { <i>the cost</i> }. It's is it a better option to what exists already? | RE |
| And if for a particular patient the existing drug works then I'll always use that. | RE |

| | |
|---|----------|
| And only if there was a reason not to use the old one would you go for a new one. | CO RE |
|---|----------|

The final extract (Table 25) in this group is from a GP's recollection of a medication withdrawal, reinforcing his mistrust of new medications. The narrative appeared dramatic and is a testimony to his vigilance of new medications. Amongst the narratives are descriptions of various drugs, which together reinforced his past negative experiences of drugs.

Like Mike, he explained a biomedical benefit to the use of exenatide for overweight patients. The narrative opened with a complicating action because James answered why he had referred to the secondary care consultant to initiate exenatide. The tension of risk with new drugs persists through the narrative, and despite James' acceptance of exenatide's benefit, he remained cautious. James believed that the various medications caused a similar one per cent HbA1c improvement and was directed by the patients' biomedical history and the medication side effect profile. So, for example, he would not prescribe glitazones for patients with heart failure.

However, James' experience of drugs that were introduced and later withdrawn was most dramatic with a particular drug that was being launched in the UK. He invited a pharmaceutical representative to share knowledge of the medication with the practice team. He felt optimistic about the medication, but James had read about patient deaths associated with liver failure just before the meeting. The meeting went ahead, and James queried the drug's risk profile but felt he was sharply dismissed by the representative in front of his colleagues. However, he was interested in using the medication and planned to commence the medication with patients the following week. James was angry about the conflict in the meeting, even recounting it years later. His anger was directed at the pharmaceutical representative and was associated with the tension he felt. The irony was that James had moved out of his comfort zone and was planning to commence medications despite his background tension with new drugs, only to receive a sudden turnaround and medical alert. James wanted to relate the most valuable message for him: prescribing medications was a serious and risky business, and he was responsible for prescribing them.

The GP's cautionary narrative conveyed a dramatic sense of vigilance and foreboding. He knew he had ethical and medico-legal obligations to prescribe safely. However, James' emotional narrative related his sense of personal guilt and fear that patients could be harmed, which became a persistent and ongoing tension.

Table 15: James's narrative extract on cautiousness with new medications.

| | |
|---|----|
| Well it's because it's { <i>Exenatide</i> } a new drug. | CA |
| And you know, after 33 years experience as a doctor you've still got to know your limitations [...] | AB |
| Erm, it's a new drug, at our portfolio meeting I heard several lectures about it. I've read several articles about it and I agree if you're at that stage where you're thinking of either swapping one of your second line drugs or adding in a third line drug, you know, there are certain indications where I would use Exenatide. | OR |
| So if the patient was overweight and had been through all this er, the dietician and the nurse and even RIO { <i>local weight loss programme</i> } and they were still struggling with their weight, | EV |
| then it's unfortunate, but the better you control someone's diabetes, the worse their weight gets sometimes [...] | EV |
| So you know, there have been one or two patients where I've thought for that reason I think this patient needs Exenatide and just because we've never initiated it before, I referred that patient up to secondary care [...] | OR |
| Er well early on in my training, one of my trainers told me never use a new drug for the first 2 years. | RE |
| I never used Opren [...] You don't even know it. Er used to clear your grandma's, it was an anti inflammatory. Opren. | OR |
| Er I can take you downstairs I've got a cupboard full of mugs for drugs that have withdrawn [...] | CA |
| Erm, had a particularly nasty experience with one of them- | CA |
| I'm very conservative, very wary of using new drugs. | AB |
| But you know, glitazone's come out, Gliptins come out and you go ok, erm, I'm happy with what I'm using. And then you look at the research and it goes well may reduce the HBA1C by 1% as well. So there's no need to stop using Metformin, there's no need to stop using Gliclazide... But when you're looking at third line, you can use this, this, this or this, they're all the same in their effect [...] | EV |
| But you wouldn't use a glitazone if the patient had heart problems, heart failure[...] | OR |
| You know, you might want to use Exenatide if you also want to help them lose weight [...] Or at least stay stable. Put them on Exenatide and one or two patients, we've got have already lost half a stone. | OR |
| Yes { <i>Exenatide is a new drug and I am considering using it earlier</i> }. In that it is creeping in to the guidelines. NICE bring out their guidelines and I'm thinking right so there is a | OR |

| | |
|---|----|
| place for Exenatide. Erm, if you want to add in a third agent and you're keen that they don't put any more weight on or you definitely want them to lose weight, so I would use it. | |
| But I'm genuinely very conservative. | AB |
| as I say when the glitazones came out I probably didn't use them for 2 or 3 years. | OR |
| But there was one that came out before [...] <i>{a company}</i> launched a brand new drug for diabetes and it was the forerunner of the glitazones [...] | OR |
| And it looked so good that I actually rang them up and said could the rep come and see me? [...] | OR |
| I organised our own meeting in the practice on a Wednesday lunchtime [...] And I got all my partners and the couple of nurses who did the diabetic clinics - | OR |
| And I asked him to show us about this drug. And he brought his usual stuff erm, and it looked wonderful. But I'd read one or two reports from America and I said can you tell me is there any problem with liver functions? | OR |
| In front of my partners, in front of these nurses, he laughed at me. | CA |
| He just "Oh for god's sake Dr, don't believe everything you read. Oh god, my, listen if you want take an LFT <i>{liver function test}</i> before you put them on it and check it again in a month alright?" And I thought you condescending {X}, sorry. | CA |
| You know, but it looked like such a good drug, you know, I thought I had 2 or 3 patients in mind that we're struggling with that we're thinking oh do they need to be on insulin, but there's nothing else we can do, well now there was. So I said right I've got 2 or 3 patients, <i>{PN name}</i> bring them in next week and we'll talk to them about it. | EV |
| The following day, Thursday, I got, I'm secretary of the BMA, I got a fax from the BMA saying this drug has been withdrawn, 20 people have died of liver failure in America.[...] | CA |
| I was looking for his card, I wanted to ring him up and say "you bastard, I want a word with you". Because he made me look about that big. | CA |
| So that was, that's anecdotal, but that's one experience with a new drug. | EV |
| And I couldn't believe it. I had the meeting on a Wednesday, Thursday morning. And I just thought oh if that had happened a week ago I'd have put 3 patients on it. | AB |
| It was available in America [...] It was being launched in this country, but we were starting to hear, you know, one or two problems with liver functions coming from America. | OR |
| And I just wanted reassurance of that and he made me look that big. And then as I say[...] | CA |
| No I can't remember the name of the drug, but it was a forerunner of the glitazones | OR |
| And then the glitazones came out and they're safe, but now they're not safe are they because heart failure and heart problems and so we've started using the glitazones for a couple of years and now we're getting off them. Now the gliptins have come out we'll probably be using those instead [...] | EV |
| So you can see if it's not a very nice class of drugs, but you know, this one was killing people | CA |

| | |
|--|----------|
| [...] because at the end of the day these are reps selling drugs er, but I'm actually putting people on these drugs and if I'm making them poorly or it the patient the dies, how do I feel? | CO AB |
|--|----------|

5.2.1 Summary

The three extracts show how GPs view insulin and new medications with a cautiousness but a willingness to prescribe when the benefits outweigh the risks. The GPs took account of a biomedical and person-centred patient perspective in doing so.

Alice's narrative account showed that the concept of insulin as a potentially harmful medication, when prescribed to a vulnerable elderly patient, caused her to override the secondary care diabetologist's expert opinion. Moreover, Alice's knowledge and experience of insulin were powerful enough to inform her decision.

The narrative second and third accounts reinforced the theme of cautiousness amongst GPs when prescribing new medications. They recollected patterns of medications that were believed to benefit patients and were later withdrawn, which created a sense of vigilance and mistrust of new medications. Both GPs justified the delay in prescribing new medications but were both willing to consider them if they were convinced the medication would suit individual patients – as was the case with Exenatide.

The accounts emphasised the level of tension and fear of causing patient harm that GPs associated with the introduction of new medications. In the GPs' minds, they were ethically and legally responsible for the consequences of prescriptions, but significantly, they felt personally and emotionally responsible if patients were harmed. Consequently, the GPs continued with an enduring tension of mistrust and scepticism of new medications.

Interesting, both narratives are about the doctor-centred biomedical agendas about when to use the medications, the fear of harm as an attitude towards drugs belongs in the GP mindset. This doctor-centred attitudes may be challenged with education and support, but significantly, the sharing of this information with patients is not shown in this research and a limitation. The researcher could have returned to question the GPs further about person-centred sharing or explanation of these cautious attitudes with patients.

5.3 Insulin as a failure and blame

This subsection will revisit the concept of insulin as a failure generated thematically, representing the tension created between GPs' biomedical belief in the idealistic early control of diabetic diet and lifestyle in the diabetes journey and the negative perceptions of insulin from a biomedical and person-centred perspective. The result was the construction of the patient requiring insulin as having failed biomedically and failed in their health care engagement.

GPs perceived insulin initiation in T2DM as the expected and anticipated result of failed diet, lifestyle change, and medication management. In addition, the patient was perceived to have suffered a gradual biomedical failure of their glycaemic control during their diabetic journey. Consequently, insulin initiation was constructed as a biomedical and person-centred failure of diabetic management. When counselling patients, threat explanations were used to outlining the consequences of lack of engagement in diabetic self-care to patients, which compounded this negative framing of insulin as a failure.

Moreover, when patients had not engaged in diabetic health care or self-care, they were framed negatively by GPs. Consequently, insulin initiation resulted in blame towards the patient by GPs, and they were aware patients felt they had failed and blamed themselves for that failure. The three narrative extracts analysed in this subsection show similar blame towards patients who did not engage with diabetic self-care and believed that gradual diabetes deterioration resulted from biomedical failure. They also showed different attitudes towards the tension of lack of patient engagement and how to resolve the tension created by viewing insulin as a failure.

The first GP extract (table 26) is a typical biomedical narrative that the GP constructs about the patient. There were defining features of age, alcohol, and smoking history, and the patients' failing kidneys with the mention of microalbuminuria. The complicating action and tension presented early in the narrative as the patient's lack of interest in changing his lifestyle or taking medication.

The account appeared to have a pattern of positive interjections from the GP, which were interspersed with negative descriptions of an unengaged patient. Andy described the patient as “*amenable*” but then appeared to contradict himself by explaining that the patient was unwilling to engage with healthcare advice. Arguably, Andy implied a non-judgmental attitude towards the patient whilst still negatively framing the unengaged patient.

The tension escalated for Andy when the patient’s health was deteriorating, and he developed complications of diabetes, including chronic kidney disease, and so, needed to escalate his therapy to insulin. The patient was described as transformed into a “*brilliant patient*”, balancing the so far negative framing and reinforcing that his healthcare engagement was critical to the change.

Andy evaluated the patient’s diabetic journey and used the history to show how he had also changed to emphasise cardiovascular health. An additional subplot in the narrative account was Andy’s message that diabetes management had changed during his career from focusing on glycaemic control, including vital cardiovascular disease management.

The patient’s engagement in health and improved glycaemic control resolved the tension of his deteriorating health. Andy showed no persistent tension feelings such as guilt. In Andy’s opinion, the deterioration in the patient’s health was due to the patient’s unhealthy lifestyle and lack of engagement in diabetic care, which contributed to developing cardiovascular disease. This combined biomedical negative framing of patient deterioration was compounded by the person-centred perspective of patient lack of engagement, ultimately leading to blame towards the patient.

This narrative extract from Andy’s interview appeared out of place, when previously, in 5.1.1, Andy is framed as a positively empathic, relationship building and collaborative GP in his person-centred approach. Andy’s has been shown to shift back to a doctor-centred biomedical blaming. The research design to use insulin has been helpful to highlight the GPs biomedical orientations, and how when challenged by patients’ beliefs, Andy has been shown to shift into the negative doctor centred paternalistic attitude.

Andy has now been constructed as a GP that shifts from doctor-centred delegating to a person-centred and proximal chronic disease patient care delivery, and then back to doctor-centred biomedical blaming. His narrative lacks the person-centredness of his other narrative and

shows how the same GP can sometimes reflect and see person-centred actions and patient needs, and other times, focus on the purely biomedical.

Re-evaluating this structural analysis, highlighted an important resolution: the patient had been referred and other HCPs may have educated him, and he is engaged in his diabetic self-care. The orientating features of the narrative contain no person-centred history of the patient, unlike his previous narratives. Again, this could be a failing of the insider GP not responding adequately in the co-produced interview. However, from a narrative approach, the participants narrative-self comes through in this long section of text, and Andy is biomedical and doctor-centred throughout this account.

Table 16 Andy's narrative extract- biomedical and person-centred view of insulin as a failure.

| | |
|--|-----------|
| One in particular, a chap who's late 50s, | OR |
| very amenable chap | EV |
| but certainly not very keen on injecting himself and starting insulin and in fact certainly even after the point of diagnosis of diabetes, not very keen on changing his lifestyle. | CA |
| So he was a big drinker, he was a smoker and we'd obviously identified he had diabetes. | OR |
| He's commenced on oral medication; he was not very keen on taking that and was very hit and miss with it and I think really it took a long time. | CA |
| I saw him regularly for a couple of years and we got him off smoking, he cut down his drinking, he started taking his medication regularly | OR |
| but he started to develop microalbuminuria and other complications, at which point really we had to throw the book at him and say 'look, really this is what we have to do' because he still was not controlled on multiple medications. | CA |
| So he ended up, because of the complications he was starting to get, to refer him on | AB and RE |
| and in fact he's been a brilliant patient on insulin because he now controls his blood sugars very well, he takes insulin, he takes Metformin and he's very much better controlled. | RE |
| I guess – this was – I mean I've seen him this week for example, but this was a few years ago and I think at that stage the idea was trying to get tighter and tighter control of your blood sugars, | OR |
| which is probably one of the indications that we referred him on for insulin therapy whereas I guess now, the idea of what the studies suggest is maybe tighter control or very tight control is not beneficial and in fact, you know, targeting the lifestyle things, the blood pressure and stuff like that, the cholesterol, was much more important. I think with him we sort of targeted those but as I say, probably we also targeted the blood sugars | EV |

| | |
|--|----|
| more and now more evidence has come to light to say blood sugars, OK, don't worry too much if it's a little bit high but actually blood pressure and all that. | |
| So our perspective with him has changed a little bit although we have treated his blood pressure and his cholesterol but it's taken four or five years | OR |
| but he has completely changed around and is now a very good patient. | AB |

The following narrative extract (Table 27) is a persuasive account from a GP who assuredly believed that insulin indicated a failure in T2DM patient management. Dan had reflected on the first patient that he initiated insulin on at his practice many years before and began this account to share his opinion. The alternatives to insulin were limited at the time, and Dan's knowledge of the alternatives and plan to initiate Exenatide himself showed his confident knowledge. Despite the opportunity of alternatives to Insulin, Dan also framed the medications negatively. Biomedically, the diabetic journey was doomed to failure over time, and these medications delayed inevitable insulin initiation.

The characters in the narrative were overweight patients that felt physically unwell from the symptoms of uncontrolled diabetes: fatigue and loss of energy, thirst and excess urination. Insulin provided a resolution to these symptoms and made the patient feel well again. However, Dan spurned insulin because of its unpleasant side effect of increasing weight, a sustained background unresolved tension throughout the narrative.

Moreover, weight management was the origin of diabetic patient problems. They had failed to manage weight through diet and exercise or lifestyle change. Dan moved into another related opinion driven sub-narrative about treating obese patients with surgical interventions. He believed the NHS's costs in diabetic drug management, especially insulin, meant successful surgical bypass operations offered credible methods to help patients lose weight and reverse their diabetes. He witnessed dramatic improvements amongst a small number of his patients that had come off diabetic medications. Dan was enthused by the prospect of surgical weight loss opportunities, and it gave him hope that patients could halt the negative spiralling journey to insulin.

Interestingly, in contrast to his account of the memorable patient, Dan remained biomedical throughout his opinion. He did not appear to blame patients explicitly but using insulin would

only add to the patient's weight problem. However, the patient's inability to lose weight and the gradual deterioration of diabetes remained a background thread in the narrative, indicating patient blame.

Table 17 Dan's narrative extract- biomedical and person-centred view of insulin as a failure.

| | |
|---|----|
| ... my views as to how useful insulin really is, is I do regard it slightly as a sense of failure for the Type II diabetics –[...] | AB |
| - they, it does bring their sugars under control but usually at some cost in terms of weight and unacceptable costs in weight, um, you know, and, of course, naturally enough the impact in terms of the potential for hypos but, you know, I am increasingly now, you know, using Exenatide –[...] | AB |
| - and, um, I've just reached the point where I'm going to initiate Exenatide myself for the first time, rather than referring them up to the diabetic liaison service because they've just allowed us to start, you know, initiating Exenatide in this area[...] | OR |
| The PCT, yeah, well the diabetic team are saying it's no longer a red lighted drug so, you know, we can get going and have a go. | OR |
| Yes, those just then, um, the Pioglitazone or the glitazones hadn't come on the market – [...] Um, it was essentially just Sulfonylureas and Metformin - | OR |
| Um, because really, you know, these poor people with their, sort of, BMIs in their high thirties and onwards on insulin is just not great long term thing for them.[...] | EV |
| - um, and this was a person on, you know, maximum dose, Gliclazide, on maximum dose Metformin – [...] | OR |
| I think the only other drug that we could play around with at that stage was, um, oh gosh it's just escaped me for the moment, the one that's, sort of, bound to glucose in the gut, er –[...] Er, I've forgotten the name and, really, of no value because patients, the GI side effects were just utterly intolerable.[...] | EV |
| Glucophage, um, no, um, oh gosh what's it called, um, it'll come to me in a sec, um, but that was it, really, so very limited choice, um, the Glitazones made a big difference, er, in terms of staving off by a year or two at least that moment where you inevitably have to go to, er, insulin, um, and I, you know, I just keep on impressing on these people the need to get the weight off, um –[...] | EV |
| Well, I mean, um, [clears throat], just, well, I mean, when you're talking about people with HbA1c's of 8s and 9s and 10s and you start them on a Glitazone as a third-line drug, and suddenly their HbA1c is 7, you know - | EV |
| - you go fine, well this is, you know, staving off the evil hour, um, [clears throat], and it gradually drifts off over time, I don't think I can quote a paper saying based on this particular evidence, but the time frame seems like that in my head, [...] | AB |
| Yeah, I mean, um, the, you know, the fact is I don't, I don't particularly feel that patients end up with a demonstrably better quality of life once they're on insulin –[...] | CA |
| - unless, of course, they were so osmotically affected or, you know, their, their level of fatigue was such because of the high sugars that, actually, | EV |
| getting them normoglycemic just makes them feel like a new human being, sometimes | RE |

| | |
|--|----|
| you get that strong sense that you've certainly given them a new lease of life, | |
| but at the cost of being a darn sight fatter, um, so you know, and in terms of the dialogue, um, clearly, er | CA |
| , the patient seems enthused by the idea of starting on injections is rare so, you know, patients just don't want it,[...] | CA |
| so the most persuasive element that I have, of the argument that I have available to me, is a sense that this is a treatment that has the potential of making them feel better, er, in terms of giving them more energy because they're just not thirsty all of the time or getting up at night or they're just more energised through the day.[...] | RE |
| And I have to say, the feedback from patients is that because they've generally been so resistant to the idea, I've finally persuaded them at the point where, actually, they're feeling a bit rubbish so, by and large, they're not unhappy with the move.[...] | CA |
| Alright, um, but you know, it's a one way street, once they're on insulin, unless they, the only people I've actually got off insulin are people who've had gastric bypass surgery.[...] | OR |
| And they've just become new human beings as a result of that,[...] | EV |
| so, er, I must admit, I'm increasingly of the opinion the NHS would save money if it just did, you know, endoscopic, you know, bypass, four grand or something like that, they'd be saving money hand over fist over the insulin that you would give over the time and their health would improve enormously, the most amazing intervention.[...] | EV |
| I mean, I've got four of my diabetics with a BMI of 50 or more.[...] | OR |
| Undergo, undergo gastric bypass surgery, I've got a guy who went from 155 kilos currently to 82. | OR |
| And he was on 400 units plus per day of insulin and is now, I've just stopped his Metformin, he's now a diet controlled diabetic and, in fact, his sugars are all in single figures and I said in six month's time, I'm going to be saying that you're no longer diabetic.[...] | OR |
| Yeah, they { <i>diabetes and obesity</i> } are just inextricably linked, um, if you can find a way of getting them to lose weight, they stop being diabetic, it's stunning, really. And, um, you know, which is why, er, increasingly now, it's, it does seem illogical to start them on a drug ultimately that's going to make them fatter. | EV |
| You know, so I'm, I'm, although I will initiate it, I do so with a sense of failure that it's, | AB |
| you know, I, I, I have to now assume that I've tried everything that I possibly can. [...]And, er, you know, that's it, I've almost given up. | CO |

The final narrative extract (Table 28) in this group is from Alice, a GP with T1DM. Alice provided a monologue aimed at pointing blame at colleagues who failed to understand diabetic patients. The abstract in the extract is composed of Alice's belief in showing caring towards diabetic patients and presenting insulin as a positive solution to uncontrolled diabetes.

Alice believed Insulin could be utilised through understanding that insulin worked over small amounts of time compared to OADs. Patients had to adjust life to suit the insulin timings, and because she had become accustomed to the way of life, she expected her patients to.

Alice complained early in the narrative that colleagues had used the concept of insulin as an ominous end if they did not follow healthcare advice. She claimed this negative presentation of insulin could be reframed positively as a benefit and not as a terminal end in the diabetic journey. Moreover, she recognised that other GPs blamed patients for their deteriorating health. Alice presented a contradicting tension that indicated blame towards the patient that does not look after themselves despite her empathy. While stating the disease progression was expected in the diabetic journey and patients were not to blame, she also said complications of diabetes occurred if patients did not look after themselves. Like other GPs, Alice's attitude implied blame towards patients who do not engage in self-care.

However, Alice's approach to patients early in their journey was critical to her belief in positively framing insulin: to avoid using insulin as part of threat explanations in diabetic care and present insulin as a positive and effective method to manage glycaemic control. The tension of insulin as a patient failure was resolved by seeing insulin as a positive response to biomedical failure that was not the patient's fault and using positive explanations early in the patients' diabetic path to encourage a healthy lifestyle and medication compliance.

Consequently, Alice saw the tension created by GP blame towards patients and patients not engaging with therapy. The former could be resolved by reframing insulin positively, presenting insulin as a therapy managed in set periods around the patient lifestyle. The latter remained unresolved, BUT like other GPs, patient lack of engagement remained a persistent background tension leading to blame towards patients.

Alice has previously been constructed as the most person-centred of the group of GPs, but in this narrative analysis, Alice also is shown to be blaming and takes the biomedical doctor centred stance.

Table 18 Alice's narrative extract on positively framing insulin

| | |
|--|----|
| I think they respond if they know that you care for them, you know, | AB |
| I think the difference is that the other partners didn't really listen | CA |
| and they just sort of told him 'you have to do this or else you'll end up on insulin for not taking care of yourself'. | CA |

| | |
|---|----|
| It's a different way of doing it and it doesn't mean that if you do end up on insulin, really, it's erm – I tell them that I quite like being on insulin and that has a very positive effect | RE |
| because it's easier to work with something that controls you in small gaps of time, like small sections of time, whereas if you took a tablet it's sometimes a 24 hour tablet | EV |
| , you know, the regimes are only once a day so if you take a tablet that's a whole day caught up there whereas if you're on insulin you just manage four hours at a time or six hours at a time and that's easier | EV |
| , you know, because I've always done it so I don't know any other way probably | EV |
| so it makes it not a sort of a punishment if you have to go on insulin because you didn't look after yourself. | RE |
| 'So that's what I was warning you about so now you have to go on it this time'. It's not like that | CA |
| and they respond to just being positive and understanding why and it's really to preserve their health | RE |
| and there were days – and I say to them sometimes, in the old days all diabetics went blind or lost toes and feet, it was just a matter of time. It wasn't if but when it would happen, you know, | OR |
| and they're lucky to have these treatments because very very few diabetics go blind now and not very many lose feet or toes because they look after themselves. | OR |
| It gives them something to keep in perspective that if you don't look after yourself these things happen but it wasn't because of you, it's just the disease | CA |
| and if you have the ability to do something about it, do it. | EV |
| I quite like fixing people so I like fixing them and saying, you know, this is how we're going to fix it, this is what we can do. Here's a problem, this is what we can do and then adapt it to their lifestyle. | CO |

Comparing the GPs, one accepted that the patient failed to engage and believed in the transformation of the unengaged patient had led to a resolution.

Another GP believed patients were expected to deteriorate gradually, were also to blame if they did not engage with therapy. However, insulin contributed to the deterioration by making patients more obese and, over time, worsening diabetes. Resolution lay in managing obesity early and later in the disease, even considering surgical solutions.

A third GP believed the threat of insulin early in the patient diabetic journey created a negative framing of Insulin as an undesirable outcome of deteriorating diabetes and took focus away

from diabetic self-care. Across the three GP extracts analysed narratively, there was a consistently negative attitude to patient failure to engage with therapy and self-care, contributing to deteriorating diabetes and need for Insulin. In this situation, GPs indicated blame towards patients, even when the GP stated the patient was not to blame.

5.3.1 Summary

Insulin was perceived as a failure from the biomedical perspective and the person-centred perspective by GPs. This negative framing created a persistent background tension that the patient's diabetes had progressed biomedically and that the patient's lack of engagement in lifestyle change and therapy had led to insulin requirement. Consequently, insulin was often constructed as a representation of biomedical failure, and these narratives highlight how drawing on the medication to research made GP mindsets on delivering person centred care in a chronic disease, caused GPs to focus their decisions on the balance of biomedical need versus the person-centred need. That the patient had contributed to by not engaging in self-care. So, from the GP perspective, when patients' diabetic health deteriorated, patients were often to blame.

5.4 Distal practice

This subsection will look at the tensions created by the GP duties of generalist and service provision and delegated duties to the nurse. GPs described how they delegated diabetic care and monitoring to practice nurses and the distance created between the GP and the patients. There was an apparent tension between the increased nursing role in diabetic chronic disease management and the more distal roles for GPs within diabetic patient care. The concept of distal was used in similar term the constructs in nursing research (Malone, 2003). When proximal, a practitioner has a closer relationship figuratively to the patient and distal implies patient care from a distance. Consequently, in this thesis, When delegating care for T2DM patients to nurses, GPs are positioned as distant and so, distal.

The strain between being more distal diabetic leads and proximal person-centred care did not consistently cause tension across the GPs. Thus, the value placed on the proximal role in diabetic care by the GPs was inconsistent. Some GPs valued their GP distal duties, which

created more managerial and leadership roles, such as the practice-centred GP managing the business. GPs also saw themselves as proximal to patients at times of acute and urgent patient management or when the practice nursing team requested problem-solving.

5.4.1.1 Distal practice and leadership attitude

The first extract was from a GP who explained how the change in general practice chronic disease monitoring impacted GPs' work.

Charles (Table 29) was a GP partner, and the tone of the narrative is business-like throughout. He included talk of practice nurse time, an increased workload, a different business model and duty to plan service provision in an unemotional way. However, the tension in the narrative was created by transforming general practice from personal services provided directly from doctor to patient to a more distant organisational approach. The duty to provide diabetic chronic disease monitoring services meant delivering specific parts of patient care at different intervals, such as blood pressure. When patients had not had their blood pressure checked at appropriate intervals, they would be recalled to an appointment by the new proactive administrative systems.

The GP identified the chronic disease management work as preventative and public health orientated work that had changed to become more systematic and rigorous. Previously, if patients did not engage with care, practices did not have mechanisms to monitor attendance and invite patients who failed to engage in health care. The work was always aimed at service provision, but the increasing workload of CDM associated with QOF meant delegating to practice nurses was necessary.

Charles spoke confidently of the QOF target driven services and the financial rewards that motivated the change in his practice. For Charles, QOF was more than a task to fulfil NHSE requirements to monitor quality patient care. Achieving QOF targets bolstered practice finances allowing them to employ nursing staff, resource the practice and expand the practice business.

Significantly, Charles' openness when describing the need to plan the practice-centred business reinforced his confident attitude toward delivering healthcare. He is aware of his contractual duty to NHSE to provide healthcare services, and he attended to funding and resources that

were part of his responsibilities. Charles described no negative tensions, and significantly, he showed no feelings of any conflict of interest between his duty of care to patients and managing the practice finances. He implied his duty was to provide and deliver services efficiently and successfully. Consequently, when planning insulin initiation at the practice, he considered the practice business, the resources needed and remained steadfast in his mission as the GP partner leading the service provision.

Charles' displayed an instrumentality towards the nurses, patients and even the chosen insulin therapy types- they were all a means to an ends. The value of practice population care and effectively steering a practice team was part of his persuasion throughout the interview. Although he recounted fewer individual memorable patients, he asserted the need to balance caring for the practice team whilst still considering the practice patients' needs. Charles initially appeared to be an outlier in the stance he took towards the service delivery of insulin initiation. However, his narrative reinforced GPs' distal care of patients provided by other doctors delivering insulin initiation (Dan and James), or were planning to and then withdrew (Jen and Sally). The distalness of the GPs was relative to the described roles of the practice nurses and a contrasting image to an ideal proximal, person-centred GP stance.

Moreover, Charles service delivery stance reinforced the message that was presented thematically: that the infrequent presentation of insulin initiation made it a service that was untenable in a normative sense and he implied he would not be continuing. Additionally, Charles is firmly positioned as a doctor-centred leader and has not shifted to a PC stance.

Table 19 Charles' extract – showing the distal and GP-centred attitude.

| | |
|--|-----------|
| So, actually, the cost of this sort of work, this preventative work globally is actually much more than a few hours of a practice nurse's time. | Moral, AB |
| We have twice as many appointments in this practice for the same population as we did fifteen years ago.[...] | OR |
| And because preventative medicine –[was so different then] | EV |
| I mean, probably, you know, OK, maybe Type II diabetics you would have made a reasonable attempt to follow up in the past | EV |
| but, you know, you think about, you know, the person with just, you know, on a statin, where we'll probably see them once a year, we'll probably do a blood test, we might, you know, there might be a nurse appointment, a couple of doctor appointments, we'll do their blood pressure | OR |
| , none of those consultations would have happened ten years ago, twenty years ago, the person having blood pressure treatment, if they haven't bothered to identify themselves, | EV |

| | |
|--|----------|
| we wouldn't have been bothering to identify them, do you know what I mean? | |
| So those consultations wouldn't have happened. | AB |
| And with the diabetic ones, you know, because we're trying to do so well with A1Cs, they might end up having two or three sets of test in a year, changes of medication, you know, | EV |
| there's a more rigorous, there's much more rigour to it | EV |
| , so maybe half of those consultations wouldn't have happened and many of them are with us, as doctors, so. | EV |
| Well, I mean, of course, in the past, actually, how we did with all of this stuff was absolutely irrelevant to the business, do you know what I mean? | CA |
| Yes, of course, you were in a position of providing GP services so you had to engage with these issues, | CA |
| but you were, kind of, feeling, well if the patient was engaging with me then I'm engaging with the patient and if the patient wasn't engaging, we might have had a card type recall system | CA |
| but, for most practices, these things just simply did -, you had to be pretty obsessional to make that kind of thing work.[...] | EV |
| So I think, um, and, of course, you know, some of the business model being that, actually, you know, | EV |
| the QOF means that some of our money comes from doing this well, therefore, you employ more nurses hours and you, actually, you've improved your service, you know, I don't think the whole of the QOF has just kept me going, do you know what I mean, I think we've expanded our business based on it. | EV |
| So, yes, to some extent[...]Doing more things and yeah, this [insulin initiation] is another example, this is something we would not have conceived of doing ten years ago. | AB CO |

5.4.1.2 *Distal practice and proximal problem-solving*

The second extract portrayed a GP asked to see a patient by the practice nurse because he was not engaging with his diabetic management. The practice nurse aided the GP to manage diabetic chronic disease patients in regular review appointments whilst collecting monitoring data for QOF, and he appreciated her efficiency in doing so.

In this narrative extract (Table 30), the patient had developed a poor relationship with the practice nurse, and she was described as aggressive in her manner. Andy blamed the nurse for the poor rapport and the lack of trust, resulting in the patient not taking his diabetic or cardiovascular medication. Andy believed this patient had not challenged the advice given but lacked trust in the nurse, and communications had failed. The tension included the patient's lack of engagement with diabetic care and the nurse's poor rapport with him. A background

narrative was the doctor's belief that the nurse's manner was aggressive, and he elaborated later in the interview that other patients also complained. He valued the nurse's experience and knowledge. He also understood she had time pressures in her appointments but accepted that her manner was sometimes unsuitable for some patients. They worked together as a team to resolve patient problems. Despite his overall respect for the nurse's work and efficiency, Andy appeared as the hero character that resolved the conflict between the unengaged patient and the nurse. Although the extract highlighted the potential for self-reported narrative data to be self-aggrandising, elsewhere in the interview, the GP reiterated his respect for the practice nurse competencies and the collaborative way they managed diabetic patients.

Andy decided to see the patient in a separate appointment and planned to rebuild rapport. Andy had the opinion that patients could vary in the involvement they wanted in decisions. Andy described two extreme types of patient involvement in decisions: patients may believe GPs lack knowledge if they attempted to share decisions, whilst others wanted involvement and were offended at decisions made on their behalf. Andy appeared to believe that this patient wanted less involvement in the healthcare decisions but was anxious and required explanation, reassurance and trust.

To resolve the tension, Andy assumed the role of the proximal healthcare professional. Significantly, the rapport development was more valuable than the healthcare decisions. Andy recognised the patient was anxious and additionally worried about losing his driving licence. The patient gradually engaged with his medications after explanation. With further follow up appointments, Andy reinforced his rapport with the patient spending more time building the patient's confidence than on the detail of the healthcare problem. With other diabetic patients, Andy generally became involved in diabetic patient care at times of medication escalation. In this narrative, he became proximal at a time of conflict between the nurse and patient, highlighting that his usually distal role could become proximal when required to meet patient care. This shifting from distal to proximal was driven by the need to be person-centred and adjust the practice protocols for the nurse to lead the CDM care for patients. Andy's respect towards the nurse also showed a respectful attitude toward her as an individual, her assertive style of nursing and acceptance of the patient's unmet needs. Although this research is limited to speak of GP reflections, because the RQ does consider the PCC approach towards patients, the nurses attitude and example from Andy does extend the issue delivering PCC to nurses

also. The case highlights that in the primary care setting, nurses may also retreat to the biomedical and blaming role when they feel patients are not engaging in self-care, and as described in the literature, patients may withdraw from goal-setting because of the biomedical nature of the clinicians focus (Murdoch et al., 2020).

This individualising care and flexibility showed a positive characteristic that is collaborative with the nurse as well and the patient. Andy aligns with the patient gradually and show his collaborative and partnership approach as advocated in the PCC recommendations ((Health Foundation (Great Britain), 2016; Britten *et al.*, 2017).

Significantly, Andy is constructed as a proximal and person-centred in his approach to the patient in this account and he shifts to the position of proximal from distal is key to the developing theory on person-centredness in this thesis. As an individual, Andy's narrative shows how he can be constructed to shift from proximal to distal and back to distal on a case-by-case basis. Arguably, the person-centred self-awareness may not be evident, indicating the need for reflection and potential for education, and may have been explored further at the time if the interviewer had aided him to reflect on on the shifting from PC to DC and vice versa.

Table 20 Andy's extract – distal GP acting proximally

| | |
|---|----|
| ...this particular gentleman really didn't get on with our practice nurse and I think that was a problem initially why he was very reluctant to sort of deal with his diabetes. [...] | OR |
| And then the practice nurse called me in and said 'right, can you tell this bloke off' and I said 'right, come and see me next week' so, you know, I took a different approach but generally when I say 'we', it's myself and the practice nurse because as I say, she does a lot of the diabetes management. If I've got an issue or something I'm unsure of I'll go and ask her.[...] | CA |
| because he won't go and see her anymore.[...]Well he will if it's for something, you know, if he has to go for blood tests or something then he will see her but he's quite reluctant and as I mentioned, we haven't started initiating insulin yet so he was one that we referred up to the hospital and he has his annual reviews at the hospital and so he is still reviewed up there. But he's had lots of issues, he's had lots of abscesses at injection sites and stuff so he has had lots of problems with it but really as I say, anything to do with that now he'll come and see me, he doesn't like the practice nurse. | CA |
| , I think she's very forceful in the sense that 'you're going to have a heart attack if you don't do this, so bloody well go and do it' and he'll go 'I'm not taking that from you', so I think it's a personality sort of thing. I think she's quite abrupt – well intentioned and she says the right things but I think her manner is quite abrupt and a number of patients in our practice sort of don't like her manner.[...] But he took particular exception to it and in a way, I mean she's quite surprised that he's done so well with his diabetes and controlled it so well because really she was getting nowhere with him. | EV |
| Yeah, so it was a complete different tack and, you know, he did come round to the idea and he's now very good at looking after himself. | RE |

| | |
|--|----------|
| I'm much less abrasive and abrupt than she is. | OR |
| Erm, I think it's just – it is really explaining to the patient, you know, I think there's all this thing about involving the patient in their own management | EV |
| and sometimes it's very funny because you try to do this, you say 'right, you've got this, these are the options, what do you think?' and they go 'you're the bloody doctor, you tell me!', 'OK then' but you think I'm trying to involve you | EV |
| but I think, as I say, sometimes if you go down the other route and you tell them what to do they're going 'hold on a second, I don't know if I want to do that' and they can become quite defensive. | EV |
| So I think it's judging the patient. I mean every patient is different and | AB |
| as I say, I walked in and saw this five minute consultation with the practice nurse going nowhere | CA |
| and I just thought right, I'm not dealing with this now because you're wound up because she's wound you up, | CA |
| so you come back and see me next week. I thought I'll just give you time to calm down, | RE |
| you can come back and see me and we can take a completely different tack with it and that's what I did. | RE |
| It [the next appointment] was quite long but I think he was really | OR |
| – it was sort of explaining to him and saying right, you know, you have this condition, it's something that's not going to go away so it is something you have to deal with | OR AB |
| and I said 'although you may feel fine now, you know, there are these other issues. There's all sorts of blood pressure, blah, blah, blah, you know, there's risks of these things, heart attacks, strokes, damage to your kidneys' and I said 'you know, giving you treatment now, OK it might bring your blood sugars down but it may not necessarily make you feel better now but it's really looking in the long term and saying if we do these things, if we treat your blood pressure and everything else, then your risk of heart attacks and strokes, if you look ten years down the line, is going to be less'. | OR |
| I mean again it was quite hard because there were lots of things, you know, he wasn't taking blood pressure tablets, he wasn't taking diabetic tablets | CA |
| so it was having to deal with them and saying 'right, there's lots of issues so what I'm not going to do is – you've got a list of five repeats here that you're not taking so I'm not going to say take all five of these now, we're going to start again', | EV |
| so I said 'we'll start at the beginning and –' and this is probably the thing of saying, you know, 'right, let's start your Metformin again' | EV |
| instead of saying 'now let's start your blood pressure treatment', you know, if you're going by what the proper studies are telling you. | EV |
| But yes, it was – and it was seeing him quite regularly and really sort of building up his confidence that things were going in a direction that he could manage. | RE |
| I think that rather just being stood against the wall and saying 'you will do this, that and | EV |

| | |
|---|----|
| the other' erm - maybe he said 'perhaps then I won't do any of it' - | |
| whereas doing it this way, you know, we have got him back on his diabetic medication, we have got him on his blood pressure medication, we have got him back on his statins and just doing it gradually like that and you know, within two or three months he was back on everything and well controlled so - at the time so -[...] | RE |
| Well, one thing [laughter] we both found out I think probably at that consultation that we both had an interest in classic cars, it really broke the ice [laughter] - so that was that sorted I think after that, he saw me as an ally - erm - the difference between these various classic kind [of buses] and Mercedes and he works in the motor industry so he was constantly going round the country. | OR |
| So every time that he comes in now we would have a sort of 5 or 10 minute chat about cars and then we would get onto his health issues - erm - and I think it was probably that first consultation - I can't remember how it came up but it was just one of those things I think that you sort of, | OR |
| you know, I was going to do the medical side of things and we touched on it, | EV |
| but mentioned that and that was it, he was just off - a different person and whether it was sort of showing an interest in him | RE |
| , you know, rather than just saying 'you have got your disease, I will treat it' sort of thing [...] I think it was perhaps taking an interest in him not just as a series of disease, not just as a person sitting in front of me, but sort of what he does and everything | AB |
| and obviously he was worrying about, you know, informing the DVLA about, you know, sort of his diabetes and stuff like that. | OR |
| So yes, it was a whole sort of raft of things, but err - I think that was probably what broke the ice after that - and he was quite happy to come and see me. | AB |

5.4.1.3 *Distal practice versus proximal person-centred care*

Vicky lamented the change in her role to be more distant from patient care. The narrative structural analysis of an opinion extract (Table 31) revealed overt feelings of regret and loss of the past proximity and holistic care she provided to patients as a younger doctor.

The narrative began with Vicky's opinion that patients used to be more dependent on GPs for health care decisions and that paternalism required more GP time than was available during short consultations.

Vicky compared her interest in palliative care, which involved one-to-one care over a shorter but undefined period, to diabetic care over many years. Palliative care patients were dependent, required family support, home visits, and deserved close and regular GP attention. She defined holistic care to involve family and psychological support but then identified the same needs in

diabetes. She was aware of the contradiction in her opinion that diabetes management would benefit from a holistic approach. She focused her argument on the lack of GP time for a similar proximal relationship with diabetic patients.

Vicky's tension was created by her feelings of loss of the joy she felt in her career many years before. She missed the continuous relationship with patients and their families, emphasising family dynamics and support structures. Home visits were enlightening, and knowledge of patient home situations informed her decisions, but they were no longer feasible due to lack of time and only appropriate for housebound patients. Vicky resolved her tension through palliative care work at her practice which restored satisfaction to her work.

Table 21 Vicky's tension – Distal GP

| | |
|---|----|
| As I say, that's not the way I er, I work now, whether I did before I can't remember, because, as you say, I – erm, we did have a much more dependent approach. But certainly in the last 20 years we haven't been working like that have we? | OR |
| We don't have the time to start to develop the paternalistic approach.[...] | CA |
| There are times when I think it's appropriate and develop some interesting palliative care – and then I think the close, one to one relationship is appropriate and is –[...] | EV |
| Yeah, is of a great benefit to the patient. I don't think that one to one relationship with a diabetic that requires me to see him literally just to check that they have lost a little bit of weight, I don't think that is ultimately of benefit to the patient.[...] | EV |
| Because we all move on. In the situation of palliative care that's slightly different because ultimately the patient moves on somewhere else and they no longer need you. But if you have helped them in that short time then that's good for them. | OR |
| But to be encouraging dependency in the – in an illness that's going to go on for years, that isn't healthy for them.[...] | CA |
| And it is not healthy for the GP either. [laugh] [...] | CA |
| I am not saying that you can do more for them, I think we are trying to do different things. | EV |
| You know, palliative care is about making sure that they are comfortable with er, their illnesses or their symptoms, in terms of psychology, that their family is comfortable with the psychology of it all – it is a much more holistic approach. | EV |
| There is a high holistic approach to the managing of diabetes too and we talked about families becoming involved, | EV |
| but with palliative care, as I say, there is a definite end point, erm – and whilst you want the holistic approach with diabetes, | CA |
| it is going to be 30 – 40 years potentially | OR |
| and you can't have that sort of intense one to one throughout that time. | CA |

| | |
|--|----------|
| I regret the fact that there isn't the time now to develop the relationship with whole families. | AB |
| The only time that we're able to do that is with the palliative care and so that's why I have moved into that for the latter stages of my career | EV |
| , because it's giving more joy and satisfaction, almost to go back to some aspects of general practice from my initial training, which were good.[...] | AB |
| When I was doing my certificate in palliative care, erm, working at the hospice for a week, I actually came to the – back to the practice completely re-enlightened about it all and saying 'it is just like general practice in the old days' – | OR |
| we had time to consider the whole family and we hardly do a home visits anymore because there just isn't the time and they are inappropriate.[...] | OR |
| It sounds like a contradiction, because on the one hand I am saying I'm glad that we moved away from paternalistic, but I think you can have a holistic approach without being paternalistic. | EV |
| I don't like it when the patient says 'well, you're the doctor, you tell me what to do'. So I am glad we have moved away from that, | EV |
| but there isn't the time to see the patient as a whole, which there was when I first trained.[...] | CA |
| Yes, so to be completely politically non-correct I actually enjoy home visits. [laugh] | EV |
| Because when you see, you know, how they're living at home it suddenly all makes sense, the sort of things that you're telling them to do in surgery are completely unrealistic.[...] | EV |
| Not telling them to do – suggesting that they do | EV CO |

5.4.2 Section summary

From the thematic findings, the GPs welcomed the move towards more collaboration between patients and health care professionals and the move away from paternalistic care (see section 7.2.6). However, to counter this, there was recognition of a change in the GP and patient relationship, most evident in chronic disease management because of the routine and regularised care by practice nurses. As generalists or diabetic leads, GPs saw patients attending for acute and urgent issues, and nurses managed diabetic routine care. The three GP narrative extracts were all distal to the diabetic patient and showed varied reactions. There was evidence of GP conflict between leading an efficient service distally and a feeling of loss from a GP because she was no longer personally delivering proximal, continuous and holistic care.

The other two GPs showed a contrasting business-like attitude towards service provision. The tension for all three GPs and made explicit by Charles was the need for service and organisational change that had occurred during his career from a more proximal to a distal role in diabetes care. Tension was created by these changes in service provision and workload management. The GPs were motivated to provide routine preventive care, meet CDM and QOF requirements, and delegated diabetic care to nursing staff. However, GPs were involved in proximal care when required. Contrasting Andy and Charles, Andy did not expect the nurse to change her behaviour to meet the patient's need for a more time-consuming, rapport building and person-centred approach. However, Charles' narrative and attitude indicated he expected the practice nurses to deliver empathic person-centred diabetic care while continuing his leadership and managerial role.

All three GPs had experienced the changed primary care services in the UK during their careers, and all were partners with interests in the business. However, Vicky's sense of loss of the proximal aspect of personal GP service provision indicated a different sense of satisfaction in their work that may not be generic across all GPs but deserves recognition as a positive feeling towards person-centred care, to be respected and potentially nurtured by education and policy makers if they want to see more PCC care from GPs in the primary care setting.

Further to this distal and proximal behaviour shown by the GPs there was also indication of shifting from person-centred proximal care to the distal less person-centred care and sometimes paternalistic care.

5.5 Person-centred versus doctor-centred: positions and shifts

Chapter five has shown the narrative structural analysis of the textual accounts from the co-produced interviews between GP participants and insider GP. Although not all the GPs are presented in this chapter, accounts have been chosen that generate tension and indicate potential for deeper insight into the GPs experience of PCC when deciding patient care. Some textual accounts focus on other aspects of patient care delivery, such as prescribing new medications and the role of the proximal GP in CDM delivery. It is significant the GPs co-produced the interviews and also directed the insider GP towards topics they valued. As result, the analysis also generated honest accounts of persisting and unresolved tensions, and significant negative doctor-centred attitude of biomedically led blame towards patients.

This shifting to doctor-centredness is a significant finding. This shifting and occurs at times of challenge to their biomedical beliefs, but also seems to occur at frustration and having to fulfil service delivery roles, and delegation of proximal care to nurses. At these times, GPs are positioned in their doctor-centred leadership role and even in scenarios that describe patients and their care, appear doctor-centred, biomedical, and paternalistic.

The following table summarises the thematic derived tensions that were narratively analysed. The columns present the individual GPs, the tension in the narrative extract, the abstract of the narrative, the previous stance of the GP (either from thematic analysis or from the previous narrative SA) and the shift from PC to Dc or vice versa. The previous stance in this table (column 4) is the generated stance from the reflexive thematic analysis, or if the GP has been part of a narrative analysis in the earlier section, then the last narrative structural analysis PC/DC approach or stance.

Table summarising the narrative structural analysis of the thematic tensions.

| GP | Thematic tension | Narrative topic/AB | Previous PC/DC position/approach/stance | SHIFT TO after the Narrative structural analysis. |
|---|--|---|---|---|
| Patient Lack of engagement (of self-determining patients) | | | | |
| Harry | Lack of engagement (LoE) (of self-determining patients), frustration | CDM delivery- “[...] <i>accept the diabetic management [...] still remains, um, below par. [...]</i> ” | DC- thematically generated- Patient Lack of engagement, feelings: frustration, GP leader, Blame | No shift. DC |
| Jen | Lack of engagement (of self-determining patients), frustration | CDM delivery- [...] <i>I don't have any problems selling it {biomedical advice} to them really [...]</i> ” | PC: empathy, trust, positive patient-GP relationships | DC- biomedical doctor, feelings: frustration, |
| Charles | Lack of engagement (of self-determining patients) | CDM delivery- duty to recall and counsel the patient to self-care | DC- thematically generated, GP lead, Business of GP | No shift. DC |
| Lack of engagement (of self-determining patients): Memorable patient | | | | |
| Cath | Lack of engagement (of self-determining patients), frustration, guilt, sadness | Memorable patient: “[...] <i>it's the patient's responsibility [...]</i> ” | PC: empathy, trust, positive patient-GP relationships. | PC to DC- blame, feelings: guilt, frustration |

| | | | | |
|---|--|--|--|--|
| Mike | Lack of engagement (of self-determining patients): Memorable patient; frustration, guilt, sadness | Memorable patient: “[...] <i>do patients understand? [...]</i> ” | DC- thematically generated, GP lead, Business of GP; insulin as failure and blame. | DC- thematically generated, GP lead, Business of GP; DC- blame, feelings: guilt, frustration |
| Jen | Lack of engagement (of self-determining patients): Memorable patient; frustration, guilt, sadness | Memorable patient: “[...] <i>overwhelming and just like nihilistic, not going to do anything.</i> ” | From CDM delivery Narrative analysis: DC- biomedical doctor, feelings: frustration: narratively derived | DC to DC- blame, feelings: guilt, frustration, sadness. |
| Patient transition: disengaged to engaged: memorable patient. | | | | |
| Alice | Self-determining patient engagement, depression and diabetes, lack of engagement | Memorable patient: “[...] <i>to get him to face up to the diabetes we had to treat the depression [...] it's just really how you approach people {MORAL} [...]</i> ” | PC: empathy, trust, positive patient-GP relationships | No shift; PC: empathy, trust, positive patient-GP relationships |
| Dan | Self-determining patient engagement, depression and diabetes, lack of engagement | Memorable patient: “ <i>if you do try and, sort of, impose stuff upon them, um, they will find opportunities to disagree with what you've done [...]</i> ” Dan's MORAL | DC: diabetic lead, business of GP, the problems solver. | Shift: PC: empathy, trust, positive patient-GP relationships |
| Cautious prescribing or 'pharma-sceptic' stance | | | | |
| Alice | Person-centred GP prescriber, prescribing for the person; and elderly, insulin prescribing for the person, GP duties: duty of care | Memorable patient: “[...] <i>You wouldn't want to put her at risk of going hypo in the night on her own. [...]</i> ” | PC: empathy, trust, positive patient-GP relationships; prescribing for the person. | Shift: DC: duty of care, driven by a fear of harm; insulin as 'strong' medicine. |
| Mike | GP duties: duty of care, GP use of new drugs. | GP use of new medications: “[...] <i>I'm very conservative, very wary of using new drugs.</i> ” | DC- thematically generated, GP lead, Business of GP; insulin as failure and blame. | No shift DC: duty of care |
| insulin as a failure | | | | |

| | | | | |
|-------------------|---|--|---|---|
| Andy | Lack of engagement (LoE) (of self-determining patients), frustration | Memorable patient: “ <i>[...]because of the complications he was starting to get, to refer him on [...]</i> ” | DC: diabetic lead, business of GP, the problems solver, [Was PC, involving patients in care, patient as a person (from thematic analysis).] | No shift DC: blaming |
| Dan | Insulin as failure: tension | Reflection and opinion: “ <i>[...] although I will initiate it, I do so with a sense of failure that it’s,[...]</i> ” | PC: empathy, trust, positive patient-GP relationships | Shift: DC: diabetic lead, business of GP, the problems solver, blame. |
| Distal practice | | | | |
| Charles: Table 29 | Distal and leadership attitude: business of GP and organisational change | Reflection and opinion: “ <i>[...] cost of this sort of work, this preventative work globally is actually much more than a few hours of a practice nurse’s time [...]</i> .” | DC- thematically generated, GP lead, Business of GP, instrumentality | No shift : DC; GP lead, Business of GP, instrumentality. |
| Andy | Distal practice and proximal problem-solving: Lack of engagement (LoE) (of self-determining patients), business of GP, duty of care, instrumentality (delegation to the nurse) | Memorable patient and nurse delegation: “ <i>[...]So I think it’s judging the patient. I mean every patient is different and [...]sort of explaining to him[...]really sort of building up his confidence that things were going in a direction that he could manage [...]</i> ” | DC: diabetic lead, business of GP, the problems solver, | Shift from DC to PC: GP becomes proximal in patient CDM care, involving patients in care, patient as a person. In the narrative, the GP comes across as collaborative/ in partnership with the patient. |
| Vicky | Distal practice versus proximal person-centred care: GP reflection | “, because it’s giving more joy and satisfaction, almost to go back to some aspects of general practice from my initial training, | DC: diabetic lead, business of GP, the problems solver (thematically) | PC: empathic, GP feelings, |

| | | | | |
|--|--|------------------------|--|--|
| | | which were good.[...]" | | |
|--|--|------------------------|--|--|

5.6 Summary of the narrative analysis of tensions

The thematically derived tensions were analysed with an alternative narrative structural analysis method and the results explained GP attitudes and memorable patient encounters through a different lens of qualitative research. It is argued that GPs were constructed in richer and multifaceted ways.

The reflexive thematically derived tension themes were taken back to the level of the textual interview data and constructed as narrative structures. Narrative structural analysis interpretation thereby also generated GPs as cautious prescribers, viewing insulin as failure, blaming patients for their lack of engagement, and explained at times, frustrated negative relationships with patients. GPs expressed frustration, sadness and guilt when patients failed to engaged and developed health issues or deterioration. Guilt was associated with expressed and implicit feelings of whether more could be done, and on reflection, if other care providers had found similar experience with the patient, the feelings were partly resolved: the lack of engagement was an issue of the patient. However, there remained uncomfortable tensions that remained unresolved, and potential for ongoing healthcare professional stress and overwhelm. When resolution to patient lack of engagement was found, it was in situations where patients had changed from unengaged to engaged, and through narrative exploration, indication that this was a patient choice: when they were ready.

There were also three different ways that the distal GP may manifest and create different attitudinal stances towards patients; the distal leadership stance, the proximal problem solver, and proximal patient care stance in different related or unrelated acute or chronic disease.

T2DM care and the related chronic disease management and monitoring, as well as insulin initiation when it was planned, was delegated to practice nurses. Instrumentality, which is the use of an agent or entity as a means to an end, was evident towards nurses, but also towards

insulin initiation itself: it was an extra service provision worth doing if it delivered a benefit of an additional income and adequately resourced.

Additionally, the arguably richer contextual accounts showed how narrative structural analysis may provide an alternative qualitative and subjective way to analyse the accounts of reflective clinical practitioners.

However, the contrasting positive and negative patient-GP relationships indicated how PCC approaches may be fostered differently by GPs in positive and negative ways. Perhaps reflective practice and education could influence those with negative attitudes.

Significantly, GPs have been constructed in person-centred (PC) and doctor-centred (DC) ways and found to be in particular stances on a case-by-case basis. This shifting occurs at times of biomedical challenge, frustration, and delegation of proximal chronic disease management (CDM) care to nurses. At these times, GPs may be positioned in their doctor-centred leadership role and even in scenarios that describe patients and their care, GPs appear doctor-centred, biomedical, and paternalistic. This shifting between PC and DC may provide an alternative way GPs may consider and reflect on their practice with an aim to provide better person-centred care.

6 Discussion

6.1 Introduction

This final chapter will provide discussion and summary of the thesis, and further reflections on the findings with reference to the initial thesis literature review. The analysis findings did mention the empirical literature and reflect from thematic findings and narrative interpretations to consider how the wider literature contextualised such knowledge and aligns this work to qualitative methods of reporting analysis (Braun and Clarke, 2022).

There will be first a reminder of chapter one's surmise of PCC, PtCC and WPC, and subsequent empirical literature review, iterative change to the thesis research questions journey, there will be an initial reminder of key literature review findings, and the subsequent research data analysis before discussion.

A fragmented approach to multimorbidity and chronic disease patient care with single disease research, healthcare delivery, and professional education has led to unmet patient needs and poorer outcomes (Barnett et al. 2012; Witty et al., 2020). T2DM represents a multimorbid condition with prevalence and arguably representative a common condition in general practice the represents a 'cluster' (Whitty, 2020) of diseases. As such, it is arguably a key chronic disease to understand primary care PCC approaches to patient care, and despite its high prevalence, and arguably common research investigation. However, the literature review confirmed persisting negative PCC clinician attitudes, patient complaints of unmet needs (Mathew et al., 2022; Abdulhadi et al., 2007) and disease-centred clinician focus (BurrIDGE et al., 2017).

This thesis introduced current approaches to person-centred care (PCC) as identified in the literature and recommendations from authoritative guidance. PCC is a recognised approach to patient care and not a formulaic method of delivery. The evolving nature of PCC, the nature of PCC as an 'approach' and the lack of a clear agreed definition across the academic literature has been argued to make PCC delivery difficult to operationalise in practice and problematic for healthcare professionals (Entwistle and Watt, 2013b; Hakansson Eklund et al., 2019).

Moreover, whole person care (WPC), patient centred care (PtCC) and PCC have been explained in chapter one to be used differently and interchangeably in the literature (Thomas et al., 2018; Entwistle and Watt, 2013b; Hakansson Eklund et al., 2019) However, all three approaches (PCC, PtCC and WPC) acknowledge individuality and personhood. However, the various approaches to PCC and PtCC relied on key components that have been summarised in chapter one in table 4, and provide various approaches to person-centred care. When reviewing the empirical research, each paper may have conceived PCC, PtCC or WPC care differently (Thomas et al., 2018; Entwistle and Watt, 2013b; Hakansson Eklund et al., 2019).

Consequently, this thesis acknowledges and utilises the concept of personhood and individuality as core to PtCC, PCC and WPC to view the literature, guidance and also, the interview data. WPC also emphasises the multifaceted delivery WPC in terms of biopsychosocial, whole person and medicalised ‘holism’ constructs. So, the empirical research and other review or guidance papers were reviewed bearing in mind the possible interchangeability in meaning by authors. By seeking the principles of personhood and individuality as key concepts, and resemblance to identified approaches to PCC thesis has aimed to seek a consistent approach to the empirical research and during analysis and interpretation of the interview data.

The subsequent literature review aimed to seek what was presented by the empirical research on the person-centeredness of GPs in the primary care chronic disease management. The systematic search and review, screen 242 papers at abstract, and found 49 papers were reviewed and critically appraised at full paper level.

These papers that related positive feedback from patients, and positive attitudes towards delivery PCC from clinicians, but there was ongoing evidence of unmet needs of patients and clinicians’ disease-centred (or biomedical) resistant attitudes.

Internationally, the papers investigating PCC delivery, and interventional changes, emphasised the importance of the patient-provider relationship and the principles of trust, autonomy, and medical ‘holism’ (in the medical sense as opposed to alternative therapies). The papers reported doctor-centred themes related to PCC delivery: skills, knowledge and experience, health system factors, and the perceived adherence to medication or medical recommendations. Patient or person-centred barriers to PCC delivery related to barriers to patient self-care and

patient fear. There also were papers investigating the effectiveness of person-centred approaches to PCC delivery seeking feedback from the perspective of patients or clinicians.

In summary, according to the empirical literature, PCC is not commonly provided, interventions may or may not improve patient satisfaction, do not improve measurable outcomes, and doctors, patients, and the system continue to act as barriers.

Clinician perspectives also showed positive attitudes toward delivering PCC in practise, but disease-centredness and doctor-centredness were present. These patient and provider perspectives on PCC in chronic disease management emphasise patient-physician relationships, trust, autonomy, and holism. However, negative PCC clinician attitudes persist across the literature in various forms: poor physician communication skills may imply a lack of respect to patients (Abdulhadi *et al.*, 2007); possible judgemental attitudes of clinicians and patient fear of blame which may or may not be related (Mathew *et al.*, 2022); and disease-centred focus that may be a barrier to patient engagement (BurrIDGE *et al.*, 2017).

Semi-structured interviews with 16 GPs based in South Yorkshire UK were performed in the ‘travelling style’ as explained by Kvale (2005) and the resultant audio-recorded and professionally transcribed interviews were analysed thematically and narratively.

As a reminder of the key methods, GPs described and reflected upon their experiences when managing diabetic patients using exploratory semi-structured interviews analysed through reflexive thematic and narrative structural analysis methods. Analysis generated person- and doctor-centred perspectives of patients and patient care in T2DM when considering insulin initiation in T2DM. T2DM presented as an example of a chronic disease in the primary care setting, whilst insulin initiation was a decisional point in diabetes care through which to explore a person-centred decision. The qualitative research was underpinned by a critical realist ontological perspective, and constructionist episteme. Reflexive thematic analysis method followed the principles of Braun and Clarke, and subsequent narrative structural analysis followed methods outlined by Riessman and exemplified by Robichaux (Robichaux, 2002; Riessman, 2008).

Efforts to motivate patients to engage were described and the involved biomedical explanations of disease and health deterioration as a consequence of continuing poor compliance with either diet, lifestyle or medication. These threat explanations- that were dramatic at times (e.g. Harry in section 4.9.3 Insulin as failure), and insulin as failure, created negative blaming GP stances which may pose barriers to PCC approaches and were potential for reflection and change.

Negative relationships were also evident in the form of paternalism towards patients of low SED and possible lack of GP awareness of differing patient care because of the 'lower expectations' of this group. The result confirms the literature that reports lower SED groups complain of unmet needs and even less 'talk-time' in appointments (Houle et al., 2012). It is significant that reflective practitioners may need to be aware of this self-reported attitude and behaviour and may improve PCC care for lower SED amongst the local South Yorkshire population.

The distal and delegating GP was also evident across the GPs, there was evidence of differing attitudinal stances, and was another activity displaying instrumentality, with the use of nurses as a means to an end. However, positive framing of nurse relationships was evident and GPs valued the support to patient care. Thematic and narrative analysis from one GP indicated breakdown of a nurse-patient relationship, triggering the GP to plan proximal care, and may indicate that nurses may also experience similar person-centred patient negative relationships that may also be aided by similar reflective practice

6.2 The findings in relation to the literature review

The findings support the literature that show tensions between the biomedical or disease-centred clinician beliefs and patients dis-engagement with care. The subsequent discussion will unify the already identified findings.

6.2.1 Biomedical constructions in person-centred contexts

The reflexive thematic analysis generated person-centred themes and argued for the framing of biomedical care within the context of person-centred when biomedical decisions, such as prescribing, have been explained clinicians within the context of the person. That means that personhood and individuality has been respected within the context of the persons autonomy,

individuality, and psycho-social context. Where collaborative or evidence of alignment was explained or interpreted to be present, this was acknowledged also. Such collaborative thinking fits in with PCC approaches such as the Gothenburg principles where collaboration and respect for the individual's narrative or life history is key the PCC approach (Britten et al., 2017). From the thematic perspective this was particular the evident when elderly patients were considered and confirms the literature which recognise clinician anxiety over the risk of hypoglycaemia and the biomedical fears for 'harm' (Haque et al., 2005; Ratanwongsa et al., 2012; and Ngassa Piotie et al., 2021).

6.2.2 Mindlines

GPs did explain using evidence to explain utilising guidance and aiming to use guidelines rather than latest evidence to direct their knowledge. Whilst the latest research evidence was not useful, GPs appeared to take a 'mindlines' approach, as mindset of reliance on local and national guidelines as "*collectively reinforced, internalised tacit guidelines*" (Gabbay and May, 2004). Similarly atypical constructions of patients that did not fit the typical diabetic patient profile caused GPs to question diagnoses and therapy and indicated another type of mindlines or aide-memoire. In a normative sense, as an insider GP reflecting of biomedical training with classification and typical presentations, such mindsets or mindlines are a recognisable part of practice, especially when sharing knowledge or reflecting on patients with colleagues.

6.2.3 Person-centred prescribing

As another biomedical construct of patient, when prescribing took account of the patient it appeared person-centred when analysed thematically. However, narrative structural analysis review of prescribing related tension themes of insulin showed the benefit of researching a insulin initiation as a difficult decision when placed on the person-centred context for some patients. For example, Alice in particular presented a n empathic and PC GP, who took into account her patients' narratives. However, her narrative and taking account her recurrent thread in the narrative of her personal history of T1DM and insulin use, Alice was arguably projecting her biomedical and doctor-centred worry about the risks of insulin onto decisions for her patients. As a very different form of 'internal mindline', Alice was shifted from

person-centred to arguably doctor-centred or even ‘personal-clinician-centred’ and influenced the patient.

However, this shifting does not undermine the person-centred theme of prescribing for the person but is a reminder that reflective practice is required to apply the theme to a clinician’s attitudinal stance.

There was also evidence of tensions created at times of biomedical prescribing, when GPs themselves worried about medications, the risk of harm and prescribing to patients. This applied to insulin, but also to new medications that became available for diabetic management. The indication was that chronic disease management required PCC and sharing of information to decide the use of such medication, but GPs were not sharing decisions of risk of new medications with patients, moreover, there were accounts across the doctors of the negative experiences of medications for diabetic management (Roziglitazone was specifically named across the group) that later was withdrawn. The cautious prescribing theme generated a **‘pharma-sceptic’ stance of GPs**. The cautious prescribing theme resulted in GPs taking a ‘pharma-sceptic’ stance, which was doctor-centred and not shared with patients. The GPs’ caution was implicitly related to a fear of patient harm and a duty of care that they could not share with patients.

6.2.4 Depression and diabetes

Depression and diabetes was a particular theme where GPs appeared aware and recognised the interplay between depression and diabetes. there was opinion and memorable patient recall from different GPs where the biological status of diabetes was contextualised in the mental health issue, and life context of the patient. Reflexively this was an unsurprising finding and reinforces the literature that clinicians self-report empathic beliefs in such situations (Fagerli et al. 2015).

However, significantly, when significant patient mental health issues were set against the biomedical agenda of the GPs, there was evidence of doctor-centred treat to the biomedical stance without collaboration or sharing information with patients, and indication of paternalism. As an insider GP the narrative from Mike appeared initially appropriate and safe practice. However, even Sally, through delegation to the nurse reported no sharing of risks. Jen shifted from an empathic GP to doctor-centred reactive complaining about resources use for a

man she believed was depressed but was too demanding of community services for his insulin delivery. The subjectivity of these interpretations is relevant and appropriate for outsider readers to recognise, and another medical or non-medical researcher will view the analyses differently.

However, the doctor-centred attitudes have been generated in this data and confirm the literature review that patients prioritise their mental health over their physical health (Kristensen et al., 2018a), and physicians prioritise mental health over physical health when it is significant or severe (Trachtenberg et al., 2014).

6.2.5 Patient-GP relationships

This theme was generated from the perspective of GPs and so requires a critical stance with considering if GPs do have positive relationships with patients. This may be ironic and lack credibility when the insider GP is reflexively analysing the data too. However, there were positive reports and accounts of patient -GP relationships, and most evident in narrative SA accounts from doctors like Alice and Dan. This confirms empirical research that does report positive patient survey reports of positive relationships with their GPs (Millar et al., 2018).

Involving patients in care was also described in various positive ways, that could be argued to be self-reported GP person-centred approaches: sharing information with patients and explaining disease in aligning ways, but these were limited, and this thesis cannot confirm GPs are involving patients in PCC care and is limited by the research design. For example, interactional research with video-consultation or comparison of patient and doctor survey may better inform on involvement and was reported in the literature (Trachtenberg *et al.*, 2014; Wiley *et al.*, 2015).

However, the doctor-centred themes show negative attitudes that are arguably barriers to individual GP delivery of PCC approaches. Paternalism towards the low SED groups has already been mentioned.

The **distal GP** has been discussed in the narrative section and exemplifies GPs own wishes to be proximal and fulfil the patient-provider relationship positively. Reflexively, this distal relationship is commonplace in the region I work in, with fewer GPs available and high demand

for GP appointments. If more individualised care for chronic disease and ‘clusters’ of disease require more clinician time, these distal relationships may pose problems.

Another negative related to **paternalism attitudes** expressed explicitly about low SED populations (section 4.6.2.7). It is ironic that an insider GP may expose such attitudes when analyses GP co-produced interviews, and reflexively, I did not recognise the issue in early coding and theme development. However, the finding confirms the literature that has shown The paternalistic provider relationship with patients of low SED may be a barrier to PCC care for low SED patients (Houle *et al.*, 2012; de Figueiredo, Snoek and Barreto, 2013; Rutten *et al.*, 2018). Houle *et al.* specifically reported low SED groups with complained about ‘less talk-time’ in appointments (Houle *et al.*, 2012). If paternalism is a factor, then education of clinicians in PCC approaches, and improving self-awareness of such attitudes may improve PCC delivery at the individual level.

6.2.6 Instrumentality

This thesis has argued that the GPs appear to behave in instrumental ways to achieve their biomedical agenda or business need. Obvious examples are the delegation of CDM and chronic diabetic care to nurses. The result is a distal position of the GP with resultant generation of the ‘problem-solving GP’ stance.

The infrequent presentation of patients requiring insulin initiation in T2DM influenced GPs to not plan the service provision and was another manifestation of the instrumentality of GPs towards an entity: this time the service provision and small group of patients that may require it. Of the three GPs that were delivering it, the service provision was designed in an instrumental way with specific nursing resource planning and even limiting the type of insulin used. The instrumentality finding is generated by the insider GP and able to see the business argument and attempting to be critical. However, with research supervision from a non-medical social research expert aiding this criticality, providing external eye to the analysis, and the theme is argued to be credible and significant to address as part of reflective practitioner practice.

The infrequent presentation of insulin may be an issue that appears to be an unrecognised barrier to insulin initiation. The lack of initiation of insulin in T2DM across the GPs was evident and a commonality across nearly all the GPs was that T2DM patients infrequently

required insulin initiations, so delivery of the service in the practice setting would use staff and appointment resources that was not adequately funded. This finding supports the complaints by Canadian doctors that an intervention to improve chronic disease management in practice was difficult to implement within the systems of care (Russell et al., 2008).

Most significantly, chapter one identified the multiplicity of ways that PCC or words and approaches and may cause GPs to interpret them in confused or incorrect ways. Entwistle et al. argue if PCC is developed as a process, or criteria-based process, then the PCC approach and effectiveness is lost. This devaluing of PCC becomes a strategy and compared to biomedical processes, such as interventions to improve measurable outcomes like HbA1C (Entwistle and Watt, 2013b).

Furthermore, if GPs believed that PCC is only suitable when there are favourable consequences, such as improved health care outcomes, it might be argued that they are only considering person-centredness in an instrumental way.

6.2.7 The Shifting GP PC/DC stance

Finally, the finding that GPs do place themselves in doctor or person-centred stances, in self-awareness (e.g. Fiona describing low SED patients), without awareness or in reactionary ways (e.g. Harry's explicit negativity about patient lack of engagement), is confirmatory to the empirical literature. However, the particular finding that GPs can shift, and even the most empathic GPs may be shift from PC to DC or vice versa may be a new contribution and add to the field of understanding reflection practitioners.

This research began with interviews with 16 GP that were in the ‘travelling’ style and explored the GPs approaches to insulin initiation in T2DM in the primary care setting. The audio-recorded and transcribed interview data was analysed from two different qualitative approaches: reflexive thematic analysis and then a narrative structural analysis. The two different lenses of the qualitative approaches have been argued to be a complementary form in terms of critical realism ontology and constructionist epistemology. The outcome from such combined use is a form of triangulation or crystallisation of the data.

Reflexive thematic analysis found GPs were at times person-centred in their self-reported patient encounters and reflective practitioners. Positive patient relationships involved viewing patients as persons, empathy, and trust, and collaborating to deliver patient care. Patient centred themes included the biomedical construction of the patient within the person-centred context. Reviewing the coding and themes allowed an alternative framing of biomedical themes. When GPs considered the patient biomedical needs in the context of the person, the GPs were constructed as being person-centred in their approach. GPs took account of the multimorbidity or cluster of diseases that patients may live with, and there was report of engagement with patients to manage T2DM and associated chronic diseases in positive PCC approaches.

However, doctor- centred attitudes and memorable patient encounters generated themes of negative perceptions of patients and doctor-centred attitudes. As may be expected, this was commonly at times of oppositional attitudes between patients and doctors towards biomedical care and recommendations.

This discussion will review the analytic thematic and narratively derived findings and reflect back on more of the literature review on person-centred care of chronic disease in the primary care setting.

The findings began on a reflexive TA journey to seek GP approaches to person-centred care in T2DM when considering insulin initiation in T2DM. GPs were found to be at times to be person-centred in their self-reported patient encounters and reflective practitioners. Positive patient relationships involved viewing patients as persons, empathy, and trust.

Patient centred themes included the biomedical construction of the patient within the person-centred context. Reviewing the coding and themes from the person-centred perspective allowed an alternative framing of GPs biomedical constructions of patients. When GPs considered the patients' biomedical needs in the context of the person, the GPs accounts were constructed as person-centred in their approach.

However, doctor-centred attitudes and memorable patient encounters generated themes of negative perceptions of patients and doctor-centred attitudes. As may be expected, this was commonly at times of oppositional attitudes between patients and doctors towards biomedical care and recommendations. When patients were perceived to have failed to engage with therapy as a population or individuals (when reflecting on memorable patients), GPs showed discomfort, frustration and even anger, indicating tensions. Themes of threat explanations- that were dramatic at times (e.g. Harry in section 4.9.3 Insulin as failure), and insulin as failure, created negative blaming GP stances which showed barriers to PCC approaches and potential for reflection and change. The findings confirm literature that report clinician motivation of patients early in disease can amount to threat explanations and result in negative patient self-blame (Peyrot et al., 2006).

Negative relationships were also evident in the form of paternalism towards patients of low SED and possible lack of GP awareness of differing patient care because of the 'lower expectations' of this group. The result confirms the literature that reports lower SED groups complain of unmet needs and even less 'talk-time' in appointments (Houle et al., 2012). Reflective practitioners may need to be aware of such self-reported attitude and behaviour toward low SED populations, and through reflective practice, try to improve PCC care.

The infrequency of patients requiring insulin initiation in T2DM influenced GPs not to plan service provision.

Of the three GPs that were delivering it, the service provision was designed in an instrumental way with specific nursing resource planning and even limiting the type of insulin used.

The distal and delegating GP was also evident across the GPs, there was evidence of differing attitudinal stances, and was another activity displaying instrumentality, with the use of nurses as a means to an end. However, positive framing of nurse relationships was evident and GPs valued the support to patient care. Thematic and narrative analysis from one GP indicated breakdown of a nurse-patient relationship, triggering the GP to plan proximal care, and may indicate that nurses may also experience similar person-centred patient negative relationships that may also be aided by similar reflective practice.

There was also evidence of tensions created at times of biomedical prescribing, when GPs themselves worried about medications, the risk of harm and prescribing to patients. This applied to insulin, but also to new medications that became available for diabetic management. The indication was that chronic disease management required PCC and sharing of information to decide the use of such medication, but GPs were not sharing decisions of risk of new medications with patients, moreover, there were accounts across the doctors of the negative experiences of medications for diabetic management (Rosiglitazone was specifically named across the group) that later was withdrawn. The cautious prescribing theme generated a 'pharma-sceptic' stance of GPs. The cautious prescribing theme resulted in GPs taking a 'pharma-sceptic' stance, which was doctor-centred and not shared with patients. The GPs' caution was implicitly related to a fear of patient harm and a duty of care that they could not share with patients.

Significantly, the GPs were constructed in person-centred and doctor centred stances through reflection on the thematic findings. The narrative accounts further constructed the GPs as shifting from PC to DC and vice versa. This seemed to occur for even the more PC GPs such as Dan and Alice and signifies case by case shifting towards and away from a person-centred stance. The implication is that the person-centredness may improve, or worsen dependent on the scenario, and the GP negative attitude associated, which in turn has implications for reflective practice.

7 Limitations

This chapter will review the trustworthiness criteria applied to assess the quality and generalisability of the research findings. The limitations of the thesis will be discussed in further detail after, including the changed RQ to transcend the biomedical bias of the initial research design and expose as much of the insider GP bias as possible.

7.1 Trustworthiness review

Previously, the methods section 3.3.6 discussed and explained the trustworthiness from the perspective of qualitative research. Transferability was discussed and different possible views of ways of considering trustworthiness and so the concepts of generalisability. This thesis had considered the possibility of flexible generalisability that has been used for combined discourse analysis and reflexive TA methods. Even though there has been research to use these methods under the ontology of critical realism and constructionist episteme (Goodman 2008; Braun and Terry, 2016), the fragmented approach to language in discourse moves away from aim to consider the ‘whole’ account narrative in the NA structural analysis used in this thesis (Riessman, 2008).

Consequently, overall, the thesis accepts the concepts of transferability to apply to this research and has tried to apply the quality criteria checklist developed by Braun and Clarke to apply a standard and review the work.

Whilst this thesis will not claim a positivist generalisability, the data may be transferable, and the thesis attempts to show consistency and dependency in methods and findings. The following table explains the criteria and the methods used in the thesis to meet the criteria.

Table of quality criteria now updated as explained in section 3.3.6, as a 15-point checklist by Braun and Clark (at p269 of Braun and Clarke, 2022).

| Process | Criteria | Methods in this thesis |
|---------------|--|---|
| Transcription | Transcription of the data in appropriate detail, and checked against the original recordings | The use of experienced transcribing specialist services that contractually adhered to the University’s assigned ethical and governance processes. Immersion in the data through listening and |

| | | |
|------------------------------|---|--|
| | | reading transcripts for analysis also quality checked transcribed data. |
| Coding and theme development | Each case has been thoroughly and repeatedly examined. | Repeated iterations of codes that were kept as separate journals. |
| | Coding as a “ <i>thorough, inclusive and comprehensive process</i> ”, and themes are not superficial or anecdotal (Nowell et al., 2017; Braun and Clarke, 2022) | Iterations display in this thesis; review during analysis with supervisor for consistency, dept and relevance of themes. Attempts have been made to remain inductive as possible and themes generated through the researcher interpretation- albeit influenced by the insider GPs sensitising concepts. Any superficial and descriptive themes have been evaluated, and where themes may appear as topic topic summaries- they have been considered from the subthemes coded to reviewed or changed- ch 4. |
| | All coded extracts for themes are categorised and collected. | Audit trail with NVivo and iteration display in this thesis. |
| | Themes checked again back to the original codes and dataset. | Audit trail with NVivo and iteration display in this thesis |
| | Internal coherence, distinctiveness and consistency of themes, with a central organising concept. | Review with supervisors when themes were developed at hierarchical stages. The themes have been defined within the written report of the analysis. |
| Analysis and interpretation | Data has been analysed and interpreted, not described. | Evident from the interpretations in the written report before and after the quotes, discussion of the interpretation and relation to the literature within the thematic analysis findings chapter. |
| | The reported analysis and quotes coherently match eachother | Reviewed by supervisor over years of thesis review, reviewed with eh Language tutor in the last 4 weeks also. |
| | Analysis is convincing as an organised story of the data and research topic. | The thesis has made attempt to show the thematically analysed findings have been elevated to show the transition from tensions to the final selected positions. Following this, the reflection on the literature to consider the implications for GP practice, reflective practice and the engagement of GPs in the work of person-centred care. |
| | A balance between the analytical report and the quotes provided. | Yes, the degree of quotes and analysis can vary, and this thesis has chosen a lower percentage than the 50/50 mentioned for sociology papers (Braun and Clarke, 2022). Discussion with the supervisors also recommending reducing quote length for the TA process, rather |

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| | | than increasing for healthcare research. |
| Overall | Time and attention applied to the analysis process. | Immersion, TA analysis and NA structural analysis in the past, review of the TA data back to the level of phase 2 of the TA process. |
| Written report | The theoretical positions and assumptions are explicitly written | Chapter 3 |
| | Consistency between the method and the reported analysis findings | Yes, reported constructionist episteme to generate the findings , shown with maps of codes to themes, and appendix pictures of the NVivo coding names in the early stages, at initial more descriptive level, then at the point of further review and iteration of the newly worked RQ. |
| | The report language and concepts match analysis ontological positions. | Constructionist approach and language used throughout, data has been generated, not emergent (Braun and Clark, 2022 The theme concepts have been inductive on the whole, and deductive reasoning for findings data has been made explicit where possible trying to make the prior concepts explicit and referencing the empirical or literature influencing the deduction where possible- such as the theme of 'infrequent presentations'. |
| | The researcher is active in the research process, generating the data. | There have been numerous attempts to show reflexive interpretation in the analysis report for TA and narrative SA. The insider sensitising concepts have been made explicit and further reflection made at the point of consideration of the limitations and the insider GP journey (Kvale, 2007), the travelling style of interview and attempt to emulate the respective reflexive TA processes as per Braun and Clarke and NA structural analysis as per Riessman and Robichaux (Robichaux and Clarke, 2006; Riessman, 2008a, 2015). |

7.2 Limitations

The strengths of this research lie in the use of narrative to expose the complexity and tensions involved in diabetic care. The detailed accounts provide rich descriptions of GP experiences analysed using a narrative structural analysis method. This method applied to expert narratives of generalists is novel. It shows potential for understanding person-centred encounters in other settings from the doctor, nurse, other HCP, or patient perspective.

Despite the time-lapse discussed below, these experiences provide transferable and enduring images, feelings and a sense of commonality for other GPs reading this that, and arguably, will not have changed. The planned reflexivity was another strength, and the insider GP is arguably a greater strength than limitation (section 9.13.4).

Several limitations are recognised in this research and are explained in this section. Firstly, as will be expected of qualitative work, other GPs may identify with the findings, and they may transfer to other family practitioners' settings across the world. However, the findings are not generalisable in the quantitative sense and will not represent the wider national and international GP community. Also, the GPs were recruited from a local region of South Yorkshire and so reflected specific regional GPs with a demographic providing a similar NHS primary care health service in the area. No private GPs were involved, which will be relevant internationally with different healthcare systems. The following sections discuss specific and relevant limitations.

7.2.1 Sampling

The GPs were recruited through a purposive and snowballing technique. Although successful in recruiting sixteen GPs, snowballing does have limitations. The sample aimed to be diverse, but it is intrinsic to snowballing techniques that the method cannot ensure sample diversity because interesting and relevant participants may network differently from the sample recruited. (Kirchherr and Charles, 2018). Diversity was successful to a certain extent and was displayed in the demographic data in chapter 4. The GPs had varied training, age, gender, two

GPs with diabetes, some actively initiating insulin, those recently planning the service and those not interested. The local GP network may have limited the variety of the GPs contacted, so snowball sampling of later contacts may have missed further potential diversity.

The research design had a developed question at the outset to understand insulin initiation, and so the biomedical question directed recruitment and the type of GPs recruited resulted in mostly partners, diabetes leaders and delegators, leading to the business themes and distal GP. Further research may involve nurses, other allied professionals, and GPs of more varied demographic. However, to counter this view, the narratives were rich with person-centred views of how GPs viewed patients in the chronic disease setting.

Arguably, GPs can be described as a professional elite that was difficult to reach because of self-perception as busy GPs and the lack of reward or incentive the interviews offered. In terms of practice development, sessional GPs that may have been involved in clinical development roles such as diabetes may have been recruited. However, none could be found through the purposive and snowballing techniques employed.

The GPs were mainly practice partners, and only one sessional GP was interviewed. This meant salaried and locum GPs were not represented. Also, the research question invited GPs to discuss insulin initiation. Those interested in the topic may have been more motivated to participate than others and may have reduced the group's diversity. However, sessional GPs were less likely to be interested in practice delivery insulin initiation, and the topic may have discouraged them. The recruited sessional GP also had T1DM and arguably had interests in sharing her knowledge and experience as a patient and GP. However, her insight as a patient and a GP offered valuable observations to contribute to the group's accounts. Other GPs had varied interests in insulin initiation, from no plans to initiate insulin to actively initiating for many years. Consequently, although the sample may arguably be self-selecting, the GPs provided illustrative and valuable insights into their experiences and decisions when working in frontline general practice and how that shaped their decisions to initiate insulin in their setting.

7.2.2 Exceptions and outliers

Some themes were generated from only one or two GPs; nevertheless, they provided important insights within the findings. Observations that may appear to be exceptions to the norm (or

outliers from a positivist view) can advance qualitative analyses to more complex and sophisticated conceptualisations (Braun et al., 2018). The concept of thematic saturation applied in this research was explained in section 3.7.7 and aligned to reflexive TA premises that saturation is not sought in the positivist sense (Braun and Clarke, 2019).

In addition, exceptions can prompt new insights, uncover assumptions or revise the current understanding of the phenomena being investigated (McPherson and Thorne, 2006; Braun and Clarke, 2020). Exceptions identified in qualitative research may be manifestations of important diversity within the dominant data and present to the qualitative researcher as alternative positions, experiences, or attitudes (Braun and Clarke, 2020). Most importantly, they may allow an opportunity to see complexities within the world that the findings may influence.

From this research in primary care, there were two prominent examples of arguably significant exceptions. Firstly, GPs that were business orientated and GP-centred in their focus may have been influenced by payments for services and resources available for insulin initiation. The more dominant attitude was represented by GPs that had no plans to initiate insulin and were not influenced by the implementation of QOF. Exceptions in the group who were influenced may be masquerading as apparent outliers but were instances of diverse GP behaviour amongst a larger group. These exceptions may reveal how GPs may be motivated by financial incentives to implement change in their practices.

Another example was the GP that complained about the distal role she had in diabetic patient management. The sense of loss she described for proximal care was not shared across GPs but showed a GP position that may be meaningful to practising GPs who notice a similar transition and increasing distal primary care work towards systematic care of populations.

These exceptions are argued to be relevant. Although they are not representative of the majority of GPs, they highlight GP attitudes and behaviour that may be influencing change and service delivery in primary care and give an insight into complex GP attitudinal stances that could be researched further.

7.2.3 Historical data

The data provides historical data of a time when insulin initiation may arguably be more relevant than now due to the increased availability of alternative antidiabetics. Guidelines have been updated, and there are more available anti-diabetic medications. However, insulin therapy remains an increasingly prescribed option, although it has a status as a last resort. Clinical inertia to insulin initiation and intensification remains a current and topical issue in T2DM primary care management with increasing diabetic population burden (Khunti and Millar-Jones, 2017; Bain et al., 2020; Rajab et al., 2020; Motilal, 2020). Although the time-lapse since the data collection may arguably lead to a lack of applicability to current practice, the qualitative outcomes are argued to add knowledge to current and enduring aspects of general practice that remain relevant. Most significantly, the thesis adds new insight into how an expert group of GPs position themselves in the generalist arena. They make sense of a complex chronic disease and attempt to manage the escalation of therapy in person-centred ways that are arguably relevant to current concepts of interpretive medicine in primary care (Reeve and Byng, 2017).

7.2.4 Insider GP

The issue of the insider researcher is a limitation that can involve bias because the researcher's opinions may influence the data collected. This type of qualitative research requires engagement with the data and interpretation, and all researchers bring prior beliefs and biases. Acknowledging these biases and self-reflection throughout the research journey was an attempt to minimise this prejudice. Early in the project, potential bias and checking of interpretation for potential interpretation bias was addressed with a supervisor review of data interpretation and a specific review of interview transcripts with a research colleague. The departmental research staff member performed a verification checking exercise by analysing the first two interviews separately and discussing disagreements and learning points for the subsequent research journey. The key identified issue was to be aware of tacit assumptions as an insider researcher during interviews and analysis.

However, on reflection, after review of the research question, literature review on person-centredness, review and reflection on the data, the person-centeredness of GPs was at the core of this work and the travelling metaphor (Kvale, 2007) clearly applied. When GPs talked of

their overall management of chronic disease, I welcomed it openly and enjoyed the narrative approach to the interview and the narrative SA methods, despite the time required, and the time-consuming review for my supervisors.

What may be a limitation and failing at the time of the interviewees was the lack of criticality towards the GPs in the interviews and not recognising questions to return to ask them whilst the governance procedures allowed. For example, talking Harry again about his frustration and anger and uncovering potential personal GP narratives of single -hander GPs and the stress and toll of working at his practice for so many years. This was part of the researcher journey.

Additionally, the bias towards the biomedical was led by the insider and department bias towards the interest in the research question that was biomedical. The learning journey on reflection now has to include the need to be assertive, take ownership and direct the work, but lack of experience and knowledge of the big 'Q' research made that difficult with a biomedically bias supervisor at the time, who reinforced by biomedical bias. After reading Braun and Clarke's papers from 2016 onwards, now formally in a textbook (Braun and Clarke, 2022), qualitative research seems firmly placed as a key and valuable type of research to inform primary care work.

Insider researchers are known to have both advantages and disadvantages in the wider literature. The benefits of understanding the participants' culture, topic area, group, status and language give the insider researcher the advantage of overcoming potential barriers to information from the group being investigated (Merton, 1972; Saidin, 2016; Costley et al., 2010). Alternatively, Merton argues that even if the researcher is of the same group, the researcher may not hold the same views as the participants, and it is not so easy to separate the insider and the outsider researcher on this issue (Merton, 1972; Saidin, 2016; Costley et al., 2010). In this research, most of the interviewed GPs were more mature, experienced, and had more diabetes management experience than the researcher, rendering the supposed insider GP different from the participant group.

The insider GP in this research provided a benefit to access this difficult to reach group by understanding the medical language and the nuances of the biomedical, person-centred and practice-centred concepts described by the GPs. Together with this insight, there remains a

potential for bias toward the participant GP, empathy or sympathy for the GP concerns, and be blind to any issues with complicit acceptance of the ‘normal’ GP world and lack criticality by not enough probing questions. There was a difficult balance between openness, making the tacit explicit, awareness of time, allowing the representation of the GP view and directing the interview away from any prior agenda of the researcher other than the research objective.

Reflexivity was a goal throughout the project and was aided by discussions with supervisors following the interviews and subsequently after analysis, which increased the researcher’s self-awareness and criticality toward the data. Additionally, the reflexive approach and semi-structured interview techniques were purposively chosen to allow the richness of the GP experience to be shared and address the aim for representation. Moreover, the interviews involved clarification, probing and sometimes challenging questions to expose frank and revealing GP experiences.

As GPs described aspects of their work that appeared unrelated initially. It became clear as the interviews progressed, with further interviews and then the analysis, that these seemingly unrelated GP-centred aspects of insulin initiation were vital and were informing how GPs managed a chronic disease in their practice. Consequently, despite shared tacit knowledge of biomedical agendas or general practice related concepts, such as the quality outcome framework (QOF), when GPs presented seemingly peripheral concepts, the insider GP researcher was aware to allow the GPs to explain their experience.

Some GPs themselves saw the reflective process as a beneficial personal development process. For example, Matt reflected at the end of the interview that he had benefited from learning from memorable patient encounters:

“I’ve found it useful myself because you don’t think about why you make decisions very often.[...] how different patients pop into your head, I’ve never really formally thought about that but it does, it happens all the time.” Matt

Overall the insider GP was beneficial to allow access to this group of healthcare professionals and insight into how they perceived and experienced their generalist world.

7.2.5 Elite interviewing

Interviewing of GPs can be likened to interviewing elites. Elites can be experts in the community, and power asymmetry between the interviewer and respondent can affect the information. The GP researcher may be in a potential position of power in the interview relationship. As a result, any dominant power an interviewer can have in probing questions can be cancelled out by the position of power of the respondent (Kvale and Brinkmann, 2015). It is possible that the agenda of the respondent guided the interview to a greater extent and influenced the outcome. The exploratory approach aimed to understand the experience of the teller. So, while maintaining representative accounts, the analysis has attempted to be critical towards the GP views and been open to negative conceptions such as instrumentality and blame. For example, perhaps a GP had an agenda to share, such as their personal experience and had a “*talking track*” (Kvale and Brinkmann, 2015) to promote his view (Pickering and Cleary, 2017). The study aimed to explore and seek the GP perspectives using clarification, summarising, probing and sometimes challenging questions. The participants related frank and complex experiences focused on the GP experience of insulin initiation. Reflexive data recording in NVivo soon after transcription and reviewing these annotations during analysis and re-analysis aided credible thematic and narrative results.

So, in summary, the study has both strengths and limitations. The identified limitations add to the transparency of the method whilst attempts have been made to address issues of time-lapse, ‘elite’ GPs as participants, diverse demographics but with potential for over-representation of insulin initiating practices in the area. The strengths are situated in the reflexive TA and triangulation with a narrative method, with attempts towards transparency. Reflection on the literature after analysis and continuous reflexivity is hoped to have added credibility, validity, and trustworthiness to the findings.

8 Implications

This inductive research offers knowledge that may interest educationalists, policy-makers, GPs in practice, other practitioners of interpretive medicine, and possibly patients.

Funding of insulin initiation in primary care with adequate nursing care and GP time to deliver the service will be vital for delivering such a service. This arguably obvious outcome was not the participants' experience and indicates how service delivery and change management may need to be explicit in recognising resources required in primary care. There may be a need to consider if the added burden of new services for practices with high proportions of low socio-economic patients and offer additional funding, staffing resources, or consider extra measures for targeted diabetes health promotion.

Policymakers may still consider delegation of services - such as insulin initiation - from secondary to primary care. These findings may be helpful to indicate potential barriers and facilitators to service delivery that could be investigated before delivery of services. This research showed the failure to implement a pilot service for two GPs trained to take part. If there had been recognition of the practices' available resources of time and staff available before recruiting them or making more explicit the resources required, the pilot scheme might have succeeded. Furthermore, the variety of involvement in insulin initiation reinforced the barriers of time and funding in the literature. Further quantitative research through a survey design may further identify how practice resources vary across regions or nationally. This type of knowledge may help the implementation of new services by targeting ready practices.

Education of under- and post-graduate doctors may include the may consider their person-centred stance in consultations, reflectively consider their attitude to patients or even service provision. Moreover, the doctor's PC or DC position may aid in modelling and framing different types of barriers and promoters for change management when planning service

delivery change. For example, authorities producing guidance may benefit from appreciating that GPs' focus is on service delivery and implementing guidance amongst their local population and providing individual patient care. By directing educational resources for new guidance to the distal and practice-centred GP may make guidance centred on the needs of a busy GP. Promoting education initiatives towards developing the confident GP by providing appropriate and perhaps limited knowledge may also aid the implementation of change.

Guidelines have remained detached from the 'mindlines' approach to medical knowledge and decisions. This research indicated a 'mindlines' approach across the GPs, and there was also evidence of GP behaviour to override guidelines in person-centred situations. Further targeted research to understand how GPs and other HCPs behave in the guideline-orientated position and when they are willing to consider EBP or override guidance may enlighten the arguments for and against the 'mindlines' approach to medical knowledge in medical decision making. Moreover, this research found doctor-centred mindsets, and mindset of what was typical and atypical. These 'tacit' mindsets may be open to interpretation and require critique, investigation as to the appropriateness- both from the biomedical view, but from the person-centred. For example, the mindset of the 'minimalist' (Trachtenberg *et al.*, 2014) performing less investigation or less aggressive medical care for patients with significant mental health problems may require reflection in practice, and perhaps to be challenged.

Exploring the GP doctor-centred stance further in other chronic diseases may reveal new opportunities to understand reflective practice differently, and potential barriers and facilitators of chronic healthcare delivery within the primary care setting. Looking after individuals with a 'cluster' of disease is an increasing need for healthcare and particularly for the generalist (Whitty *et al.*, 2020).

9 Conclusion

This thesis has considered how GPs approach person-centred care for T2DM in the primary care setting, using the question of insulin initiation to reflect on memorable patients, and their practice overall. The constructionist episteme aided the insider GP researcher to apply reflexive TA processes construct GPs as doctor- (DC) and person-centred (PC). GPs were found to be biomedical in arguably person-centred and contextualised ways. However, there was frequent and recognisable doctor-centred negative construction of patients, associated with tensions that revealed richer, more nuanced narrative structural analysis data. GP paternalistic expectations of patients 'engage' in care, frustration, anger and blame when individuals or practice population were unengaged in healthcare- and viewed as not taking responsibility or self-determining patients. The GP mindsets or 'stances' created negative threat explanations when explaining diabetes, the ultimately led to blame (Peyrot et al., 2006) when patient health deteriorated- confirming the literature on practitioner biomedical approaches to person-centred activities such as goal-setting, and patient withdrawal or retreat from practitioner care (Murdoch, et al., 2020). Evidence of doctor-centred paternalism toward low SED populations, and patients with significant mental health problems has implications for PCC care for these groups and indicates need for practitioner reflection.

Other tensions generated GPs as at times distal, and other times proximal to patients. In T2DM care, GPs were proximal as problem-solvers, which was problematic if the GP need to consider the PCC approach for patients with deteriorating diabetic health despite prescribed medications.

The instrumentality theme constructed GPs as business or diabetic leads that chose to not deliver insulin as a service explicitly and implicitly leading to an attitude of instrumentality towards service provision, and delegation. Arguably the instrumentality stance may not be negative, and has implications for practitioner reflection, and policy maker planning.

Finally, whatever stance GPs appeared to hold- distal, blaming, pharma-sceptic, or person-centred, GPs were shifting, and moved from doctor-centred to person-centred and vice versa dependent on the memorable case or attitudinal stance.

10.1.1.1 Quality appraisal of the papers

A quality appraisal of the papers was tabulated and is presented within this section. Table 3 provides the detailed appraisal of individual papers and the systematic approach taken is shown.

Table of the Quality appraisal of the papers: using the Mixed Methods Appraisal Toolkit (MMAT), survey checklists from the Centre of Evidence Medicine (CEBM) and the Critical Appraisal Skills Programme (CASP) checklist.

Key: Pt = patient; ID no= number in the original 242 papers searched at abstract; S1 = Were there clear research questions (RQs)? S2=Do the obtained data enable you to answer the research questions? PCC= person-centred care, DCC=disease centred care; columns 7 to 11 are numbered 1 to 5 and relate to the equivalent part of the MMAT methods quality criteria, e.g, in a survey appraisal this would be criteria 4.1 to 4.5 and related to columns 1 to 5; C= Can't tell, Y= Yes, N= No; CDM= Chronic disease management; PHQ-9 = Patient Health Questionnaire-9; GAD7=Generalised Anxiety Disorder scale. For mixed methods papers, the relevant other questions for the research types were also applied (MMAT quality criteria 1.1 to 4.5).

| Paper ID no., First author' year, country. | Research Aim or RQ. | Appraisal tool used | S 1 | S 2 | Methods and participants | 1 | 2 | 3 | 4 | 5 | Comments on quality appraisal: Value and Limitations |
|---|--|---|-----|-----|--|---|---|---|---|---|--|
| 21. Wollny, 2021 (Wollny <i>et al.</i> , 2021) Germany | An educational intervention to increase PCC and SDM for patients with poorly controlled T2DM | MMAT 2.1 to 2.5 and the CASP RCT checklist. | Y | Y | Cluster RCT, 833 patients and 108 GPs | Y | Y | Y | Y | Y | 24 months of follow up Study participants were not blinded, but patients and the study researchers collecting data were not aware of group allocation. There was low loss to follow up and attempts to reduce bias such as standardised interviewer training. The subjective assessment of SDM and the possible inclusion of motivated GPs may create bias but does not explain the negative outcome. |
| 238. Kinmonth <i>et al.</i> , 1998. UK | GP and nurse training | MMAT 2.1 to 2.5 and the CASP RCT checklist. | Y | Y | Pragmatic parallel group design with 250 patients with T2DM and randomisation into intervention versus routine care. | Y | Y | Y | Y | Y | The baseline variables were similar for both groups and the practitioners were not aware of the hypothesis and so, blinded to the intervention. The data also relied on self-reported effects of diet and exercise and may suggest knowledge of patients, but not actual behaviours. The intervention was a short (1.5 days for nurses and 0.5 days for GPs, and two further 0.5 day |

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| | | | | | | | | | | | follow up sessions) training on a biological and psychosocial based communication style. |
| 29. AlRuthia , 2020 (AlRuthia <i>et al.</i> , 2020) Saudi Arabia | Diabetic patient trust in HCP measure compared with patient depression and anxiety scores. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 367 diabetic patients | Y | Y | Y | Y | Y | Patients with significant mental health diagnoses were not included and the results apply to patients with mild or moderate depression or anxiety only. Patients' recall bias may reduce internal validity. Psycho-social issues or other medical/non-medical problems were not sought and may have been important confounding factors |
| 17. Ngassa, 2021 (Ngassa Piotie <i>et al.</i> , 2021). South Africa | Attitudes and beliefs of primary care HCP towards insulin initiation | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 23 doctors and 50 nurses from 23 clinics. | C | C | Y | Y | Y | The adapted survey had credible sections relevant to the topic and adapted to extend to nurses. The process of inclusion/exclusion of the participant HCPs were not detailed to confidently know if there could be selection bias. The sample was small so statistical power calculations were not possible or mentioned, and the results are not generalisable. |
| 55. Tamir <i>et al.</i> , 2018 (Tamir <i>et al.</i> , 2018) Israel | Comparing physician and patient understanding of diabetes-related QoL | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey: 136 patients completed a QoL survey before their appointment; 39 physicians completed the same questionnaire after the visit. | Y | Y | Y | Y | Y | Convenience sampling of patients recruited within clusters of practice populations- so there is a risk that the data is not generalisable wider than these demographics and a risk the sample is not representative of the population within the cluster. Calculations were made of the minimum sample size based on assumptions explicit in the paper. |
| 62. Millar <i>et al.</i> 2018 New Zealand | The health care experiences of patients with multimorbidity | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Survey questionnaire of 234 patients | Y | Y | Y | Y | Y | Despite researchers' attempts to strengthen recruitment to work closely with the two health primary healthcare organisations, a poor response rate to patient invitation during recruitment was observed. As a result, satisfied patients, or patients with difficulties to complain about may be overrepresented, underestimating or overestimating the outcomes. Similarly, non-responders may include individuals who were |

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| | | | | | | | | | | | | concerned that their GPs would see their response, causing the results to overestimate the population perception of their doctor. |
| 73. McCreedy <i>et al.</i> , 2018 (McCreedy <i>et al.</i> , 2018). 7 USA | Individualised goal setting for HbA1c targets for diabetic geriatric patients. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | 336 primary care clinicians (internists, nurse practitioners and family physicians) answered a vignette-based survey on their intended management | Y | C | Y | N | Y | Vignettes may provide a reliable source of evidence of doctor clinical behaviour, and results align with another survey s showing 1/3 rd of doctors may not follow recommendations for older adults. - Results are not generalisable: Convenience sample of doctors, and low response rates. The sample may not represent the target population of doctor due to: 1) non-response error (doctors less motivated to respond may be missed and so, underestimate those not following guidelines and that may over /under treat older T2DM patients; 2) coverage bias (only 60% of the licensed doctors' emails were available when recruitment began with a limited access to all possible eligible doctors). | |
| 122. Ali <i>et al.</i> , 2016 (Ali <i>et al.</i> , 2016). USA | HCP management of patients with diabetes during Ramadan. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Survey of 45 HCPs | Y | C | Y | N | N | As a pilot study the research was important due to the lack of knowledge on the topic. The numbers were too low to allow outcome generalisation and there were no power or statistical significance figures provided. There was also a low response rate which may add response bias. The self-reported data may also recall bias towards socially desirable beliefs. | |
| 166. Kurpas <i>et al.</i> , 2013 (Kurpas <i>et al.</i> , 2013). Poland | Correlations between patient characteristics and their assessments of the quality of primary healthcare. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Survey of 232 patients. | C | C | Y | C | C | Recruitment: patients were given questionnaires to complete at home after clinic attendance and signing a consent form, with a 49% response rate. Further details are not given other than the resultant demographics. The outcomes relate a correlation between male gender and satisfaction with PCC aspects of care and there is lack of clarity of female gender and satisfaction and may have led to important gender-based findings if they had been sought in the survey data. | |

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| 172. de Figueredo et al., 2013 (de Figueiredo, Snoek and Barreto, 2013) Brazil. | Exploration of patient and physicians' agreement over diabetes management. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | This cross-sectional survey study of 282 patient-physician pairs | Y | Y | Y | Y | Y | Efforts were made to increase the quality of the survey: a qualitative study to explore patient understanding of the questions, and questionnaires were pre-tested. The diabetes training of doctors was unknown and may have confounded the results e.g., better trained doctors may communicate differently. Interviews with drs to complete the survey took place after doctor appointments and may have influenced the motivation and quality of the doctor patient interactions. |
| 177. Houle et al., 2012 (Houle <i>et al.</i> , 2012). Canada | PCC: evaluation of chronic illness care delivery from the patient perspective. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | A cross-sectional survey study of 364 patients with diabetes, hypertension, or COPD using the patient assessment of chronic illness care (PACIC) score. | Y | Y | Y | Y | Y | Cross sectional design- so located at a point in time and unable identify a direction of associations observed. Recruitment bias: convenience sample of patients recruited in waiting rooms, so bias towards frequent attenders and potentially subgroups of patient with high levels of need. All the practice locations were training centres and so, limits the generalisability, but may also emphasise bias towards biomedical outcomes and less towards chronic care management (CCM). |
| 188. Ratanawongsa et al., 2012 (Ratana wongsa <i>et al.</i> , 2012). USA | PCPs' self-reported perceptions of the barriers to insulin initiation in T2DM. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 83 primary care physicians (PCPs). | Y | Y | Y | N | N | Sampling from the three different health systems may not be generalisable to other health systems nor demographic populations. GPs were interviewed and asked to reflect on patient care to answer the survey questions- with possible recall bias; sample sizes were small, and no statistical power or significance calculations were provided confidently associate factors such as experience to attitudes. |
| 183. Luijks et al., 2012 (Luijks <i>et al.</i> , 2012) Netherlands | Explore GP perspectives of the main aims and influencing factors on their management in practice. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Five focus group interviews with 25 GPs, analysed by applying the technique of constant comparison. | Y | Y | Y | Y | Y | The focus groups were kept to 4 to 6 GPs to increase likelihood of individuals participating in discussion. Limitations: high numbers of academic GPs, with possible bias towards well- informed PCC advocates; GP perspectives were sought but cannot be |

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| | | | | | | | | | | | extrapolated to observed GP behaviours; the focus groups took place in Dutch, so translated quotes may not have the exact meaning as imparted by the GP. |
| 205. Christensen et al., 2010 (Christensen <i>et al.</i> , 2010). USA | Patient and physician attitude to health locus of control (HLOC) compared to medication adherence, BP and HbA1c. | Quantitative descriptive, MMAT 4.1 to 4.5 | Y | Y | 18 primary care physicians and 224 patients with T2DM and hypertension were recruited as dyad pairs. | Y | N | Y | Y | Y | The sample was composed of older Caucasian male veteran patients, and so, women and diverse populations were excluded, reducing generalisability. Additionally, the response rate was 58% and the final sample may be nonrepresentative of the population overall. Adherence was measured by prescriptions refilled at patient request, but that does not ensure patients are compliant. However, this method is believed to be the most reliable measure of adherence in retrospective data. |
| 242. Joos et al., 1993 (Joos, Hickam and Borders, 1993) USA | The frequency with which physicians met patients requests and needs. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | 243 patients, 41 doctors | Y | Y | Y | Y | Y | Located in a university affiliated veterans' clinic with no female patients limits the generalisability of the data. |
| 189. Green et al., 2012 (Green, Rothman and Cavanaugh, 2012). USA | Relationship of depression symptoms with patient centred communication. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Audio-recordings of consultations with 95 diabetic patients were coded using the Rota Interaction Analysis System (RIAS) | Y | Y | Y | C | Y | Sited in an academic primary care unit: limiting transferability. This study uses the construct of physician-centeredness and disease-centeredness or biomedical focus synonymously- which ignores possible confounding by other factors that make for a physician or doctor-centred focus. Recruitment sampling and response rates are not clearly described. |
| 211. Swenson et al., 2008 (Swenson <i>et al.</i> , 2008). | Relationship of depression symptoms with patient centred communication. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 231 T2DM patients using a measure of interpersonal processes of care (IPC) tool | Y | Y | Y | Y | Y | The authors used multivariate logistic regression to adjust findings for age, sex, ethnicity, language, diabetes comorbidities and trust, which adjust for possible confounding factors. The Centre of Epidemiologic Studies Depression scale CES-D 10 scale was used to measure |

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| USA | | | | | | | | | | | depression which was self-reported by patients and may overestimate depression compared to the standard of diagnostic appointments with doctors. However, CES-D 10 has high specificity and the findings reported relate severe depression, which is likely to be more credible. Patient reports of clinician-patient communication may be open to recall bias, but is defended by the authors by citing literature that shows patient recall of visits may be accurate. |
| 45. Sidorkiewicz et al. 2019 (Sidorkiewicz et al., 2019) France | Agreement between patients and GPs on What are the chronic conditions affecting patients prioritising them. | Cross-sectional Survey MMAT 4.1 to 4.5 | Y | Y | Convenience sample of 16 GP practices in Paris, recruiting 233 patients. 153 patient-GP pairs were analysed. | Y | Y | Y | Y | Y | Convenience sample so may not represent the target population. In addition, the sample was small- so may not provide enough internal validity. The urban setting, with higher-than-average educational levels of patients may have improved outcomes and agreement with GPs and may not represent the wider French population. The language used in the survey was similar for GPs and patients with a risk for patient misunderstanding of medical terms and under/overestimate patient agreement. |
| 163. Kutob et al., 2013 (Kutob et al., 2013). USA | Impact of a cultural competence diabetes care course physicians' self-reported cultural competence. | Quantitative non-randomised study: Case-control study: MMAT 3.1 to 3.5 | Y | Y | Doctor groups: Control=41; intervention=4 Self-reported cultural competence measure: the cultural competence assessment tool (CCAT). | Y | Y | Y | N | Y | The recruited doctors had background experience in working with diverse populations (by virtue of the Medicaid patient populations in their care), who had already had previous cultural competence training, so may not be typical of the possible wider USA doctor population. The small sample size limits comparison between subgroups. There was no pre-test data in the design, so baseline differences between the intervention and control groups before and after intervention cannot be understood to account for the lack of impact of the study. |
| 80. Rutten, 2018 (Rutten | Patient and provider survey after an interventional consultation | Cohort non-randomised intervention trial MMAT 3.1 to 3.5 | Y | Y | Survey of 1487 patients with T2DM and T1DM, 57 GPs, 23 PNs in primary care; | Y | Y | Y | Y | Y | The research practices were not randomly selected, so selection bias is possible, especially with over representation by group practices. The number of participating GPs and nurses age |

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| <i>et al.</i> , 2018). | model to aid PCC. | | | | and 17 medical specialists and 8 diabetes specialist nurses (DSNs) from hospital outpatient clinics. | | | | | | and sex were comparable to the target population. For 28% of patients, care providers reported that the model was not fully applicable, due to a social or other specific complaints. The authors argue that the model intervention would have helped in these cases as part of the social determinants of chronic ill-health. However, these cases may have been confounding factors for patient health, and moreover, the HCPs were not cognisant and so fully trained in the model- an indication that the training may not have been delivered as intended. |
| Netherlands | | | | | | | | | | | |
| Hojat et al., 2011. (Hojat et al., 2011) USA | Physician empathy compared to patient clinical outcomes (HbA1c and LDL-cholesterol) | Quantitative non-randomised cohort study MMAT 3.1 to 3.5 | Y | Y | 29 primary care physicians, 1154 patients. The study used the Jefferson Scale of Empathy (JSE). | Y | Y | Y | Y | Y | Multiple confounding factors (culture, race, ethnicity, severity of disease) and the research does not control for all these factors. The setting was academic with bias toward motivated GPs, and so overestimating the empathy scores. |
| 53. Chaitoff, 2019 (Chaitoff et al., 2019) USA | Physician empathy compared to patient clinical outcomes (HbA1c and LDL-cholesterol) | Quantitative non-randomised cohort study MMAT 3.1 to 3.5 | Y | Y | 4176 patients, 51 primary care professionals. The study used the Jefferson Scale of Empathy (JSE). | Y | Y | Y | Y | Y | Use of a credible quantitative empathy scale, and conceptually linked to measurable outcomes, and the outcomes were measured over 3 years, which is longer than most. It replicated a Spanish study (Hojat et al., 2011) with a larger cohort and diversity of patient population, adding validity. Although not detailed in the paper, it is assumed that linear logistic regression statistical method used involved power calculations. The study's different setting and time may account for the likely unfavourable outcome for Chaitoff et al, compared to (Hojat et al., 2011), confounded by more CDM care available as part of systematic processes in the intervening years in the USA. |
| Lee and Lin, 2011 (Lee and Lin, 2011). | To investigate if patients with high levels of decision-making preferences | Quantitative Non-Randomized cohort study. MMAT 3.1 to 3.5. | Y | Y | A one-year longitudinal study with 614 T2DM patients, comparing | Y | Y | Y | Y | Y | The research design recognises the patient physician relationship and inherent longitudinal nature of patient care in contrast to previous |

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| Taiwan | have higher levels of trust and better outcomes. | | | | self-reported health survey outcomes with health outcome measures within medical records. | | | | | | primarily cross-sectional research. The SF-12 health survey is believed to credibly deconstruct the concept of self-reported health. Also, observed outcome measures may add objective validity. The high dropout rate (396 patients completed the study), and may indicate bias towards a motivated patients more engaged with self-care. |
| 41. van Vugt, 2020 (van Vugt <i>et al.</i> , 2020) | <i>After</i> a new PCC diabetes consultation model was used, T2DM patients' intended choice of care was assessed. | MMAT 3.1 to 3.5 Cohort intervention study | Y | Y | 1284 patients, 57 GPs and 23 PNs and 17 hospital Drs and 8 DSNs) received surveys after the use of the model. | Y | Y | Y | Y | Y | The finding may not be generalisable beyond the Dutch systems. The questions may be arguably subjective and less valid, but as a cohort study, the finding cannot be causally linked. Possible confounders were not accounted for in the paper, and non-response bias may be significant. |
| Netherlands | | | | | | | | | | | |
| 159. Griffiths <i>et al.</i> , 2014 (Griffiths <i>et al.</i> , 2014). UK | Typology developed for from the perspective of the chronic disease patient | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Semi-structured interviews with T2DM (37), chronic back pain (15) patients. Focus groups of 20 healthcare professionals and 14 patients refined and validated the typologies. | Y | Y | Y | Y | Y | Only English-speaking patients were included and potential lack of diversity. The diabetes and back pain patient were recruited differently – back pain from one urban and one rural GP practice; T2DM from a separate clinical trial about improving self-efficacy in DM management through an educational intervention, however, recruitment bias may have been mitigated by seeking patients with a range of self-efficacy scores using the diabetes management efficacy scale. Small samples of patients and potential for more diverse data that has been missed and so, possible additional typologies, but the diversity in the group of patients in terms of age, gender, ethnicity allay this limitation to an unknown degree. |
| 195. Cocksed <i>et al.</i> , 2011 (Cocks) | PCC: explore the concept of 'holding' as a management | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | GPs and patients were recruited from urban and suburban areas | Y | Y | Y | Y | Y | 'Holding' is defined as "establishing and maintaining a trusting, constant, reliable relationship that is concerned |

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| edge <i>et al.</i> , 2011). UK | strategy in primary care. | | | | in northwest England participated in interviews and the data was analysed with constant comparative analysis. | | | | | | with ongoing support without expectation of cure". Convenience sampling: recruitment of possibly homogenous sample of GPs known to researcher may result in a lack of diversity of GPs and bias towards academic/GP trainers with lack of transferability. All were white British GPs, However, limiting responders to over those in practice over 5 years and urban/suburban location complemented previous research. Patients were recruited by the GP and this process may have had selection bias with agreeable patients, as all patients invited agreed to participate. As with self- reported data in qualitative research, there may be recall bias. The data informs on what doctors believe they do, but this may not be what they do. |
| 193. Adams et al., 2011 (Adams and Carter, 2011). Barbados | Patient experiences: knowledge, attitudes, practices, and barriers to T2DM and hypertension care experienced | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 5 focus groups with 21 patients over 40 years of age (5 diabetic, 5 hypertensives, and 11 with both diseases) with a mean age of 59 years, content analysis methods applied to the transcribed interviews. | Y | Y | Y | Y | Y | Patients were recruited randomly, through cold calling from the Barbados voters register. Smaller focus groups than planned with unexplained drop out rate. |
| 5. Mathew et al., 2022 (Mathew <i>et al.</i> , 2022) Singapore | Aspects of the patient provider relationships (PPR) that affect insulin related behaviours: initiation and adherence | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Grounded theory approach, thematic analysis of transcripts; semi-structured interviews. 21 patients. | Y | Y | Y | Y | Y | Recruitment: purposive sampling. Multiple coders and seen as positive by the research team which indicates an arguably neopositivist and less reflexive thematic analysis (Braun and Clarke, 2021b). Patients that were non-adherent also expressed views. Transferability limited to primary care patients on basal or premixed insulin only. |
| 64. Kristensen et al., 2018 (Kriste | Understanding patient perspectives of disease and self-care and | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 13 patients with T2DM underwent qualitative interviews that | Y | Y | Y | Y | Y | Given that it is set among poor socioeconomic groups, the research may be confounded by a high occurrence of psychosocial disorders. The |

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| nsen et al., 2018a). Denmark | the GP's role in supporting patients that the GP had labelled as impaired in self-care ability. | | | | were analysed using a systematic text condensation method. Theory used: shifting perspectives model of chronic disease. | | | | | | researcher was a GP: a risk of patients withholding information. The authors argue the use of other HCPs to reduce conceptual blindness by the researching GP, but qualitative research is argued to be from the perspective of the researcher- so additional HCPs can provide disparate perspectives (Braun and Clarke, 2021b). |
| 97. Young et al, 2017 (J. Young et al., 2017). New Zealand | Patient and HCP perspectives on the concepts of a vision of care (VoC), shared vision of care (SVoC) and the patient's own care network- 'community of clinical practice' (CoCP). | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Social constructionist theory, Ethnographic methodology observing nine CoCP in one GP setting. In-depth qualitative interviews thematically analysed using a 'template organising style'. | Y | Y | Y | Y | Y | The small number of participants may be argued to narrow the subjective knowledge achieved, especially if the selection of patients by the HCPs was biased. The researcher was also involved in clinical care of patients- with a risk that participants may have been less open about negative tensions amongst the CoCP. |
| 103. Burridge et al, 2017 (Burridge et al., 2017) Australia | Explore patients views of a service innovation aimed at supporting T2DM management of their diabetes and maximise patient engagement. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Normalization Process Theory (NPT) provides a framework to understand patient self-care and engagement with a GP-led specialist multi-disciplinary clinic. Semi-structured and audio-recorded interviews with 25 patients' , thematically analysed. | Y | Y | Y | Y | Y | Transferable outcomes that may apply to specialist GP led services in similar settings to the suburban Brisbane locality. The study is an qualitative evaluation for a cluster RCT. 30 patients were interviewed at baseline and 5 were lost to follow-up at 12 months after first contact with the care model, with potentially bias towards patients able and motivated to feedback on the innovation. |
| 108. Methley et al, 2017 (Methley et al., 2017). UK | Patient and provider perspectives of UK healthcare services for MS. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 24 patients with MS, 13 practice nurses, 12 GPs, 9 MS nurses; semi-structured interviews analysed thematically; | Y | Y | Y | Y | Y | MS is a fluctuating and progressive disease, so additional interviews over time may have helped. Focus on the role of primary care in MS management, and a gap in the wider knowledge. Most patients were over 50 years, white British and nearly half the group were fully |

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| | | | | | used the theoretical framework of candidacy and themes were mapped to the NICE guidelines. | | | | | | ambulant. The research may have benefited from a more diverse participants in age, ethnicity, functional disability, and socio-economic demographic. A low response rates from GPs and PNs impacted the low primary care recruitment of MS patients, and most patients were recruited via secondary care run community clinics where patients may have had more stable symptoms. |
| 212. Russell et al., 2008 (Russell et al., 2008). Canada 35 | To evaluate the impact of the chronic illness care management plan (CICM). | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Semi structured interviews with a purposive sample of 13 family physicians (FPs) and 20 patients. | Y | Y | Y | Y | Y | Analysis considered two frameworks for understanding physician perspective: whether they understood principles of care planning and whether they implemented practice change. The purposive sample was from small practices in Ontario already involved in research so, may be over representative of enthused FPs. This sampling reduces transferability of the findings. The FPs nominated patients and there may have been bias toward patients with positive experiences. |
| 215. Abdulha di et al, 2007. Oman | PCC: perception of patients with T2DM of medical encounters and quality of interactions with primary care providers. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Purposive recruitment of 27 patients from 6 primary health centres took part in four focus groups (2 male and 2 female groups). The principles of content analysis were applied to code data and produce themes. | Y | Y | Y | Y | Y | Men and women were placed in separated focus groups and is credibly defended as culturally appropriate to the region and allowed more active participation by women. In contradiction, a male moderator conducted the female group- however the findings were similar in both types of groups and may indicate trustworthiness. Authors attempted to increase dependability with team debriefing during data collection, and independently reviewing transcripts- but this arguably may increase the researcher variability in the interpretation of data (Braun and Clarke, 2021b). |
| 221. Fagerli et al., 2005 (Fagerli et al., 2005). | PCC: Norwegian HCP perspective of experiences with patients of Pakistani background | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Semi-structured interviews, with a purposive sample of 6 dieticians and 6 primary care | Y | Y | Y | Y | Y | All the GPs were women, the 2 male GPs recruited cancelled their appointment due to their own lack of time. The interview guide was loosely followed to allow the participants to freely express themselves and adds to validity. |

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| Norway | when giving dietary advice T2DM. | | | | doctors or specific healthcare workers. transcribed and analysed phenomenologically. | | | | | | Iterative process was followed with successive transcription and analysis of each interview, as well as informal discussion with some of the participants with regard to the findings. |
| 220. Haque et al., 2005 (Haque et al., 2005). South Africa | PCC: barriers to the initiation of insulin in type 2 diabetes to patients on maximal oral medication in community health centres. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 5 focus groups of a purposive sample of 46 medical officers (MO), followed by 10 in depth semi-structured interviews with MOs at primary care community health centres managing T2DM patients. | Y | Y | Y | Y | Y | Knowledge, beliefs, and fears are grouped together as constructs for doctors and separation may have made the physician attitudes clearer. There was little information of the researchers and the role or potential bias. However, the triangulation with focus group, 1:1 interviews and feedback to the participants adds to validity, though detail is limited on feedback outcomes. |
| 235. Bartz et al., 1999 (Bartz and Francisco, 1999). USA | A single-family doctor's use of the biopsychosocial model in the care of an urban population of Native American patients with T2DM. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Case study: Dr M and the 9 patient interactions were audio-recorded and analysed using narrative discourse analysis. | Y | Y | Y | Y | Y | The transcribe interviews were interpreted using methods adapted from Narrative and discourse analysis, interactive ethnography, and grounded interpretive research, which arguably may lead to methodological confusion as they all have different epistemological underpinnings. However, the themes that emerged were analysed using interpretive dialogue (ID) with the case doctor and contextualised her understanding of the interactions with additional reflection. This added reflection caused iterative reframing of the problem by considering Dr M's knowledge of the person and disease within the context of mistrust and misunderstanding. The transferability of the data may be limited with specific cultural narratives, and an initially idealised representation of a community doctor selected for her patient empathy and reflective nature. |
| 237. Helseth et al., 1999 | FP attitudes towards diabetes, patients with | MMAT 1.1 to 1.5, and CASP | Y | Y | In-depth interviews with 10 family physicians | Y | Y | Y | Y | Y | Purposive sampling was used to recruit male and female doctors, with a wide age range, but there is little information of the |

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| (Helseth <i>et al.</i> , 1999). USA | diabetes, and diabetes care compared to internal medicine physicians. | Qualitative Appraisal checklist | | | (FP) and 9 internists were audiotaped and transcribed. A 'text analysis' following the strategy of McCracken, and Crabtree and Miller was applied to the data. | | | | | | participants demographics, and the transferability will be limited by the locale of Connecticut in the USA. A medical student conducted the interviews with potential power differentials and arguably, lack of experience in both research and clinical care to probe the qualified and senior doctors. Although the interviews took place in 1991, before the guidance for tight diabetic control and apparently of that time, but still has the current themes of doctors balanced disease centred perspectives with those of patient centred care. |
| 33. Murdoch, 2020 (Murdoch <i>et al.</i> , 2020). UK | Goal setting for patients with multiple long-term conditions (LTC). | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Uses 'Goffman's concepts of frames to understand goal setting. Conversation analysis was used to analyse 22 video-recorded consultations between patients and doctors from 3 UK general practices. | Y | Y | Y | Y | Y | The transferability is limited to the geographical location, practice type and patient population in Norfolk and Suffolk in the UK setting. More diverse populations may include marginalised populations with arguably lower agency and involvement in SDM and goal-setting. |
| 198. Williams <i>et al.</i> , 2011. UK | Explore and compare the asthma goals of health professionals and people with asthma in primary care and identify barriers to shared goals. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Semi-structured interviews, with 15 patients with asthma, 7 GPs 6 primary care nurses transcribed and analysed through a 'Framework' methodology. | Y | Y | Y | Y | Y | A purposive sample of medical rural (4) and urban (4) practices in Tayside, Scotland. The authors hypothesise that smaller practices may have fewer HCPs and so, more personal goal-setting practices with patients (stronger relationship implied). There was a dominance of female non-smokers in the high asthma severity and duration group- and may reflect increased presentation for this group of patients compared others, e.g. young male smokers, of which there were few. Recall bias by HCPs may reduce credibility of the finding that HCPs failed to recall specific goals in asthma care, but in most cases, the HCPs had seen patients recently and selected by |

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| | | | | | | | | | | | the HCPs. Also no patients had successfully changed their asthma care- cause a possible bias toward negative findings. |
| Zafar et al., 2015 (A Zafar et al., 2015) UK | Aim to explore the clinical inertia and barriers to medication escalation in T2DM from the perspective of primary care prescribers | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist. | Y | Y | Purposive recruitment of low and high QOF achieving practices, targeting diabetes leads at practices. Semi-structured interviews by phone and face to face were audio-recorded and transcribed verbatim and analysed using framework analysis. | Y | Y | Y | Y | Y | Purposive sampling to target high and low QOF achieving practices may not have helped achieve variability, especially because the participants themselves had subjective meanings to the QOF achievements and indicated the measure was not meaningful to their own ideas of what involved in T2DM management. May be generalisable to similar practices. Nurses' views with no lead role may have different views of the barriers to T2DM care may have been achieved. The GP insider may have biased toward both the biomedical aspects pic, but also the GP-centred views of chronic disease management. |
| 143. Wiley et al, 2015 (Wiley et al., 2015). Australia | Whether T1DM patients engage with the MDT management processes and why. | MMAT mixed sequential explanatory design. 5.1 to 5.5, 1.1 to 1.5 and the CASP qualitative study checklist; survey 4.1 to 4.4. | Y | Y | Web-based survey of 150 T1DM patients aged 18 to 35y; Semi-structured interviews of 33 patients analysed for thematically. | Y | Y | Y | Y | N | The survey was small with no statistical significance figures provided and obvious potential for recruitment bias identified by authors as being towards females, educated, with health insurance and suspected better glycaemic controls than national averages. It took 40 minutes to complete, and the length may have added response bias if less motivated patients found this too long. The qualitative methods appear credible with appropriate themes and supportive quotes. Despite the limitations the survey data has informative results and provides meaningful support to the qualitative data. |
| 175. Trachtenberg et al., 2014 (Trachtenberg et al., 2014) USA | To examine clusters or physician decision-making behaviours for patients with T2DM, including for those with mental health comorbidities. | Mixed methods sequential exploratory design: Qual, Quan; MMAT; 5.1 to 5.5; 1.1 to 1.5, and CASP Qualitative Appraisal checklist. | Y | Y | The researchers presented video vignettes of patients with uncontrolled T2DM to 256 primary care physicians and structured interviews about clinical | Y | Y | Y | C | Y | The authors related a previously published study that used the same methodology: using physicians' qualitative interview responses and used a quantitative statistical method to cluster doctors' responses about how they managed their patients. The epistemology of this process of analysis is arguably, the methods is quantitative and positivist in nature. The subjective coding of the structured interviews adds |

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| | | | | | management were analysed. | | | | | | <p>bias to the resultant quantitative outcomes, the use of cluster analysis techniques is a method to show data saturation of behaviours.</p> <p>Despite the possible methodological issues of performing quantitative analysis of qualitatively achieved data, the output clusters appear credible and informative of a 'styles' of management, supporting another similar study based on cardiac management.</p> |
| 176. Wiley et al., 2014 (Wiley <i>et al.</i> , 2014). Australia | T1DM patients' perceptions of the SDM delivery of different clinician groups. | MMAT mixed sequential explanatory design. 5.1 to 5.5, 1.1 to 1.5 and the CASP qualitative study checklist; survey 4.1 to 4.4. | Y | Y | Web based survey of 150 patients with T1DM aged 18 y to 35 y. 33 patients (27 female, 8 male) took part in 7 focus groups rating the 7 aspects of SDM in their interactions with endocrinologist, DM educators, dietitians, and GPs. | Y | Y | Y | Y | Y | <p>Recall and reporting bias risk: The survey asked patients about their interactions with the HCP and gave no timeframe limit for when the patient/HCP interaction had occurred.</p> <p>Recruitment bias: self-selection recruitment through advertisements.</p> <p>Gender bias- - 80% were female, Socio-economic bias to highly educate groups with 79% with tertiary or high education level. Potentially- these limitations may lead to patient bias toward the active use of SDM</p> |
| 217. Lawn et al., 2007 (Lawn <i>et al.</i> , 2007). Australia | The feasibility and utility of the Flinders model: a partnership model of care between GPs, mental health case managers, and patients for people with significant mental illness. | Mixed method: sequential explanatory design: Quantitative non-randomised cohort study, MMAT 3.1 to 3.5 and qualitative evaluation: MMAT 1.1 to 1.5. | Y | Y | 38 patients identified their self-management using the Flinders model, which was compared with the peer-led Stanford patient self-management education course and one to one peer support interventions. Measures: Self-Management and QoL, and survey and focus group | Y | Y | Y | C | C | <p>The Flinders Model used allowed patients to choose individual or group interviews, with the explicit reports from patients that group work exacerbates their mental health. The Flinders model comprises measures of Partners in Health (PIH), Cue and response (C+R) and Problems and Goals (P+ G), which allowed 3 different ways to measure patient preferences and perspectives of care plan negotiation.</p> <p>Convenience sampling may limit generalisability of outcomes. 20 patients also undertook the Stanford course may have confounded the results, and little account was made for other confounding factors of family, lack of social support, diagnostic differences,</p> |

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| | | | | | | | | | | | age, gender- which may affect self-care. There is insufficient information provided to know if the if the quality criteria of survey or focus group evaluation. |
| 239. Kinmonth et al., 1996 (Kinmonth, Spiegel and Woodcock, 1996). UK | Aiming to develop a training programme on patient centred consulting for GPs and nurses through action research methods. | Mixed methods: Sequential explanatory design: qualitative Action research, and later survey. MMAT 5.1 to 5.5 | C | C | Action research with 4 primary care teams and their patients, with 23 GPs and 32 practice nurses. The diabetes review consultations were observed before and after training, and they also answered a survey evaluation of training after each session. | C | C | C | C | C | The design of the research to develop the training programme involved multiple methods, and they were not described in enough detail to critique the development of the programme itself. E.g. a psychologist observed and taped 12 GP or nurse-Patient consultations, but not enough detail of the qualitative method is given. However, the evaluation of the programme was through a survey which rated a series of questions on a Likert scale, but the numbers of GPs and nurses were too small with no statistically significant figures given; and may not be representative of HCPs beyond the locale, with potential for nonresponse bias. |
| 40. Claramita et al, 2020 (Claramita <i>et al.</i> , 2020) Indonesia | Doctors' perceptions through self-assessment and patient perceptions of experiences of a PCC method of partnership orientated communication- testing the 'Greet-Invite-Discuss' guideline. | Mixed methods 5.1 to 5.5 sequential explanatory: cohort study 3.1 to 3.5, later qualitative MMAT 1.1 to 1.5. | Y | Y | 30 doctors were assigned to consult 45 patients with hypertension or T2DM. Doctor training in PCC delivery, and updates in hypertension or T2DM; then assigned to consultations with patients. Outcomes: patient and doctor surveys, Biological outcomes; focus groups. | Y | Y | Y | Y | Y | The follow up time was only 6 weeks and arguably too short to allow for the observed biomedical changes, but the results are presented with statistical significance, so appear credible. A longer cohort study may have helped to show a sustained effect of the intervention. The small sample size of doctors and patients may make the data less generalisable or transferable to the wider community of GP nationally and beyond. |
| 89. Lee et al, 2017 (Lee, Ng and Low, 2017). | The identification of patient concerns prior to | Qualitative MMAT 1.1 to 1.5. | Y | Y | Patients reported their concerns into a website tool: Values In | Y | Y | Y | Y | Y | The recruited doctors worked at a university primary care clinic, where both patients and doctors may have higher academic and |

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| Malaysia | consultations with doctors to address patient unmet needs during chronic disease interactional consultations. | | | | Shared Interactions Tool (VISIT), and doctors viewed the information before consultations. Transcribed in-depth interview data after the consultations with 8 patients and 7 doctors were analysed thematically. | | | | | | so motivational levels to engage with PCC. In addition, the EMR required electronic and internet literacy and so limits the transferability to different practice population and possibly of lower socio-economic groups or the elderly. |
| 50. Roper, 2019 (Roper <i>et al.</i> , 2019) USA | Patient and clinician perceptions of pre-diabetes care: including attitudes to the national diabetes prevention programme (NDPP). | MMAT convergent mixed methods: 5.1 to 5.5; 4.1 to 4.5 (survey), CEBM survey checklist, and the CASP qualitative study checklist. | Y | Y | 31 clinicians completed a Likert scale survey on attitudes and barriers to prediabetes care. 15 patients took part in 3 focus groups, transcripts were thematically analysed. | Y | C | Y | Y | N | The decision to survey clinicians assumes they are hard to reach but reduced the comparison of patient and clinician data. The survey method limited the understanding of physician attitudes, which may have been better explored qualitatively. The study was conducted in academic family medical practices in the United States so, reduces transferability to similar western populations, but even the survey may not generalisable with the lack of statistical significance. |

11 References

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12 Appendix

12.1 Quality appraisal of the papers

A quality appraisal of the papers was tabulated and is presented within this section. Table 3 provides the detailed appraisal of individual papers and the systematic approach taken is shown.

Table of the Quality appraisal of the papers: using the Mixed Methods Appraisal Toolkit (MMAT), survey checklists from the Centre of Evidence Medicine (CEBM) and the Critical Appraisal Skills Programme (CASP) checklist.

Key: Pt = patient; ID no= number in the original 242 papers searched at abstract; S1 = Were there clear research questions (RQs)? S2=Do the obtained data enable you to answer the research questions? PCC= person-centred care, DCC=disease centred care; columns 7 to 11 are numbered 1 to 5 and relate to the equivalent part of the MMAT methods quality criteria, e.g, in a survey appraisal this would be criteria 4.1 to 4.5 and related to columns 1 to 5; C= Can't tell, Y= Yes, N= No; CDM= Chronic disease management; PHQ-9 = Patient Health Questionnaire-9; GAD7=Generalised Anxiety Disorder scale. For mixed methods papers, the relevant other questions for the research types were also applied (MMAT quality criteria 1.1 to 4.5).

| Paper ID no., First author' year, country. | Research Aim or RQ. | Appraisal tool used | S 1 | S 2 | Methods and participants | 1 | 2 | 3 | 4 | 5 | Comments on quality appraisal: Value and Limitations |
|---|--|---|-----|-----|---------------------------------------|---|---|---|---|---|--|
| 21. Wollny, 2021 (Wollny <i>et al.</i> , 2021) Germany | An educational intervention to increase PCC and SDM for patients with poorly controlled T2DM | MMAT 2.1 to 2.5 and the CASP RCT checklist. | Y | Y | Cluster RCT, 833 patients and 108 GPs | Y | Y | Y | Y | Y | 24 months of follow up Study participants were not blinded, but patients and the study researchers collecting data were not aware of group allocation. There was low loss to follow up and attempts to reduce bias such as standardised interviewer training. The subjective assessment of SDM and the possible inclusion |

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| | | | | | | | | | | | | of motivated GPs may create bias but does not explain the negative outcome. |
| 238. Kinmonth et al., 1998. UK | GP and nurse training | MMAT 2.1 to 2.5 and the CASP RCT checklist. | Y | Y | Pragmatic parallel group design with 250 patients with T2DM and randomisation into intervention versus routine care. | Y | Y | Y | Y | Y | Y | The baseline variables were similar for both groups and the practitioners were not aware of the hypothesis and so, blinded to the intervention. The data also relied on self-reported effects of diet and exercise and may suggest knowledge of patients, but not actual behaviours. The intervention was a short (1.5 days for nurses and 0.5 days for GPs, and two further 0.5 day follow up sessions) training on a biological and psychosocial based communication style. |
| 29. AlRuthia, 2020 (AlRuthia et al., 2020) Saudi Arabia | Diabetic patient trust in HCP measure compared with patient depression and anxiety scores. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 367 diabetic patients | Y | Y | Y | Y | Y | Y | Patients with significant mental health diagnoses were not included and the results apply to patients with mild or moderate depression or anxiety only. Patients' recall bias may reduce internal validity. Psycho-social issues or other medical/non-medical problems were not sought and may have been important confounding factors |
| 17. Ngassa, 2021 (Ngassa Piotie et al., | Attitudes and beliefs of primary care HCP towards insulin initiation | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 23 doctors and 50 nurses from 23 clinics. | C | C | Y | Y | Y | Y | The adapted survey had credible sections relevant to the topic and adapted to extend to nurses. The process of inclusion/exclusion of the participant HCPs were not detailed to |

| | | | | | | | | | | | | |
|---|---|--|---|---|---|---|---|---|---|---|---|---|
| 2021). South Africa | | | | | | | | | | | | confidently know if there could be selection bias. The sample was small so statistical power calculations were not possible or mentioned, and the results are not generalisable. |
| 55. Tamir et al., 2018 (Tamir <i>et al.</i> , 2018) Israel | Comparing physician and patient understanding of diabetes-related QoL | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey: 136 patients completed a QoL survey before their appointment; 39 physicians completed the same questionnaire after the visit. | Y | Y | Y | Y | Y | Y | Convenience sampling of patients recruited within clusters of practice populations- so there is a risk that the data is not generalisable wider than these demographics and a risk the sample is not representative of the population within the cluster. Calculations were made of the minimum sample size based on assumptions explicit in the paper. |
| 62. Millar et al. 2018 New Zealand | The health care experiences of patients with multimorbidity | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Survey questionnaire of 234 patients | Y | Y | Y | Y | Y | Y | Despite researchers' attempts to strengthen recruitment to work closely with the two health primary healthcare organisations, a poor response rate to patient invitation during recruitment was observed. As a result, satisfied patients, or patients with difficulties to complain about may be overrepresented, underestimating or overestimating the outcomes. Similarly, non-responders may include individuals who were |

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| | | | | | | | | | | | | concerned that their GPs would see their response, causing the results to overestimate the population perception of their doctor. |
| 73. McCreedy, 2018 (McCreedy <i>et al.</i> , 2018). 7 USA | Individualised goal setting for HbA1c targets for diabetic geriatric patients. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | 336 primary care clinicians (internists, nurse practitioners and family physicians) answered a vignette-based survey on their intended management | Y | C | Y | N | Y | | Vignettes may provide a reliable source of evidence of doctor clinical behaviour, and results align with another survey s showing 1/3 rd of doctors may not follow recommendations for older adults. - Results are not generalisable: Convenience sample of doctors, and low response rates. The sample may not represent the target population of doctor due to: 1) non-response error (doctors less motivated to respond may be missed and so, underestimate those not following guidelines and that may over /under treat older T2DM patients; 2) coverage bias (only 60% of the licensed doctors' emails were available when recruitment began with a limited access to all possible eligible doctors). |
| 122. Ali <i>et al.</i> , 2016 (Ali <i>et al.</i> , 2016). USA | HCP management of patients with diabetes during Ramadan. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Survey of 45 HCPs | Y | C | Y | N | N | | As a pilot study the research was important due to the lack of knowledge on the topic. The numbers were too low to allow outcome generalisation and there were no power or statistical significance figures provided. There was also a low response rate which may add response bias. The self-reported |

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| 166. Kurpas et al., 2013 (Kurpas <i>et al.</i> , 2013). Poland | Correlations between patient characteristics and their assessments of the quality of primary healthcare. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Survey of 232 patients. | C | C | Y | C | C | | Recruitment: patients were given questionnaires to complete at home after clinic attendance and signing a consent form, with a 49% response rate. Further details are not given other than the resultant demographics. The outcomes relate a correlation between male gender and satisfaction with PCC aspects of care and there is lack of clarity of female gender and satisfaction and may have led to important gender-based findings if they had been sought in the survey data. |
| 172. de Figuerire do et al., 2013 (de Figueiredo, Snoek and Barreto, 2013) Brazil. | Exploration of patient and physicians' agreement over diabetes management. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | This cross-sectional survey study of 282 patient-physician pairs | Y | Y | Y | Y | Y | | Efforts were made to increase the quality of the survey: a qualitative study to explore patient understanding of the questions, and questionnaires were pre-tested. The diabetes training of doctors was unknown and may have confounded the results e.g., better trained doctors may communicate differently. Interviews with drs to complete the survey took place after doctor appointments and may have influenced the motivation and quality of the doctor patient interactions. |

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| 177. Houle et al., 2012 (Houle <i>et al.</i> , 2012). Canada | PCC: evaluation of chronic illness care delivery from the patient perspective. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | A cross-sectional survey study of 364 patients with diabetes, hypertension, or COPD using the patient assessment of chronic illness care (PACIC) score. | Y | Y | Y | Y | Y | Cross sectional design- so located at a point in time and unable identify a direction of associations observed. Recruitment bias: convenience sample of patients recruited in waiting rooms, so bias towards frequent attenders and potentially subgroups of patient with high levels of need. All the practice locations were training centres and so, limits the generalisability, but may also emphasise bias towards biomedical outcomes and less towards chronic care management (CCM). |
| 188. Ratanawongsa et al., 2012 (Ratana wongsa <i>et al.</i> , 2012). USA | PCPs' self-reported perceptions of the barriers to insulin initiation in T2DM. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 83 primary care physicians (PCPs). | Y | Y | Y | N | N | Sampling from the three different health systems may not be generalisable to other health systems nor demographic populations. GPs were interviewed and asked to reflect on patient care to answer the survey questions- with possible recall bias; sample sizes were small, and no statistical power or significance calculations were provided confidently associate factors such as experience to attitudes. |
| 183. Luijks et al., 2012 (Luijks | Explore GP perspectives of the main aims and influencing | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Five focus group interviews with 25 GPs, analysed by | Y | Y | Y | Y | Y | The focus groups were kept to 4 to 6 GPs to increase likelihood of individuals participating in discussion. |

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| <i>et al.</i> , 2012) Netherlands | factors on their management in practice. | | | | applying the technique of constant comparison. | | | | | | Limitations: high numbers of academic GPs, with possible bias towards well- informed PCC advocates; GP perspectives were sought but cannot be extrapolated to observed GP behaviours; the focus groups took place in Dutch, so translated quotes may not have the exact meaning as imparted by the GP. |
| 205. Christensen et al., 2010 (Christensen <i>et al.</i> , 2010). USA | Patient and physician attitude to health locus of control (HLOC) compared to medication adherence, BP and HbA1c. | Quantitative descriptive, MMAT 4.1 to 4.5 | Y | Y | 18 primary care physicians and 224 patients with T2DM and hypertension were recruited as dyad pairs. | Y | N | Y | Y | Y | The sample was composed of older Caucasian male veteran patients, and so, women and diverse populations were excluded, reducing generalisability. Additionally, the response rate was 58% and the final sample may be nonrepresentative of the population overall. Adherence was measured by prescriptions refilled at patient request, but that does not ensure patients are compliant. However, this method is believed to be the most reliable measure of adherence in retrospective data. |
| 242. Joos et al., 1993 (Joos, Hickam and Borders, 1993) | The frequency with which physicians met patients requests and needs. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | 243 patients, 41 doctors | Y | Y | Y | Y | Y | Located in a university affiliated veterans' clinic with no female patients limits the generalisability of the data. |

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| USA | | | | | | | | | | | | |
| 189. Green et al., 2012 (Green, Rothman and Cavanagh, 2012). USA | Relationship of depression symptoms with patient centred communication. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Audio-recordings of consultations with 95 diabetic patients were coded using the Rota Interaction Analysis System (RIAS) | Y | Y | Y | C | Y | Sited in an academic primary care unit: limiting transferability This study uses the construct of physician-centeredness and disease-centeredness or biomedical focus synonymously- which ignores possible confounding by other factors that make for a physician or doctor-centred focus. Recruitment sampling and response rates are not clearly described. | |
| 211. Swenson et al., 2008 (Swenson et al., 2008). USA | Relationship of depression symptoms with patient centred communication. | MMAT 4.1 to 4.5; and CEBM Survey checklist | Y | Y | Cross-sectional survey of 231 T2DM patients using a measure of interpersonal processes of care (IPC) tool | Y | Y | Y | Y | Y | The authors used multivariate logistic regression to adjust findings for age, sex, ethnicity, language, diabetes comorbidities and trust, which adjust for possible confounding factors. The Centre of Epidemiologic Studies Depression scale CES-D 10 scale was used to measure depression which was self-reported by patients and may overestimate depression compared to the standard of diagnostic appointments with doctors. However, CES-D 10 has high specificity and the | |

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| | | | | | | | | | | | | findings reported relate severe depression, which is likely to be more credible. Patient reports of clinician-patient communication may be open to recall bias, but is defended by the authors by citing literature that shows patient recall of visits may be accurate. |
| 45. Sidorkiewicz et al. 2019 (Sidorkiewicz et al., 2019) France | Agreement between patients and GPs on What are the chronic conditions affecting patients prioritising them. | Cross-sectional Survey MMAT 4.1 to 4.5 | Y | Y | Convenience sample of 16 GP practices in Paris, recruiting 233 patients. 153 patient-GP pairs were analysed. | Y | Y | Y | Y | Y | | Convenience sample so may not represent the target population. In addition, the sample was small- so may not provide enough internal validity. The urban setting, with higher-than-average educational levels of patients may have improved outcomes and agreement with GPs and may not represent the wider French population. The language used in the survey was similar for GPs and patients with a risk for patient misunderstanding of medical terms and under/overestimate patient agreement. |
| 163. Kutob et al., 2013 (Kutob et al., 2013). USA | Impact of a cultural competence diabetes care course physicians' self-reported cultural competence. | Quantitative non-randomised study: Case-control study: MMAT 3.1 to 3.5 | Y | Y | Doctor groups: Control=41; intervention=4 Self-reported cultural competence measure: the cultural competence assessment tool (CCAT). | Y | Y | Y | N | Y | | The recruited doctors had background experience in working with diverse populations (by virtue of the Medicaid patient populations in their care), who had already had previous cultural competence training, so may not be typical of the possible wider USA doctor population. |

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| | | | | | | | | | | | | | | | The small sample size limits comparison between subgroups. There was no pre-test data in the design, so baseline differences between the intervention and control groups before and after intervention cannot be understood to account for the lack of impact of the study. |
| 80. Rutten, 2018 (Rutten <i>et al.</i> , 2018). Netherla nds | Patient and provider survey after an interventional consultation model to aid PCC. | Cohort non- randomised intervention trial MMAT 3.1 to 3.5 | Y | Y | Survey of 1487 patients with T2DM and T1DM, 57 GPs, 23 PNs in primary care; and 17 medical specialists and 8 diabetes specialist nurses (DSNs) from hospital outpatient clinics. | Y | Y | Y | Y | Y | Y | | | | The research practices were not randomly selected, so selection bias is possible, especially with over representation by group practices. The number of participating GPs and nurses age and sex were comparable to the target population. For 28% pf patients, care providers reported that the model was not fully applicable, due to a social or other specific complaints. The authors argue that the model intervention would have helped in these cases as part of the social determinants of chronic ill-health. However, these cases may have been confounding factors for patient health, and moreover, the HCPs were not cognisant and so fully trained in the model- an indication that the training may not have been delivered as intended. |
| Hojat et al., 2011. (Hojat | Physician empathy compared to patient clinical | Quantitative non-randomised cohort study | Y | Y | 29 primary care physicians, 1154 patients. | Y | Y | Y | Y | Y | Y | | | | Multiple confounding factors (culture, race, ethnicity, severity of disease) and the research does not control for all these factors. |

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| <i>et al.</i> , 2011) USA | outcomes (HbA1c and LDL-cholesterol) | MMAT 3.1 to 3.5 | | | The study used the Jefferson Scale of Empathy (JSE). | | | | | | The setting was academic with bias toward motivated GPs, and so overestimating the empathy scores. |
| 53. Chaitoff, 2019 (Chaitoff <i>et al.</i> , 2019) USA | Physician empathy compared to patient clinical outcomes (HbA1c and LDL-cholesterol) | Quantitative non-randomised cohort study MMAT 3.1 to 3.5 | Y | Y | 4176 patients, 51 primary care professionals. The study used the Jefferson Scale of Empathy (JSE). | Y | Y | Y | Y | Y | Use of a credible quantitative empathy scale, and conceptually linked to measurable outcomes, and the outcomes were measured over 3 years, which is longer than most. It replicated a Spanish study (Hojat <i>et al.</i> , 2011) with a larger cohort and diversity of patient population, adding validity. Although not detailed in the paper, it is assumed that linear logistic regression statistical method used involved power calculations. The study's different setting and time may account for the likely unfavourable outcome for Chaitoff et al, compared to (Hojat <i>et al.</i> , 2011), confounded by more CDM care available as part of systematic processes in the intervening years in the USA. |
| Lee and Lin, 2011 (Lee and Lin, 2011). Taiwan | To investigate if patients with high levels of decision-making preferences have higher levels of trust | Quantitative Non-Randomized cohort study. MMAT 3.1 to 3.5. | Y | Y | A one-year longitudinal study with 614 T2DM patients, comparing self-reported health survey | Y | Y | Y | Y | Y | The research design recognises the patient physician relationship and inherent longitudinal nature of patient care in contrast to previous primarily cross-sectional research. |

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| | | | | | validated the typologies. | | | | | | <p>have been mitigated by seeking patients with a range of self-efficacy scores using the diabetes management efficacy scale.</p> <p>Small samples of patients and potential for more diverse data that has been missed and so, possible additional typologies, but the diversity in the group of patients in terms of age, gender, ethnicity allay this limitation to an unknown degree.</p> |
| 195. Cocksedge et al., 2011 (Cocksedge <i>et al.</i> , 2011). UK | PCC: explore the concept of 'holding' as a management strategy in primary care. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | GPs and patients were recruited from urban and suburban areas in northwest England participated in interviews and the data was analysed with constant comparative analysis. | Y | Y | Y | Y | Y | <p>'Holding' is defined as "establishing and maintaining a trusting, constant, reliable relationship that is concerned with ongoing support without expectation of cure".</p> <p>Convenience sampling: recruitment of possibly homogenous sample of GPs known to researcher may result in a lack of diversity of GPs and bias towards academic/GP trainers with lack of transferability. All were white British GPs, However, limiting responders to over those in practice over 5 years and urban/suburban location complemented previous research. Patients were recruited by the GP and this process may have had selection bias with agreeable patients, as all patients invited agreed to participate.</p> |

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| | | | | | | | | | | | | As with self- reported data in qualitative research, there may be recall bias. The data informs on what doctors believe they do, but this may not be what they do. |
| 193. Adams et al., 2011 (Adams and Carter, 2011). Barbados | Patient experiences: knowledge, attitudes, practices, and barriers to T2DM and hypertension care experienced | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 5 focus groups with 21 patients over 40 years of age (5 diabetic, 5 hypertensives, and 11 with both diseases) with a mean age of 59 years, content analysis methods applied to the transcribed interviews. | Y | Y | Y | Y | Y | Y | Patients were recruited randomly, through cold calling from the Barbados voters register. Smaller focus groups than planned with unexplained drop out rate. |
| 5. Mathew et al, 2022 (Mathew <i>et al.</i> , 2022) Singapore | Aspects of the patient provider relationships (PPR) that affect insulin related behaviours: initiation and adherence | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Grounded theory approach, thematic analysis of transcripts; semi-structured interviews. 21 patients. | Y | Y | Y | Y | Y | Y | Recruitment: purposive sampling. Multiple coders and seen as positive by the research team which indicates an arguably neopositivist and less reflexive thematic analysis (Braun and Clarke, 2021b). Patients that were non-adherent also expressed views. Transferability limited to primary care patients on basal or premixed insulin only. |
| 64. Kristensen et al, 2018 | Understanding patient perspectives of disease and | MMAT 1.1 to 1.5, and CASP | Y | Y | 13 patients with T2DM underwent qualitative | Y | Y | Y | Y | Y | Y | Given that it is set among poor socioeconomic groups, the research may be confounded by a high occurrence of |

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| (Kristensen et al., 2018a). Denmark | self-care and the GP's role in supporting patients that the GP had labelled as impaired in self-care ability. | Qualitative Appraisal checklist | | | interviews that were analysed using a systematic text condensation method. Theory used: shifting perspectives model of chronic disease. | | | | | | psychosocial disorders. The researcher was a GP: a risk of patients withholding information. The authors argue the use of other HCPs to reduce conceptual blindness by the researching GP, but qualitative research is argued to be from the perspective of the researcher- so additional HCPs can provide disparate perspectives (Braun and Clarke, 2021b). |
| 97. Young et al, 2017 (J. Young et al., 2017). New Zealand | Patient and HCP perspectives on the concepts of a vision of care (VoC), shared vision of care (SVoC) and the patient's own care network- 'community of clinical practice' (CoCP). | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Social constructionist theory, Ethnographic methodology observing nine CoCP in one GP setting. In-depth qualitative interviews thematically analysed using a 'template organising style'. | Y | Y | Y | Y | Y | The small number of participants may be argued to narrow the subjective knowledge achieved, especially if the selection of patients by the HCPs was biased. The researcher was also involved in clinical care of patients- with a risk that participants may have been less open about negative tensions amongst the CoCP. |
| 103. Burrige et al, 2017 (Burrige et al., 2017) | Explore patients views of a service innovation aimed at supporting T2DM management of their diabetes and | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Normalization Process Theory (NPT) provides a framework to understand patient self-care and engagement with a GP-led | Y | Y | Y | Y | Y | Transferable outcomes that may apply to specialist GP led services in similar settings to the suburban Brisbane locality. The study is an qualitative evaluation for a cluster RCT. 30 patients were interviewed at baseline and 5 were lost to follow-up at 12 months after first contact with the care model, |

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| Australia | maximise patient engagement. | | | | specialist multi-disciplinary clinic. Semi-structured and audio-recorded interviews with 25 patients , thematically analysed. | | | | | | | with potentially bias towards patients able and motivated to feedback on the innovation. |
| 108. Methley et al, 2017 (Methley <i>et al.</i> , 2017). UK | Patient and provider perspectives of UK healthcare services for MS. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 24 patients with MS, 13 practice nurses, 12 GPs, 9 MS nurses; semi-structured interviews analysed thematically; used the theoretical framework of candidacy and themes were mapped to the NICE guidelines. | Y | Y | Y | Y | Y | | MS is a fluctuating and progressive disease, so additional interviews over time may have helped. Focus on the role of primary care in MS management, and a gap in the wider knowledge. Most patients were over 50 years, white British and nearly half the group were fully ambulant. The research may have benefited from a more diverse participants in age, ethnicity, functional disability, and socio-economic demographic. A low response rates from GPs and PNs impacted the low primary care recruitment of MS patients, and most patients were recruited via secondary care run community clinics where patients may have had more stable symptoms. |
| 212. Russell et al., 2008 | To evaluate the impact of the chronic | MMAT 1.1 to 1.5, and CASP | Y | Y | Semi structured interviews | Y | Y | Y | Y | Y | | Analysis considered two frameworks for understanding physician perspective: whether |

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| (Russel I <i>et al.</i> , 2008). Canada 35 | illness care management plan (CICM). | Qualitative Appraisal checklist | | | with a purposive sample of 13 family physicians (FPs) and 20 patients. | | | | | | they understood principles of care planning and whether they implemented practice change. The purposive sample was from small practices in Ontario already involved in research so, may be over representative of enthused FPs. This sampling reduces transferability of the findings. The FPs nominated patients and there may have been bias toward patients with positive experiences. |
| 215. Abdulha di et al, 2007. Oman | PCC: perception of patients with T2DM of medical encounters and quality of interactions with primary care providers. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Purposive recruitment of 27 patients from 6 primary health centres took part in four focus groups (2 male and 2 female groups). The principles of content analysis were applied to code data and produce themes. | Y | Y | Y | Y | Y | Men and women were placed in separated focus groups and is credibly defended as culturally appropriate to the region and allowed more active participation by women. In contradiction, a male moderator conducted the female group- however the findings were similar in both types of groups and may indicate trustworthiness. Authors attempted to increase dependability with team debriefing during data collection, and independently reviewing transcripts- but this arguably may increase the researcher variability in the interpretation of data (Braun and Clarke, 2021b). |
| 221. Fagerli et al., 2005 | PCC: Norwegian HCP | MMAT 1.1 to 1.5, and CASP | Y | Y | Semi- structured interviews, | Y | Y | Y | Y | Y | All the GPs were women, the 2 male GPs recruited cancelled |

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| (Fagerli <i>et al.</i> , 2005). Norway | perspective of experiences with patients of Pakistani background when giving dietary advice T2DM. | Qualitative Appraisal checklist | | | with a purposive sample of 6 dieticians and 6 primary care doctors or specific healthcare workers. transcribed and analysed phenomenologically. | | | | | | their appointment due to their own lack of time. The interview guide was loosely followed to allow the participants to freely express themselves and adds to validity. Iterative process was followed with successive transcription and analysis of each interview, as well as informal discussion with some of the participants with regard to the findings. |
| 220. Haque <i>et al.</i> , 2005 (Haque <i>et al.</i> , 2005). South Africa | PCC: barriers to the initiation of insulin in type 2 diabetes to patients on maximal oral medication in community health centres. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | 5 focus groups of a purposive sample of 46 medical officers (MO), followed by 10 in depth semi-structured interviews with MOs at primary care community health centres managing T2DM patients. | Y | Y | Y | Y | Y | Knowledge, beliefs, and fears are grouped together as constructs for doctors and separation may have made the physician attitudes clearer. There was little information of the researchers and the role or potential bias. However, the triangulation with focus group, 1:1 interviews and feedback to the participants adds to validity, though detail is limited on feedback outcomes. |
| 235. Bartz <i>et al.</i> , 1999 (Bartz and Francisc o, 1999). | A single-family doctor's use of the biopsychosoci al model in the care of an urban | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Case study: Dr M and the 9 patient interactions were audio-recorded and analysed using narrative | Y | Y | Y | Y | Y | The transcribe interviews were interpreted using methods adapted from Narrative and discourse analysis, interactive ethnography, and grounded interpretive research, which arguably may lead to methodological confusion as |

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| USA | population of Native American patients with T2DM. | | | | discourse analysis. | | | | | | <p>they all have different epistemological underpinnings. However, the themes that emerged were analysed using interpretive dialogue (ID) with the case doctor and contextualised her understanding of the interactions with additional reflection.</p> <p>This added reflection caused iterative reframing of the problem by considering Dr M's knowledge of the person and disease within the context of mistrust and misunderstanding. The transferability of the data may be limited with specific cultural narratives, and an initially idealised representation of a community doctor selected for her patient empathy and reflective nature.</p> |
| 237. Helseth et al., 1999 (Helseth <i>et al.</i> , 1999). USA | FP attitudes towards diabetes, and diabetes care compared to internal medicine physicians. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | In-depth interviews with 10 family physicians (FP) and 9 internists were audiotaped and transcribed. A 'text analysis' following the strategy of McCracken, and Crabtree and Miller was | Y | Y | Y | Y | Y | <p>Purposive sampling was used to recruit male and female doctors, with a wide age range, but there is little information of the participants demographics, and the transferability will be limited by the locale of Connecticut in the USA.</p> <p>A medical student conducted the interviews with potential power differentials and arguably, lack of experience in both research and clinical care to probe the qualified and senior doctors.</p> |

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| | | | | | applied to the data. | | | | | | | Although the interviews took place in 1991, before the guidance for tight diabetic control and apparently of that time, but still has the current themes of doctors balanced disease centred perspectives with those of patient centred care. |
| 33. Murdoch , 2020 (Murdoch <i>et al.</i> , 2020). UK | Goal setting for patients with multiple long-term conditions (LTC). | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Uses 'Goffman's concepts of frames to understand goal setting. Conversation analysis was used to analyse 22 video-recorded consultations between patients and doctors from 3 UK general practices. | Y | Y | Y | Y | Y | | The transferability is limited to the geographical location, practice type and patient population in Norfolk and Suffolk in the UK setting. More diverse populations may include marginalised populations with arguably lower agency and involvement in SDM and goal-setting. |
| 198. Williams <i>et al.</i> , 2011. UK | Explore and compare the asthma goals of health professionals and people with asthma in primary care and identify barriers to shared goals. | MMAT 1.1 to 1.5, and CASP Qualitative Appraisal checklist | Y | Y | Semi-structured interviews, with 15 patients with asthma, 7 GPs 6 primary care nurses transcribed and analysed | Y | Y | Y | Y | Y | | A purposive sample of medical rural (4) and urban (4) practices in Tayside, Scotland. The authors hypothesise that smaller practices may have fewer HCPs and so, more personal goal-setting practices with patients (stronger relationship implied). There was a dominance of female non-smokers in the high asthma severity and duration |

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| 143. Wiley et al, 2015 (Wiley et al., 2015). Australia | Whether T1DM patients engage with the MDT management processes and why. | MMAT mixed sequential explanatory design. 5.1 to 5.5, 1.1 to 1.5 and the CASP qualitative study checklist; survey 4.1 to 4.4. | Y | Y | Web-based survey of 150 T1DM patients aged 18 to 35y; Semi-structured interviews of 33 patients analysed for thematically. | Y | Y | Y | Y | N | The survey was small with no statistical significance figures provided and obvious potential for recruitment bias identified by authors as being towards females, educated, with health insurance and suspected better glycaemic controls than national averages. It took 40 minutes to complete, and the length may have added response bias if less motivated patients found this too long. The qualitative methods appear credible with appropriate themes and supportive quotes. Despite the limitations the survey data has informative results and provides meaningful support to the qualitative data. |
| 175. Trachtenberg et al., 2014 (Trachtenberg et al., 2014) USA | To examine clusters or physician decision-making behaviours for patients with T2DM, including for those with mental health comorbidities. | Mixed methods sequential exploratory design: Qual, Quan; MMAT; 5.1 to 5.5; 1.1 to 1.5, and CASP Qualitative Appraisal checklist. | Y | Y | The researchers presented video vignettes of patients with uncontrolled T2DM to 256 primary care physicians and structured interviews about clinical management were analysed. | Y | Y | Y | C | Y | The authors related a previously published study that used the same methodology: using physicians' qualitative interview responses and used a quantitative statistical method to cluster doctors' responses about how they managed their patients. The epistemology of this process of analysis is arguably, the methods is quantitative and positivist in nature. The subjective coding of the structured interviews adds bias to the resultant quantitative outcomes, the use of cluster analysis techniques is a method to show data saturation of behaviours. |

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| | | | | | | | | | | | | | | | Despite the possible methodological issues of performing quantitative analysis of qualitatively achieved data, the output clusters appear credible and informative of a 'styles' of management, supporting another similar study based on cardiac management. |
| 176. Wiley et al., 2014 (Wiley <i>et al.</i> , 2014). Australia | T1DM patients' perceptions of the SDM delivery of different clinician groups. | MMAT mixed sequential explanatory design. 5.1 to 5.5, 1.1 to 1.5 and the CASP qualitative study checklist; survey 4.1 to 4.4. | Y | Y | Web based survey of 150 patients with T1DM aged 18 y to 35 y. 33 patients (27 female, 8 male) took part in 7 focus groups rating the 7 aspects of SDM in their interactions with endocrinologist, DM educators, dietitians, and GPs. | Y | Y | Y | Y | Y | | | | | Recall and reporting bias risk: The survey asked patients about their interactions with the HCP and gave no timeframe limit for when the patient/HCP interaction had occurred. Recruitment bias: self-selection recruitment through advertisements. Gender bias - 80% were female, Socio-economic bias to highly educate groups with 79% with tertiary or high education level. Potentially- these limitations may lead to patient bias toward the active use of SDM |
| 217. Lawn et al., 2007 (Lawn <i>et al.</i> , 2007). | The feasibility and utility of the Flinders model: a partnership model of care between GPs, mental health | Mixed method: sequential explanatory design: Quantitative non-randomised cohort study, MMAT 3.1 to | Y | Y | 38 patients identified their self-management using the Flinders model, which was compared with | Y | Y | Y | C | C | | | | | The Flinders Model used allowed patients to choose individual or group interviews, with the explicit reports from patients that group work exacerbates their mental health. The Flinders model comprises measures of Partners in Health |

| | | | | | | | | | | | |
|--|--|--|---|---|--|---|---|---|---|---|--|
| Australia | case managers, and patients for people with significant mental illness. | 3.5 and qualitative evaluation: MMAT 1.1 to 1.5. | | | the peer-led Stanford patient self-management education course and one to one peer support interventions. Measures: Self-Management and QoL, and survey and focus group | | | | | | (PIH), Cue and response (C+R) and Problems and Goals (P+ G), which allowed 3 different ways to measure patient preferences and perspectives of care plan negotiation. Convenience sampling may limit generalisability of outcomes. 20 patients also undertook the Stanford course may have confounded the results, and little account was made for other confounding factors of family, lack of social support, diagnostic differences, age, gender- which may affect self- care. There is insufficient information provided to know if the if the quality criteria of survey or focus group evaluation. |
| 239. Kinmonth et al., 1996 (Kinmonth, Spiegel and Woodcock, 1996). UK | Aiming to develop a training programme on patient centred consulting for GPs and nurses through action research methods. | Mixed methods: Sequential explanatory design: Action research, and later survey. MMAT 5.1 to 5.5 | C | C | Action research with 4 primary care teams and their patients, with 23 GPs and 32 practice nurses. The diabetes review consultations were observed before and after training, and they also answered a survey | C | C | C | C | C | The design of the research to develop the training programme involved multiple methods, and they were not described in enough detail to critique the development of the programme itself. E.g. a psychologist observed and taped 12 GP or nurse-Patient consultations, but not enough detail of the qualitative method is given. However, the evaluation of the programme was through a survey which rated a series of questions on a Likert scale, but the numbers of GPs and nurses |

| | | | | | | | | | | | | |
|---|--|--|---|---|---|---|---|---|---|---|--|---|
| | | | | | evaluation of training after each session. | | | | | | | were too small with no statistically significant figures given; and may not be representative of HCPs beyond the locale, with potential for nonresponse bias. |
| 40. Claramita et al, 2020 (Claramita <i>et al.</i> , 2020) Indonesia | Doctors' perceptions through self-assessment and patient perceptions of experiences of a PCC method of partnership orientated communication- testing the 'Greet-Invite-Discuss' guideline. | Mixed methods 5.1 to 5.5 sequential explanatory: cohort study 3.1 to 3.5, later qualitative MMAT 1.1 to 1.5. | Y | Y | 30 doctors were assigned to consult 45 patients with hypertension or T2DM. Doctor training in PCC delivery, and updates in hypertension or T2DM; then assigned to consultations with patients. Outcomes: patient and doctor surveys, Biological outcomes; focus groups. | Y | Y | Y | Y | Y | | The follow up time was only 6 weeks and arguably too short to allow for the observed biomedical changes, but the results are presented with statistical significance, so appear credible. A longer cohort study may have helped to show a sustained effect of the intervention. The small sample size of doctors and patients may make the data less generalisable or transferable to the wider community of GP nationally and beyond. |
| 89. Lee et al, 2017 (Lee, Ng and Low, 2017). Malaysia | The identification of patient concerns prior to consultations with doctors to | Qualitative MMAT 1.1 to 1.5. | Y | Y | Patients reported their concerns into a website tool: Values In Shared Interactions | Y | Y | Y | Y | Y | | The recruited doctors worked at a university primary care clinic, where both patients and doctors may have higher academic and so motivational levels to engage with PCC. In addition, the EMR |

| | | | | | | | | | | | |
|---|---|--|---|---|--|---|---|---|---|---|--|
| | address patient unmet needs during chronic disease interactional consultations. | | | | Tool (VISIT), and doctors viewed the information before consultations. Transcribed in-depth interview data after the consultations with 8 patients and 7 doctors were analysed thematically. | | | | | | required electronic and internet literacy and so limits the transferability to different practice population and possibly of lower socio-economic groups or the elderly. |
| 50. Roper, 2019 (Roper <i>et al.</i> , 2019) USA | Patient and clinician perceptions of pre-diabetes care: including attitudes to the national diabetes prevention programme (NDPP). | MMAT convergent mixed methods: 5.1 to 5.5; 4.1 to 4.5 (survey), CEBM survey checklist, and the CASP qualitative study checklist. | Y | Y | 31 clinicians completed a Likert scale survey on attitudes and barriers to prediabetes care. 15 patients took part in 3 focus groups, transcripts were thematically analysed. | Y | C | Y | Y | N | The decision to survey clinicians assumes they are hard to reach but reduced the comparison of patient and clinician data. The survey method limited the understanding of physician attitudes, which may have been better explored qualitatively. The study was conducted in academic family medical practices in the United States so, reduces transferability to similar western populations, but even the survey may not generalisable with the lack of statistical significance. |

12.2 Example Demographic Questionnaire

PARTICIPANT NO. ...

JEN.....Date.....1/11/08.....

| | |
|---|---|
| Age | 48 |
| Male or female | F |
| Year of qualification from GP vocational training | 1987 |
| Year of qualification with medical degree e.g. MBBS | 1984 |
| MRCGP | YES |
| Diplomas in specialist topics e.g. DFFP, DCH, DRCOG. | YES If yes please specify : DCH, DRCOG |
| Other graduate degrees or postgraduate e.g. Masters of Arts, BSc. | NO If yes please specify : |
| Special interest in diabetes | YES, (but not GPSI) |

| Practice details (please complete) | |
|---|--|
| Practice population (approx) | 4,000 |
| Number of principals | 2.5 FTE |
| Number of non-principals | 1 |
| Diabetic specialist nurse | NO |
| Ethnic minority population size | 30% approx |
| Ethnic minority population types e.g. Pakistani, South Asian, Afro-Caribbean. | Please specify: Pakastani Yemeni E. European African |
| Population over 55y (approx). | 800 |
| Do you refer to the central diabetes clinic for initiation of insulin or do you initiate insulin in the practice? | Please specify: Sonic project |

12.3 Interview Guide Outline Design

| Issue | Objective |
|--|---|
| Introduction | <p>To reinforce information about the study already given to the participant prior to the interview date.</p> <p>To sign the consent forms.</p> <p>Discuss timing and check there will be no disturbances.</p> |
| Opening topics | <p>Ease participant gently into the interview and help them appreciate the discursive, conversational style of data collection.</p> <p>Collect information that will help later stages of the interview, such as the role the practice nurse has in diabetes management at the practice. Later in the interview, the GP will be invited to discuss the decisions made by the nurse relative to those made by the GP.</p> <p>Have some discussion around of definitions such as the meaning of decision making for that individual GP, or what patient centred care means.</p> |
| Ask the GP to consider an example or situations that they have made a decision that a patient may need to start insulin. | <p>It may be easier to talk about an experience of decision making, in this case of starting insulin with a person with type 2 diabetes rather than discussing the general concepts of decision making. In this way the GP may they are talking of a behaviour they can recall and then discuss the motivational and attitudinal aspects of that behaviour.</p> |
| Take the lead from the participant as to subsequent questions. | <p>Aiming to probe into the particular perspective of that GP</p> |
| Toward the end, some discussion how the GP role in decision making with people with diabetes could be improved. | <p>This is winding the interview up, moving the perspective away from them as individuals. There may be a summary aspect to this so the interviewer can have the participant's opinion of the weight they attach to any expressed opinions.</p> |

12.4 Alices's narrative section example with interview opening

Below is the long narrative section of Alices's interview. It shows the opening interviewer question, and how Alice provided a long comfortable narrative of a memorable patient.

Interviewer: Right. So I just want you to consider any kind of diabetic patients that you've had that you've been involved in their care for and in particular just at this point, any patients that you have referred for or started insulin on that you can remember.

Alice: We've had a couple of diabetics. I'm talking about my patients from the practice I left in June this year so it's a little bit fuzzy.

Interviewer: Yeah.

Alice: But there were a couple of patients who I remember well. One of them was referred to the hospital because he had a bad foot and he had neuropathy and he was actually sent to the foot clinic and by the time they'd sorted him he came back to us on insulin so I didn't actually initiate him on insulin but I felt that it was the next step. At the time I don't think GPs were initiating patients on insulin as much then so that's one reason and he did really well. I think he realised what was at stake when his foot was really – I think he ended up losing a toe and that sort of helped him to make the transition to insulin and he was accepting of it. Unfortunately I've left the practice so I don't know what's recently become of him. He was one. There was another one who was a man who was being followed by the diabetic nurse at our practice and he hadn't come for his reviews twice and she'd sent a recall letter and the second time around he hadn't responded and she came to me and said 'what shall we do with this man?' and we brought him in and it turned out that he was diabetic, he was suffering from depression and the depression was the reason that he hadn't come for the diabetic reviews. He was depressed and I'd been seeing his wife for something else and she'd mentioned that he wasn't taking his medication and he came to me, basically because he hadn't come. We wrote him a letter to say that he needed to come and see the doctor and I'd seen him for the first time and he responded really well because when he first came he was not relating to the family, the marriage was very strained, he wasn't talking to his daughter, Christmas came and he didn't even come downstairs, that sort of picture. Really down in the dumps and nothing to live for and not performing at work and threats of redundancy and lots of problems and he actually, when I left the practice, he had gone back to work, his marriage was good and he was so turned around but to get him to face up to the diabetes we had to treat the depression and I think this was where it helped him to get there. He was just so fed up but I think when everything's coming at you all together you don't see the wood for the trees and he was brilliant, his A1C came down to something like 7 after being double figures and he'd done really well but he just needed time and the nurse was saying to him 'maybe we should, you know, if you don't respond, you don't respond, what can you do?' but there are reasons why people don't respond and you really need to see the person and you really need to be approachable and tell them – it's just the approach to him but he responded so beautifully and really a success story. I don't think he was ever started on insulin because he did well with the medication once he settled down so it's not quite the point but it's just really how you approach people I think is important.

Interviewer: Yeah. I mean that case in point that it's not just about the initiation of insulin, there is a whole load of things that you've talked about.

Alice: Yes and that may come and I think it's important to let people realise that it's not because they've failed that they need to go on insulin, if they do need to go on insulin, it's a process and the disease has a sequence of events to come and if he did have to go on insulin it wasn't because he was a miserable failure or he was delinquent or he was, you know, not compliant or anything, it was just that you have to work with the disease and sort of try and pre-empt things and try and prevent it and I think the more information you give, the better really because you have the tools to deal with it and you understand why you do it. So I'm all for patient education anyway, in a big way.

Interviewer: OK, yeah, that's interesting. You said patient education and you described tools. I mean what kind of tools – or is that what you meant when you said tools?

Alice: Yeah, just really information and the ability to access help when you need it, you can have support groups for diabetics, you know, with a diabetic clinics. A lot of diabetics often meet at the surgery at the same time and they swap stories and that's support as well. Dietician support, just keep exercising – there's an exercise group that was started in XTOWN I don't know what became of it but it was a walking group that was started to get people exercising.

Interviewer: Were you involved with XTOWN?

Alioce: Well, because we worked in the valley it was XTOWN and the health visitors did all the surgeries and they started a walking group there so we were part of the valley.

Interviewer

OK.

The interview continued after this. (XTOWN is a pseudonym for the town Alice worked in).

12.5 Pete's narrative section example with interview opening.

In contrast to Alice, Pete's interview was harder to direct around the research question, significantly, he was the first GP to be interviewed in the order of interview appointments obtained at the time. Consequently, the interviewer question may appear particularly restricted to the research question, but on reflection, the participant was less negaged in the process compared to Alice. However, he does co-produce the interview too, and directs the narrative towards his beliefs of what is valuable in. chronic disease management- based on dcotro-cnrted business attitudes. These attitudes are argued to be pragmatic and were convincing to the novice researcher, who on retrospect mayhave been more interrogating and critical of the participants views. As a salaried and sessional GP, the insider GP had little prior understanding of the mind-set Pete explained.

Interviewer: Um - And you remember you may recall the um, the question that was the project um that was on the consent form as part of the project, um and it is about um decision making in diabetes but the major interest is to how the decision making um a diabetes is really um the tool to help us talk about it.

Respondent: OK.

Interviewer: Um - But I just to - I just wanted to ask you um a little bit about your own um practice. U- You're a GP. Are you um a senior partner at the practice or not?

Respondent: No, not one, no of the other guys is the senior partner but I've been there for 25 years or so.

Interviewer: Yeah - And you mentioned you don't have um - you don't have a special interest in diabetes.

Respondent: I don't, no.

Interviewer: But you do –

Respondent: Two of the other partners do so they do most of the structured diabetic stuff and care.

Interviewer: Right, OK. And do you actually see patients with diabetes?

Respondent: Yes, but not usually to sort out the diabetic uh treatment.

Interviewer: Right, OK. So you might not get involved in that decision making process.

Respondent: Err, I think that's correct. I don't really.

Interviewer: OK. It doesn't really matter a great deal um but um it might be that you have an idea or an opinion on some of the parts of that starting to um -

Respondent: Sure.

Interviewer: The practice role for the nurse, how much of the nurse practitioner's role do you think is involved in diabetes at your particular practice?

Respondent: Erm, the practice nurse probably makes most of the decisions. Erm I guess in liaison with the two partners who are diabetic leads but um - but the practice nurse will make the decision to convert people to insulin and will then do it.

Interviewer: And then will do it as well?

Respondent: Mm.

Interviewer: Because you said that your practice does refer for insulin as well.

Respondent: Well, yes. I mean there's two – yes, but then there's a political dimension to it as well, as there always is.

Interviewer: Yes.

Respondent: Erm - The practice nurses have done it and are competent and capable of doing it but until there's a local enhanced service to enable it to be done, we tend to refer them to the hospital.

Interviewer: Ah, right.

Respondent: Erm - Because it's not something we would see as core general practice.

Interviewer: Yes, yes.

Respondent: So although we have the ability and the resources to do it um - and the technical know-how, we would - we currently are referring up because um - as I said, because it requires a process to be put in place to enable it.

12.6 Example of a thematic coding section

Note the longer section of text utilised as chunks of text (Riessman, 2008c) and contrasts to the of small line by line coding advocated by Charmaz (Charmaz, 2006). The length of the text is not considered relevant, as much as the key passages of interview different participants on the same topic (Miles, Huberman and Saldana, 2014).

The GP prescriber code (unrefined) is pictured and represents an early unrefined node stored in the NVivo software with an associated annotation (1) written at the time of early immersion in the data and first coding as nodes.

The screenshot displays the NVivo software interface. On the left is a coding tree with a hierarchical structure. The main window shows a text excerpt with a highlighted paragraph. An annotation window is open over the text, displaying two numbered annotations.

Coding Tree (Left):

- 1.0 Biomedical c
 - biomedical K
 - Biomedical p
 - Atypical p
 - Insulin I
 - biomedica
 - elderly
 - Insulin res
 - the biome
 - Chronic Dise.
 - Diabetes
 - EBM
 - GP Confidenc
 - GP prescribe**
 - Diabetic rr
 - GP annual
 - GP use of
 - Insulin
 - Medicatio
 - side effect
 - QOF
- 2.0 Person Cent
 - Depression a
 - Engagement
 - GP empathy
 - HCP with dia
 - Lifestyle
 - paternalism
 - patient and n
 - patient anxie
 - Patient belief
 - Patient Educi
 - Patient Feelir
 - Psychosocial

Main Text Window:

6 references coded, 12.23% coverage

Respondent

Yes, one in particular, a chap who's late 50s, very amenable, very keen on injecting himself and starting insulin and in the point of diagnosis of diabetes, not very keen on changing a big drinker, he was a smoker and we'd obviously identified he commenced on oral medication, he was not very keen on hit and miss with it and I think really it took a long time. couple of years and we got him off smoking, he cut down his drinking, he started taking his medication regularly but he started to develop microalbuminuria and other complications, at which point really we had to throw the book at him and say 'look, really this is what we have to do' because he still was not controlled on multiple medications. So he ended up, because of the complications he was starting to get, to refer him on and in fact he's been a brilliant patient on insulin because he now controls his blood sugars very well, he takes insulin, he takes Metformin and he's very much better controlled. I guess - this was - I mean I've seen him this week for example but this was a few years ago and I think at that stage the idea was trying to get tighter and tighter control of your blood sugars, which is probably one of the indications that we referred him on for insulin therapy whereas I guess now, the idea of what the studies suggest is maybe tighter control or very tight control is not beneficial and in fact, you know, targeting the lifestyle things, the blood pressure and stuff like that, the cholesterol, was much more important. I think with him we sort of targeted those but as I say, probably we also targeted the blood sugars more and now more evidence has come to light to say blood sugars, OK, don't worry too much if it's a little bit high but actually blood pressure and all that. So our perspective with him has changed a little bit although we have treated his blood pressure and his cholesterol but it's taken four or five years but he has completely changed around and is now a very good patient.

Reference 3: 1.08% coverage

Yes, one in particular, a chap who's late 50s, very amenable, very keen on injecting himself and starting insulin and in the point of diagnosis of diabetes, not very keen on changing a big drinker, he was a smoker and we'd obviously identified he commenced on oral medication, he was not very keen on hit and miss with it and I think really it took a long time.

Annotation Window (Right):

Search

Annotation

- 1 The doctor is here displaying his knowledge of the guidance for management of diabetes optimally versus his the management he is required to achieve targets of pay. He also presents his idealistic opinion of what is best practice for diabetic hypertension targets and what he aims for.
- 2 QOF is described here as being of lower target in order to achieve it is another idealistic presentation by the doctor setting the GP in a light that he would aim for better than the QOF target of management because he sees this as less optimal. It is an example of how he is aiming at better than

12.7 Example GP case file with coding stripes in NVivo

The following picture captures a screenshot of thematically analysed transcribed interview data from James. The coloured stripes are the actively coding stripes for that section of narrative text and show the ability code the same check of narrative section with multiple times.

The screenshot displays the NVivo interface with a list of codes on the left and a transcribed interview on the right. The interview text is segmented into paragraphs, with yellow highlighting indicating coded sections. On the right side, a vertical bar shows colored stripes corresponding to the codes applied to the text. The code list includes:

- diabetic LEAD in practice
- Diabetic medication
- glitazone
- CP Dukes
- 3.0 CP - the person
- harm
- GP use of NEW medication
- GP prescriber
- 1.0 Biomedical construction of the patient

The interview text includes the following segments:

And I asked him to show us about this drug. And he brought his usual stuff erm, and it looked wonderful. But I'd read one or two reports from America and I said can you tell me is there any problem with liver functions?
 Interviewer

Right.
 Respondent

In front of my partners, in front of these nurses, he laughed at me.
 Interviewer

Right.
 Respondent

He just "Oh for god's sake Dr A, don't believe everything you read. Oh god, my, listen if you want take an LFT before you put them on it and check it again in a month alright?" And I thought you condescending bastard, sorry. You know, but it looked like such a good drug, you know, I thought I had 2 or 3 patients in mind that we're struggling with that we're thinking oh do they need to be on insulin, but there's nothing else we can do, well now there was. So I said right I've got 2 or 3 patients, Margaret bring them in next week and we'll talk to them about it.
 Interviewer

Yeah.
 Respondent

The following day, Thursday, I got, I'm secretary of the BMA, I got a fax from the BMA saying this drug has been withdrawn, 20 people have died of liver failure in America.
 Interviewer

Right ok. That was very up to date.
 Respondent

I was looking for his card, I wanted to ring him up and say "you bastard, I want a word with you". Because he made me look about that big.
 Interviewer

12.8 NVivo coding Stage two coding

The following list of four pages of early coding shows multiple codes in alphabetical order. (Stage one coding was in an older version of NVivo software, which failed to transfer to the latest software and unfortunately not reported here.) Stage two coding displayed iterations of codes as they developed with the interview transcripts. After five GP transcripts (Rob, Andy, Alice, Jen and Matt) were analysed thematically and structurally, this sequential process of analysing one interview and then another was found to be too laborious for an individual and as part of the iterative journey and a change of supervisor, the methods process was adjusted. All the 16 GP transcripts were thematically analysed and recorded in NVivo. This list of nodes shows the stage 2 analysis.

- Name ^ | Fil
- Autonomy- self determination behaviour of patient
 - Autonomy -self determination not to be involved with healthcare team
 - Explanation of importance of follow up and Mx to patients diabetes increase in pt compliance
 - GP opinion on patient responsibility in diabetes management
 - GP annual review of diabetic patient as part of good prescribing practice
 - GP opinion on patients acceptance of diabetes education
 - GP opinion-how some diabetic patients give up
 - Multiple medications in diabetes making patients apathetic
 - GP view that patient has right to refuse therapy
 - Patient acceptance of insulin therapy
 - Patient Empowerment
 - Patient described as self aware that they are at risk of diabetes
 - Relatives of DM patients involved in care
 - Autonomy_ lack of self determination
 - Autonomy_Patient belief in Supreme being directing their destiny rather than SELF determination and control of their health.
 - Autonomy_self neglect leading to patient manipulation of HCP's
 - Carer view that they attempt to resist patient manipulation
 - Depression and diabetes
 - Autonomy_ self neglect_depression and nihilism- lack of engagement with therapy
 - Exaggerating symptoms_Depressed patient described by GP
 - symptoms of depression similar to uncontrolled diabetes
 - Diabetic patients as more Passive receivers of medical care
 - Diabetic patients not motivated to self help and lifestyle change
 - Lack of engagement in diabetic management as advised by healthcare professional
 - CKD
 - CKD as example of a NEW chronic disease
 - CKD _new chronic condition skeptical GP of patient benefit
 - Explaining CKD to patients - recalled examples
 - Clinical Judgement
 - clinical judgement as different to judgements during assessment of drs in training
 - clinical judgement as different to other judgement
 - Clinical judgement as experience driven
 - Clinical judgement in BUSY times- fast pace means compromising or not using strategies for coping with uncertainty
 - Complexity of patients' problems presenting to GP
 - Conflict in priorities in decisions made in complex medical care of patients.
-

- Name ^
- Complexity of patients' problems presenting to GP
 - Conflict in priorities in decisions made in complex medical care of patients.
 - Cost or finance expressed by GP
 - COST as the financial driver for Practice decision to have nurses and HCAs in management of chronic disease
 - Cost of Laboratory test influence decision to test patient
 - GP practice concerns of financial reimbursement for activity of insulin initiation in practice
 - New GP Contract-payment needed for enhanced services
 - LES payment for initiating insulin - lack of
 - Decision Making on basis of local EXPERT
 - Decisions in diabetes as about numbers
 - decision in insulin management to refer based on atypical features of patient
 - demographic- GP in practice over 20 years
 - Diabetes decision making around COMPLICATIONS of diabetes.
 - different authority guideline - lack of consistency - Guideline
 - EBM
 - EBM provide simplicity ti decion making
 - EBM- if lack of good quality evidence means lack of knowledge or guidance
 - EBM_attitude toward managing clinical evidence and guidelines in practice
 - EBM_GP uses evidence to make managment decsions and jsutify them to patient
 - EBM_implementing best evidence care depends on available resources
 - GP admitting lack of involvement informing patient of need for insulin
 - GP as a manager of business of General Practice or Primary Care
 - 'Political'_ GPs showing LEADERSHIP in decision making in local service development
 - partners have to consider service provision when there are a shortage of drs- decision making is fast paced and prioritised.
 - GP belief in decision to intiate insulin
 - GP belief that insulin initiation is in best inerests of patients
 - GP belief to initiate insulin- lack of belief
 - GP challenging patient belief and behaviour to fulfill a duty of care
 - GP challenging patient religious or cultural belief for medicatin prescribing
 - GP Confidence in decision making
 - Anxiety of uncertainty in patient management_coping methods
 - Confidence gained from past experience
 - Acute illness patient management
 - Confidence in medication prescribing as medications and guidance is established over time.
 - confident decsion making depsite uncertainty
-

- GP Confidence in decision making
 - Anxiety of uncertainty in patient management_coping methods
- Confidence gained from past experience
 - Acute illness patient management
 - Confidence in medication prescribing as medications and guidance is established over time.
 - confident decision making despite uncertainty
- GP managing uncertainty
 - GP communicating uncertainty to patient
 - GP giving patient safety net advice
 - Patient presenting again for home visit affects decision to admit patient
 - Seeking confident decision making through colleague discussion
 - Seeking confident decision making through colleague discussion - Acutely unwell patients as examples
 - Strategies used by GPs to cope with uncertainty
 - GP Practice Culture of communication, teamwork and GP colleague discussion to aid confident decision making
 - GP seeking EXPERT opinion informally to avoid referral to 2ndary care
 - Uncertainty of patient presentations to GP in clinic
 - GP PATIENT prior relationship informing Mx decision
 - HCP knowing their limitations and when to involve others in patient management
 - Infrequent use of a strategy to cope with uncertainty shows confidence
 - Lack of confidence in own knowledge
- RECONSIDERING DECISION after the consultation with patient
 - Additional IMP HISTORY redirecting GP decision
 - Strategies to cope with uncertainty- bringing patient back over a time period to review
 - unpredictable presentations of unusual problems_ larger practice populations and uncertainty Mx.
- GP considering best interests of patient and ethics_moral principles involved_ of situation
- GP conversations with patients around the time of need to add insulin therapy to their diabetes management.
- GP decision making in diabetes complications
- GP knowledge of local practice population_awareness of diabetes risk
- GP making referral of patient to 2ndary care for initiation of insulin.
- GP motivated by appreciation shown by patients
- GP personal development
 - Appraisal
 - How doctors learn
- Knowledge-general medical knowledge and training
 - Lack of knowledge
- Ongoing experience after medical training
 - GP experience in diabetes management
 - Strong image of patient recalled by GP
 - Patient ICE- COMM skills
 - PRACTICE development programmes - Clinical learning culture and educational update in the practice
- GP personal ideas and beliefs on clinical decision making
 - GP decision making influenced from multiple sources with ethical reflection

- GP personal development
 - Appraisal
 - How doctors learn
- Knowledge-general medical knowledge and training
 - Lack of knowledge
- Ongoing experience after medical training
 - GP experience in diabetes management
 - Strong image of patient recalled by GP
 - Patient ICE- COMM skills
 - PRACTICE development programmes - Clinical learning culture and educational update in the practice
- GP personal ideas and beliefs on clinical decision making
 - GP describing a decision making framework to deal with an ethical problem
 - GP evaluates decision making as UNCONCIOUS PROCESS
 - GP Practice 10 to 20 years
- GP Reflections_Evaluations
 - Evaluations by the GP personal journey of learning to make decisions in medical care.
- GP role in chronic disease management- part of team of decision makers
 - Concept of Thinking like a GP
 - GP role in chronic disease_ medication review
 - GP role in DM dependent on the skills and abilities of the employed nurses or HCAs.
 - GP using JUDGEMENT in decision making
- GP's own Personal Values
 - GP using words indicating VALUE descriptions of patients
 - Good patient of bad patient
 - GP opinion on social behaviour of her patients
 - GP values holistic approach to patient care
 - Personal beliefs or attitudes influencing decisions
- Guidelines
 - Decision making - opinion on acting against guidelines
 - Guideline led decision making_EBM treatment options not accessible to local primary care
 - Guideline led decision not ethically complicated.
 - guidelines need to be easily accessible for use in GP decision making
 - Protocol or guideline driven medical management
 - Decn makg IN LINE WITH PEERS DECISION MAKING
 - Focused use of NICE guidelines for GP specific population.
 - Guidelines as DISTILLED evidence from authorities like NICE
 - Service availability lags behind guidance on good practice
- HCP with diabetes
 - HCP with diabetes_the APOSTOLIC function in consultations described to gain HBM positive outcome for patient
 - The HCP diabetic patient view of dr patient trust_e
- Health Belief Model of Patient health behaviour- code showing GP views fitting this model
 - HBM transition in patient behaviour_ narrative turning point.

- Health Belief Model of Patient health behaviour- code showing GP views fitting this model
 - HBM transition in patient behaviour- narrative turning point-
 - HBM- Dr shows belief in VALUE of HEALTH
 - HBM- Patient shows belief in VALUE of HEALTH
 - Health literacy
 - Knowledge of Patient to inform pt drug compliance_under parent node of health belief model of care
- Hypertension management as an example
 - Compliance_lack of_ with prescribed medication_multifactorial
 - factors that influence choice of drug for a patient in hypertension
 - GP indicates preference when choosing hypertension medication
 - Insulin Intiation in DM_GPs not counselling patient of insulin need
 - Insulin Intiation in type 2 DM is atypical amongst low BMI patients
- Insulin need in DM described as a negative event by GP
 - Hypoglycaemia _HARM risk _Insulin initiation
 - Anxiety or fear of Hypoglycaemia when diabetic on insulin.
 - Prventing or managing hypoglycaemia when on insulin.
- Interdisciplinary relationships
 - MDT team clinical practice meetings
 - Pharmacist involvement-practice pharmacist
 - Lack of Knowledge - diabetes managemetrn or insulin initiation
 - Lifestyle
 - LIST of PATIENT FACTORS in decision making_RICH NARRATIVE
- Narratives specific to patients with diabetes
 - GP describes motivating a patientcompliance with care through consultation
 - Insulin intiation EARLY in DM disease progression
- Narratives relating to complications of diabetes and GP decisions
 - GP decision to seek 2ndary care advice for diabetes complication
- Narratives specific to starting insulin in people with type 2 DM
 - General narrative_starting insulin_S Asian population_Pakistani
 - GP beleif that type 2 diabetes is lifestyle related in obese patients
 - GP belief that type 2 diabetics can have less motivation to participate in decsions to improve their well being
- Nurse led care of chronic disease
 - importance of all HCAs and nurses recognising disease and drug complications
 - Importance of nurses confidencefor their sucesful role in chronic disease management
 - Nurse extended role e.g. of DMARD monitoring - rich description
 - nurse extended role- not just for nurse prescribers
 - Nurse extended role_feeling GP support
 - Nurse led care of chronic disease as protocol driven
 - Nurses not recognising rare but serious diabetic compliations
 - Practice management decision for extended role of nurses
 - Thinking like GPs would be to think of evidence and protocol knowledge with influence on outcomes
- Nurse led care of people with diabetes

- Nurse led care of people with diabetes.
- GP-Nurse interface in decisions about diabetes
 - Diabetes management - GP not initiating drug therapy
 - GP addresses psychosocial issues whilst nurse addresses DM chronic disease care
 - GP handing over decision to start insulin to nurse
- GP involved in chronic dis Mx when complexity arises.
 - GP making decisions when DIABETES COMPLICATIONS arise
 - Nurses recognising diabetic foot complications
 - Nurse opinion affecting GP Decision
 - patient behaviour change from not engaged to engaged in healthcare
 - Important nurse attributes- GP view
 - Nurse and HCA personal development_GP feedback
 - Nurse inconfident to be involved in therapeutic management plans for patients
 - Nurse managing patient care like a GP
 - Nurse rapport with patient
 - nurses confidence through limited management decisions
 - Rich description of nurse led DM pt management in GP
 - The role of a nurse as chronic disease manager
 - Transfer of clinical responsibility from GP to nurse.
- Nurse role in decision making
 - Medico legal position of nurse decision making
 - Nurses - making medication change decisions in diabetes management ,
 - Opinion on Evidence Base
- Opinion on guidelines
 - GP NEEDS to be SELF AWARE and JUSTIFY decisions WHEN NOT FOLLOWING guidelines
 - Guidelinebased decision makg as DEFENSIVE PRACTICE
 - Guidelines- differences between different AUTHORITIES and GPs Making decisions
- Patient characteristics that direct drug choice in management
- Patient refusal of insulin therapy
- Patients seeking health info from non HCP
- Patientn accept multiple medications as part of the -Diabetes illness-
- Potentially Idealistic opinion
- Project limitations
 - Ability or inability to recollect patient consultation in detail
 - Psychosocial problems presenting as organic disease
 - QOF- diabetes mangement
 - Relationship with practice Nurse
 - Religious beliefs of patients
 - Research question explained to interview case
 - Resolution to problem of a HCP knowing their limitations

- Risk management
 - Medical errors- how GPs view them
 - Dealing with BLAME in medical errors
- Shared Decision Making
 - communication_patient exaggerating or overpresenting her symptoms.
 - Consultation CUES impacting of GP decision making
 - Consultation skills
 - Consultation _language translation_confusion caused by misunderstanding
 - Consultation skills in picking up patient concerns affecting decision making
 - Dr as a drug (Balint), or dr as catalyst (Neighbour)
 - Dr centred agenda setting _Selective attention, selective neglect concept (Balint)
 - HCP with diabetes_the APOSTOLIC function in consultations (Balint)
 - Parent-child_GP patient relationship_transactional relationship (Eric Berne, TA, 1964)
 - training doctors to build up a hypothesis - Calg camb model
 - TRUST _Mutual investment between pt and GP (Balint)
 - Empowering patients
 - dr explanation of diabetes affecting patient behaviour (analysisi interpretation)
 - fear of needles
 - GP view pt not empowered in decision
 - GP Confidence in own SDM skills
 - GP marketing benefits of insulin in order to convince patient
 - GP planning or using PANDA project to help th shared decision making process to initiate insulin.
 - GP Rapport with patients
 - Information sharing-amount
 - Medication Knowledge and lack of understanding
- Motivating patients to make lifestyle changes.
 - DM, Lifestyle change and culture
 - Patient ability to understand explanation
 - Patient COACH
- Patient compliance with medication
 - GP relationships with patients
 - Patient trust in doctor or healthcare system
 - Rapport with patient
 - Doctor as a _human_
 - Patient Feelings_GP Narr
 - Rapport with patients and continuity of care
 - GP with understanding of her or his patient population.
 - Long narratives_LACK OF COMPLIANCE_DUE TO PSYCHOLOGICAL issues
 - Pt ACCEPTANCE of insulin initiation_concept of
 - Resources for SDM
 - SDM - as improving time control in consultation
 - SDM - GP opinion - supervised GPs offer more SDM

- SDM - GP opinion - experienced GPs offer more SDM
- SDM - handing over control of the consultation
- SDM - Institutionalism rather than paternalism
- SDM - opinion - Experienced GPs less worried about losing control of consultation
- SDM - patients not wanting SDM
- SDM aid or template mentioned
- SDM and patients family members involved in decision to change therapy_ cross cultural view
 - Influence of family or social support in diabetes management
 - SDM- and consultation time
- SDM- GP opinion on SDM
 - GP opinion - Patient choice on not taking medication
 - SDM_DEGREE of shared decision making
 - SDM_language barriers and medical literacy
 - Sharing uncertainty with a patient when making a decision on diagnosis or Mx.
 - The expert doctor
 - Time as a barrier
 - Use of family members as interpreters in consultations_
 - Patient preference for family member as interpreter
 - Statin use - balancing the guidance , evidence of use and patient benefit or risk of side effect
 - STRONG MEDICINE
 - The Generalist
- Time management
 - strategies for time management in consultations.
 - Time as a barrier
 - Typical patient presentation with NIDDM

12.9 NVivo coding stage two

The early files of NVivo coding were begun during the interview stage, and when the professional transcribed textual data were added to the NVivo software as case files within on NVivo journal for the research. The codes are held in this separate folders and this list of codes is from an early stage from coding after have been thematically analysed.

- adverse effect of medication
 - Autonomy- self determination behaviour of patient
 - Autonomy_ lack of self determination
 - CKD
 - Clinical Judgement
 - Complexity of patients' problems presenting to GP
 - Cost or finance expressed by GP
 - Decision Making on basis of local EXPERT
 - Decisions in diabetes as about numbers
 - decision in insulin management to refer based on atypical features of patient
 - demographic- GP in practice over 20 years
 - Diabetes decision making around COMPLICATIONS of diabetes.
 - different authority guideline - lack of consistency - Guideline
 - EBM
 - GP admitting lack of involvement informing patient of need for insulin
 - GP as a manager of business of General Practice or Primary Care
 - GP belief in decision to initiate insulin
 - GP belief to initiate insulin- lack of belief
 - GP challenging patient belief and behaviour to fulfill a duty of care
 - GP Confidence in decision making
 - GP considering best interests of patient and ethics_moral principles involved_ of situation
 - GP conversations with patients around the time of need to add insulin therapy to their diabetes management.
 - GP decision making in diabetes complications
 - GP knowledge of local practice population _awareness of diabetes risk
 - GP making referral of patient to 2ndary care for initiation of insulin.
 - GP motivated by appreciation shown by patients
 - GP personal development
 - GP personal ideas and beliefs on clinical decision making
 - GP Practice 10 to 20 years
 - GP Reflections_Evaluations
 - GP using JUDGEMENT in decision making
 - GP's own Personal Values
 - Guidelines
 - HCP with diabetes
 - Health Belief Model of Patient health behaviour- code showing GP views fitting this model
 - How interview has made dr reflect
 - Hypertension management as an example
 - Insulin Intiation in DM_GPs not counselling patient of insulin need
 - Insulin Intiation in type 2 DM is atypical amongst low BMI patients
 - Insulin need in DM described as a negative event by GP
-

- Insulin need in DM described as a negative event by GP
 - Interdisciplinary relationships
 - Lack of Knowledge - diabetes management or insulin initiation
 - Lifestyle
 - LIST of PATIENT FACTORS in decision making_RICH NARRATIVE
 - Narratives specific to patients with diabetes
 - Nurse led care of chronic disease
 - Nurse led care of people with diabetes.
 - Nurse role in decision making
 - Nurses - making medication change decisions in diabetes management ,
 - Opinion on Evidence Base
 - Opinion on guidelines
 - Patient characteristics that direct drug choice in management
 - Patient refusal of insulin therapy
 - Patients seeking health info from non HCP
 - Patients accept multiple medications as part of the -Diabetes illness-
 - Potentially Idealistic opinion
 - Project limitations
 - Psychosocial problems presenting as organic disease
 - QOF- diabetes management
 - Relationship with practice Nurse
 - Religious beliefs of patients
 - Research question explained to interview case
 - Resolution to problem of a HCP knowing their limitations
 - Risk management
 - Shared Decision Making
 - Statin use - balancing the guidance , evidence of use and patient benefit or risk of side effect
 - STRONG MEDICINE
 - The Generalist
 - The healthcare Team
 - Time management
 - Typical patient presentation with NIDDM
-

12.10 NVivo coding stage three

Coding after all cases thematic analysis, refining of codes as per Braun and Clarke step three, resulting in 3 higher order themes: the biomedical construction of the patient, the perso-centred GP perspective and GP-person. Although this apparently had a conceptual organisation, the codes were not settled as themes and is discussed in chapter 4.1

- 1.0 Biomedical construction of the patient
 - biomedical Knowledge
 - > Guidelines
 - > Knowledge-general medical knowledge and training
 - Opinion on Evidence Base
 - Biomedical patient
 - > Atypical patients
 - biomedical complexity
 - elderly
 - > Insulin resistance
 - the biomedical practice population
 - Chronic Disease management
 - > CKD
 - > GP role in chronic disease management- part of team of decision makers
 - > Hypertension management as an example
 - Diabetes
 - > CHANGE OVER TIME in diabetes management
 - > Shortcut to Code diabetes as about numbers
 - EBM
 - > EBM_attitude toward managing clinical evidence and guidelines in practice
 - EBM_GP uses evidence to make management decisions and justify them to patient
 - > Research studies mentioned
 - GP Confidence in decision making
 - ALL the confidence codes together
 - > clinical judgement (2)
 - > Confidence gained from past experience
 - Confidence in medication prescribing as medications and guidance is established over time.
 - > Consultation skills
 - > Decision Making on basis of local EXPERT
 - > GP personal development
 - > Lack of confidence in own knowledge
 - > Time as a barrier
 - > Uncertainty

- GP prescriber
 - Diabetic medication
 - GP annual review of diabetic patient as part of good prescribing practice
 - GP use of NEW medication
 - Cautious of NEW drugs
 - gliptin
 - glitazone
 - NSAID
 - exenatide
 - Influence of diabetic specialist team or consultant on use of new medications
 - Insulin
 - GP belief in decision to initiate insulin
 - decision in insulin management to refer based on atypical features of patient
 - GP belief that insulin initiation is in best interests of patients
 - GP conversations with patients around the time of need to add insulin therapy to their diabetes management.
 - Insulin Initiation in DM_GPs not counselling patient of insulin need
 - Negative views of Insulin in type 2 DM
 - GP views insulin as FAILURE
 - Hypoglycaemia _HARM risk _Insulin initiation
 - Anxiety or fear of Hypoglycaemia when diabetic on insulin.
 - Preventing or managing hypoglycaemia when on insulin.
 - Last resort _text word query
 - needle word text search
 - Weight increase with insulin
 - Medications as part of chronic disease management
 - Aspirin
 - hypertension medication
 - Statin use - balancing the guidance , evidence of use and patient benefit or risk of side effect
 - side effects of medication
 - QOF
 - QOF- diabetes management decisions
 - GPs nagging or pts feeling 'nagged' by GPs
 - QOF and elderly

- 2.0 Person Centred GP perspective
 - Depression and diabetes
 - Apathy
 - GP opinion-how some diabetic patients give up
 - Multiple medications in diabetes making patients apathetic
 - Autonomy_self neglect_depression and nihilism- lack of engagement with therapy
 - depress
 - Depression and diabetes
 - Passive behaviour
 - Exaggerating symptoms_Depressed patient described by GP
 - mood
 - symptoms of depression similar to uncontrolled diabetes
 - Engagement in health
 - 1.0 Patient Responsibility
 - DNA appointment
 - 2.0 self determination
 - Blame
 - self determination behaviour of patient
 - Adaptable patients
 - GP acceptance of Patient refusal of insulin therapy
 - GP challenges patient
 - GP view that patient has right to refuse therapy
 - Patient acceptance of insulin therapy
 - Adaptable patients
 - Patient Empowerment
 - patient behaviour change from not engaged to engaged in healthcare
 - Patient described as self aware that they are at risk of diabetes
 - Patient use of internet to self care
 - Relatives of DM patients involved in care
 - self determination_lack of
 - capacity
 - learning disabilities
 - Complex mental health issues
 - Patient belief in Supreme being

- ∨ Patient social support
 - Patient consent to sharing information
 - Spouse support
- ∨ self neglect behaviour
 - Carer view that they attempt to resist patient manipulation
- ∨ 3.0 Motivating patients to make lifestyle changes.
 - Diabetic patients not motivated to self help and lifestyle change
 - DM, Lifestyle change and culture
- ∨ Health Belief Model of Patient health behaviour
 - HBM _patient showing lack of belief in HBM
 - HBM transition in patient behaviour- narrative turning point-
 - HBM- Dr shows belief in VALUE of HEALTH
 - HBM- Patient shows belief in VALUE of HEALTH
 - HBM- perceived threat of disease
 - > Health literacy
 - Knowledge of Patient to inform pt drug compliance_under parent node of health belief model of care
 - Patients NAGGED by chronic disease management
- ∨ GP empathy
- ∨ patient centred care
 - holistic
- ∨ HCP with diabetes
 - Diabetic lead and diabetic patient
 - DM practice nurse and diabetic
 - HCP with diabetes_the APOSTOLIC function in consultations described to gain HBM postive outcome for patient
 - The HCP diabetic patient view of dr patient trust_e
- ∨ Lifestyle
 - driving
 - obesity
 - paternalism
- ∨ patient and medication
- ∨ Insulin
 - ∨ Fear of Insulin
 - fear text search
 - Insulin need = ill

-
- ∨ Medication means ill
 - UNWELL_uncontrolled diabetes makes pt feel UNWELL
 - Insulin and Driving
 - Patient views insulin as FAILURE
 - ∨ Practical limitations of Insulin
 - blind text search
 - keep it simple
 - Pt ACCEPTANCE of insulin initiation_concept of
 - STRONG MEDICINE
 - Medication - lack of understanding
 - ∨ Patient characteristics that direct drug choice in management
 - acceptable NUMBER of medications
 - elderly
 - ∨ Patient compliance with medication
 - long narratives_LACK OF COMPLIANCE_DUE TO PSYCHOLOGICAL issues
 - ∨ patient anxiety
 - ∨ fear
 - ∨ fear of needles
 - needle textword search
 - Patient denial
 - ∨ Patient beliefs
 - GP challenging patient religious or cultural belief for medication prescribing
 - Patient Values in decision
 - Religious beliefs of patients
 - ∨ Patient Education
 - ∨ Information sharing
 - ∨ Education programme
 - DESMOND
 - GP opinion on patients acceptance of diabetes education
 - RIO
 - Explaining CKD to patients - recalled examples
 - ∨ Explaining diabetes
 - Patients Feel ill with diabetes
 - Patient ability to understand explanation
 - Using EBM to explain to patients
-

-
- Patients seeking health info from non HCP
 - Patient Feelings_GP Narr
 - Psychosocial problems presenting as organic disease
 - QOF and person centred
 - Shared Decision Making
 - communication_patient exaggerating or overpresening her symptoms.
 - Doctor centred decision
 - Negotiating with patient
 - dr explanation of diabetes affecting patient behaviour (analysisi interpretation)
 - PANDAs project
 - Patient COACH
 - Resources for SDM
 - SDM - as improving time control in consultation
 - SDM - Institutionalism rather than paternalism
 - SDM - patients not wanting SDM
 - SDM aid or template mentioned
 - SDM and patients family members involved in decision to change therapy_ cross cultural view
 - Influence of family or social support in diabetes management
 - SDM and TIME periods for decisions in diabetes mx
 - SDM journey
 - SDM- and consultation time
 - SDM- GP opinion on SDM
 - GP opinion - Patient choice on not taking medication
 - SDM - GP opinion - experienced GPs offer more SDM
 - SDM - handing over control of the consultation
 - SDM_DEGREE of shared decision making
 - SDM_language barriers and medical literacy
 - TRUST Patient trust in doctor or healthcare system
 - Doctor as a _human_
 - GP relationships with patients
 - > Rapport
 - 3.0 GP - the person
 - distal GP
 - GP Relationship with practice Nurse
 - GP Duties

-
- GP Duties
 - diabetic LEAD in practice
 - Diabetic GP as Diabetes lead in practice
 - Diabetic lead skills
 - GP involvd in chronic dis Mx when complexity arises.
 - GP addresses psychosocial issues whilst nurse addresses DM chronic disease care
 - GP making decisions when DIABETES COMPLICATIONS arise
 - Nurses recognising daibteic foot complications
 - GP-Nurse interface in decisions about diabetes
 - Diabetes management - GP not initiating drug therapy
 - GP Decision to initiate insulin
 - GP handing over decision to start insulin to nurse
 - Nurse opinion affecting GP Decision
 - referral to initiate insulin
 - Diabetic specialist nurse in pimary care - referral to initiate insulin
 - GP making referral of patient to 2ndary care for initiation of insulin.
 - duty of care
 - continuity of care
 - harm
 - GP the problem solver
 - The business of General Practice
 - The Generalist
 - GP feelings
 - GP motivated by appreciation shown by patients
 - GP tension
 - Guilt
 - GP personal life
 - GP's own Personal Values
 - Elderly and Quality of Life
 - GP personal ideas and beliefs on clinical decision making
 - GP describing a decision making framework to deal with an ethical problem
 - GP evaluates decision making as UNCONCIOUS PROCESS
 - intuition
 - GP using words indicating VALUE descriptions of patients
 - Good patient cf bad patient
-

- Good patient cf bad patient
 - GP opinion on social behaviour of her patients
 - ✓ GP values holistic approach to patient care
 - palliative care vs DM care
 - Personal beliefs or attitudes influencing decisions
 - ✓ 4.0 Tensions
 - Blame
 - ✓ GP Confidence in decision making
 - ALL the confidence codes together
 - > clinical judgement (2)
 - > Confidence gained from past experience
 - Confidence in medication prescribing as medications and guidance is established over time.
 - > Consultation skills
 - > Decision Making on basis of local EXPERT
 - > GP personal development
 - > Lack of confidence in own knowledge
 - > Time as a barrier
 - > Uncertainty
-

12.11 NVivo coding stage three:

Initial themes identified and higher-level child nodes are shown in this screen capture and show unsettled themes. The themes are categorised into hierarchical themes appropriate to the biomedical research question of insulin initiation 'biomedical construction of the patient'. After initial examiner review and feedback, this category required review. Returning to the NVivo coding categorises and reviewing transcripts and the coded textual data generated the additional coding stage 4.

- ∨ 1.0 Biomedical construction of the patient
 - > biomedical Knowledge
 - > Biomedical patient
 - > Chronic Disease management
 - > Diabetes
 - > EBM
 - > GP Confidence in decision making
 - > GP prescriber
 - > QOF
 - ∨ 2.0 Person Centred GP perspective
 - > Depression and diabetes
 - > Engagement in health
 - > GP empathy
 - > HCP with diabetes
 - > Lifestyle
 - paternalism
 - > patient and medication
 - > patient anxiety
 - > Patient beliefs
 - > Patient Education
 - Patient Feelings_GP Narr
 - Psychosocial problems presenting as organic disease
 - QOF and person centred
 - > Shared Decision Making
 - > TRUST Patient trust in doctor or healthcare system
 - ∨ 3.0 GP - the person
 - > distal GP
 - > GP Duties
 - > GP feelings
 - GP personal life
 - > GP's own Personal Values
 - ∨ 4.0 Tensions
 - Blame
 - > GP Confidence in decision making
-

12.12 **Participant Information Sheet**



School
Of
Medicine
& Biomedical Sciences.

Participants Information Sheet

Study Title:

What factors inform the general practitioner to decide to start insulin therapy in patients with type 2 diabetes?

We would like to invite you to take part in a research study. This study aims to look into the perspective of general practitioners involved in decision making with type 2 diabetic patients.

Before you decide whether to participate, you need to understand why the research is being done and what it would involve. Please take time to read the following information carefully; talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

The National Service Framework standard 3 encourages diabetes management to involve patients in the management of their diabetes in a patient centred way.¹ The General Practitioner perspective to start insulin may be based on many factors. These factors go beyond the biomedical perspective that diabetes guidelines otherwise recommend. There could be for example time limitations, financial constraints, language barriers or consultation issues.

The aim of this study is to explore these factors in a descriptive qualitative manner. The study is a qualitative study of the general practitioner perspective to start insulin therapy in patients with type 2 diabetes.

2. Why have I been invited?

You have been invited because of your experience and expertise in managing patients with type 2 diabetes in general practice. Your views and opinions will help us to understand how you help patients make decisions about their treatment. You can also provide information on the facilitators of, and barriers to, decision-making in general practice.

3. Do I have to take part?

Your participation is entirely voluntary and it is up to you to decide. If you agree, we will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

4. What type of study is this?

This study will be conducted based on the principles of narrative research (2). This research method has developed from a concern to find meaning from every day aspects of life that are otherwise taken for granted (3). The story of the individual provides understanding of one's own actions, of the actions of others, of organizing events and objects into a meaningful whole (4). Up until now there have not been individual interviews with GPs relating their perspective on decision making in management of type 2 diabetes.

The focus group discussion is toward the end of the study with a set of general practitioners with experience in managing patients with diabetes. By recording and analysing the group discussion, we plan to obtain useful feedback on the outcome of the study.

5. What will happen to me if I take part?

If you agree to take part you will be interviewed by Dr Hina Kanabar, a GP working at the Academic Unit of Primary Medical Care at the University of Sheffield.

Prior to the visit you will be sent a participant information sheet, a demographic questionnaire and a sample consent form.

A few days after this the GP will call you or your practice manager to arrange a date and time for the interview at your chosen convenience and location. This should be in a room where we are not disturbed and you can be confident the interview is not overheard such as your consultation room.

On the day of the interview, the researcher will ask you to sign a consent form prior to commencement of the interview itself.

During the interview the researcher will ask questions related to your experience in helping patients to make decisions about their diabetic treatment. The researcher will record the conversation using a voice recorder. The purpose of the recording is to allow the researcher to capture the information discussed during the interview, which is important for us to analyse later. The interview will take approximately 40 minutes.

6. Benefits, expenses and payment

You will be able to relate your individual experience and view of managing patients with chronic conditions. You will be able to record your involvement in the project in your PDP appraisal folder. Summary outcomes of the project results and conclusions can be forwarded to you if you wish to request them.

7. What will I have to do?

You are requested to tell the story of your experience of managing patients with type 2 diabetes when considering whether to start insulin as part of their management.

The researcher will be using an interview guide to aid the direction of the interview. However from the principle of narrative research the focus will be to clarify the story of your experience.

8. What if there is a problem?

Any complaint about the way you have been dealt with during the study will be looked into. The detailed information on this is given at the end of this information brief.

9. Is the purpose of this study educational?

Yes. The data from this research will be used for work toward an MPhil degree.

10. What will happen if I don't want to carry on with the study?

You can withdraw from the study without giving a reason.

11. What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Contact Dr Hina Kanabar at: XXXXX or Professor Nigel Mathers at: 0114 XXXXXXX). If you remain unhappy and wish to complain formally, you can do this through the University Of Sheffield Complaints Procedure. Details of where to send your letter is at the end of this letter.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Sheffield but you may have to pay your legal costs.

12. Will my taking part in this study be kept confidential?

Yes. We will follow ethical and legal practice. All information about you will be held in confidence.

The recorded conversation will be transcribed by a designated secretary. Only the interviewer and the secretary will have access to the audiotape. All information will be coded and anonymised.

The information we have collected as paper copies will be stored under lock and key, while the electronic data can only be accessed with a secure password. Only the researchers, sponsors, regulatory authorities and Research & Development auditors will have access to the data.

The data we collect will be used only for the purpose of this research; if data were to be used for future studies, further Research Ethics Committee approval will be sought. The transcripts will be kept for five years according to the Medical Research Council guidelines.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the surgery will have your name, telephone and address removed so that you cannot be recognised.

13. What will happen to the results of the research study?

The results of this study may be presented at conferences and published in medical journals. A summary of the results will be sent to you by post and you will be invited to attend a research seminar.

You will not be identified in any report, publications or presentation without seeking your full consent. Direct quotes from the interview may be used in reports and publications; however, the quotes will be anonymised to ensure that you cannot be identified.

14. Who is funding the research?

The chief investigator (Dr Kanabar) is funded by a National Institute of Health Research In-Practice Fellowship. The project costs are funded by a charitable fund (Claire Wand Fund).

15. Who has reviewed the study?

Sheffield health and Social Research Consortium has reviewed the study scientifically. The National Research Ethics Service has also formally reviewed the study.

16. Further information and contact details.

Specific information about this research project:

12.13 Consent form



The
University
Of
Sheffield.

School
Of
Medicine
& Biomedical Sciences.

Participant Identification Number:

CONSENT FORM

Title of Project: Which factors inform the decision by a general practitioner to initiate insulin therapy in people with type 2 diabetes mellitus?

Name of Researcher: Professor Nigel Mathers/ Dr Hina Kanabar/Dr CJ Ng

Please initial

1. I confirm that I have read and understood the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.
3. I agree to have my interview recorded.

4. I agree to take part in the above study.

| | | |
|-------------------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Person taking consent | Date | Signature |

When completed, 1 copy for participant; 1 copy for researcher site file.

12.14 **Research Governance Sponsor: UoS**

National Research Ethics Service

NRES Committee Yorkshire & The Humber - Bradford

Yorkshire and Humber REC Office
 First Floor, Millside
 Mill Pond Lane
 Meanwood
 Leeds
 LS6 4RA

Telephone: 0113 3050128

25 November 2011

Dr Hina Kanabar
 Academic Unit of Primary Medical Care
 Samuel Fox House
 Northern General Hospital
 Herries Road
 Sheffield
 S5 7AU

Dear Dr Kanabar

Study title: Which factors inform the decision by a general practitioner to initiate insulin therapy in people with type 2 diabetes mellitus?
REC reference: 08/H1302/67
Protocol number: URMS 121882


I am writing to confirm that under the new Governance Arrangements for Research Ethics Committees (GAfREC) issued by the UK Health Departments, which came into effect on 1 September 2011, the above study no longer falls within the remit of NHS Research Ethics Committees (REC) and therefore does not require further REC review.

The REC has therefore closed the study and there is no requirement to submit any further documentation associated with the study.

R&D approval

All investigators and research collaborators in the NHS should contact the R&D office for the relevant NHS care organisation to clarify the organisation's requirements for future monitoring of the research project.

Yours sincerely


 Sinead Audsley
 Committee Co-ordinator

12.15 Research Governance Sponsor: UoS



The
University
Of
Sheffield.

The
Research
Office.

A Section of the Academic Division,
Research Services

Dr Hina Kanabar
c/o Professor Nigel Mathers
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7th July 2008

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Project title: Which factors inform the decision by a general practitioner to initiate insulin therapy in people with type 2 diabetes mellitus?
6 digit URMS number: 121882

Dear Dr Kanabar

LETTER TO CONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJECT'S RESEARCH GOVERNANCE SPONSOR

The Research Office has reviewed the following documents:

1. A University approved URMS costing record;
2. Signed, dated confirmation of scientific approval;
3. Signed, dated confirmation of ethics approval.

All the above documents are in place. Therefore, the University now **confirms** that it is the project's research governance sponsor and, as research governance sponsor, **authorises** the project to commence research activities.

You are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Good Research Practice Standards: www.shef.ac.uk/researchoffice/gov_ethics_grp/grpstandards.html