Living with advanced cancer and using medicines at home: exploring experiences and support opportunities

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Abstract

Background

Living with advanced cancer can entail the use of multiple medicines. This research was undertaken to improve understanding about the experiences people living with advanced cancer have with medicines in the context of their everyday lives and healthcare and identify opportunities to support medicines optimisation.

Method

A literature review was conducted to identify and synthesise existing evidence. Two studies were undertaken: the first used semi-structured interviews and photography to explore how people living with advanced cancer manage medicines use at home; the second used semi-structured interviews with photo-elicitation to explore healthcare professionals' perspectives about people's experiences with their medicines during advanced cancer. Finally, stakeholder engagement was carried out to disseminate research findings and obtain feedback to inform the direction of future work.

Findings

The literature review highlighted a lack of evidence about medicines self-management during advanced cancer. The first empirical study summarised people's complex self-management of medicines in five themes: having cancer that is never going to go away, getting along with medicines, navigating the system, habituation in the home, and adapting and adjusting. The second study summarised three themes intrinsic to healthcare, which impact on people's experiences: Insight and Information; Oversight and Ownership; Expertise and Resources. Engagement found that stakeholders share rationale for improving medicine optimisation in this population, to make people's lives easier, empower them and improve outcomes. Proposed strategies for implementing medicines optimisation were summarised in three themes: communicating with people, communicating about them, and person-centred service redesign.

Conclusions

This thesis has provided in-depth insight about self-management of medicines during advanced cancer. It shows that people embed an approach into their daily routine and circumstances. It highlights that the existing provision of healthcare is ill-equipped to support people and requires effort to join up services, improve contact with people and educate HCPs about medicines optimisation. More broadly, it has demonstrated an appetite amongst wider communities to improve experiences for people by developing and implementing interventions which put people living with cancer at their heart and foster approaches that are tailored to people's individual medicines use and everyday life.

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Abbreviations

CNS	Clinical Nurse Specialist
DH	Department of Health
EONS	European Oncology Nursing Society
GP	General Practitioner
HCP	Healthcare Professional
HNA	Holistic Needs Assessment
HRA	Health Research Authority
LTC	Long-term Condition
MDT	Multi-disciplinary Team
NAO	National Audit Office
NCSI	National Cancer Survivorship Initiative
NCCPE	National Coordinating Centre for Public Engagement
NMC	Nursing and Midwifery Council
NMP	Non-Medical Prescriber
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PIS	Participant Information Sheet
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCN	Royal College of Nursing
RPS	Royal Pharmaceutical Society
SPIDER	Sample Phenomenon of Interest Design Evaluation Research type
SACT	Systemic anti-cancer therapy
UK	United Kingdom
UKONS	UK Oncology Nursing Society
USA	United States of America
WHO	World Health Organisation

Chapter 1. Introduction

1.1 Introduction

Advanced cancer describes progressive primary cancer that is unlikely to be cured. Living with advanced cancer can entail many medicines. Medicines are used to treat cancer and the symptoms of cancer, prevent and address disease complications, alleviate the immediate and lasting effects of anti-cancer treatments, manage co-morbidities, and mitigate the side-effects of medicines themselves. Therapeutic innovation, and a shift in the delivery of cancer services to a predominantly ambulatory provision demands that people living with advanced cancer routinely use complex regimens of medicine independently at home.

This thesis presents qualitative research undertaken to expand knowledge about the experiences people living with advanced cancer have using medicines at home and how advanced cancer care might support them. This chapter explains the key concepts underpinning this field of healthcare, introduces existing academic understanding in the field and highlights the policies and guidance that influence current practices and have informed this novel research.

1.2 Living with advanced cancer

1.2.1 Reconsidering advanced cancer as a chronic condition

There is no universal definition for advanced cancer. Malignant cancer is a disease caused by the uncontrollable division of abnormal cells (National Health Service (NHS), 2021). Cancer disease progresses via metastasis, which is the invasion of primary cancer cells into healthy tissues and organs and whose complex pathophysiology causes serious ill health and will likely hasten death (Hanahan and Weinberg 2000; 2011; King et al., 2014; Macmillan Cancer Support, 2021). Standardised tools to grade malignant cell histology and stage the sites and extent of primary disease and secondary metastases are used by clinicians to clarify and communicate cancer progression (Cancer Research United Kingdom (CRUK), 2021; Union for International Cancer Control (UICC), 2021). Aetiologically, advanced cancer refers to stages III or IV malignancy which has rapidly proliferated systemically, or has spread locally to lymph nodes, or to distal body parts (King et al., 2014; CRUK 2021). Another broader accepted meaning of advanced cancer is malignancy that is incurable (NHS, 2021; CRUK, 2021). Whilst some metastatic cancers can be eradicated, and some primary disease are untreatable, this classification is based on the exceptionally low likelihood of fully eliminating cancer which has metastasised to other tissues. Ambiguity in definition also occurs due to changes in the advanced cancer disease trajectory. Historically, metastatic incurable cancer has been associated with poor clinical outcomes and high mortality. However, improved diagnostics, surveillance and therapy have altered the outlook for some diagnoses. Treatments may reduce or limit the progression of metastatic disease, prevent

complications, relieve symptoms, and lengthen prognosis (King et al., 2014; White et al., 2021). This has prompted a change in regard to the disease, from one solely indicative of short life-expectancy to that of a longer-term or chronic condition (Tritter and Calnan, 2002; Lage and Crombet, 2011; Howell, 2012).

The Department of Health (DH) defines long-term conditions (LTC) as those which are not curable, but controllable with medicines, treatment, and therapies (DH, 2012). Advanced cancers increasingly fit these criteria (McCorkle et al., 2011; Richards et al., 2011; Harley et al, 2012; Howell, 2012). Higginson & Constantini (2008) recognised how the combination of an aging cancer population, evolving treatments and comorbidities contribute to a functional decline more typically aligned with a chronic care model. Lage and Crombet (2011) reinforced this shift and emphasised the need to adapt care to accommodate the longer disease process resulting from innovative therapy and enhanced survival. As these ideas have developed, it is acknowledged that the trajectory of long-term advanced cancer is not altogether aligned with the same chronic condition attributes. While drawing parallels, Higginson and Constantini (2008) noted that the unique precariousness imposed by some cancer treatments and the physical volatility of advanced disease may be better reflected by comparison with the acuity of diseases such as organ failure and frailty.

The lack of consensus terminology for advanced cancer and changing status described, create confusion (White et al., 2021). The interchangeable use of terms for cancer that has in some way progressed, such as terminal, metastatic, chronic, incurable, palliative, or end-stage is inappropriate. The accurate discrimination of these specific labels is increasingly relevant due to the different clinical objectives with which they are associated (Hui et al., 2015). In their key paper, Harley et al., (2012) propose a definition for chronic cancer as active, advanced, or metastatic incurable disease, for which treatment can slow disease, prolong life and control symptoms, and that ends when treatment is no longer effective, and people's prognosis is months. Since the outset of this research, the term 'treatable but not curable' cancer (TbnC) has also been devised to galvanise the distinguishing of distinct phases of progressed disease trajectory. TbnC similarly means cancer that cannot be cured and will probably cause death, but can be treated (Maher, 2015; White et al., 2021). Although TbnC cancer is yet not a widely used definition, it could be preferable to other terms whose association with negative preconceptions about prognosis may be detrimental to shared decision-making (White et al., 2021).

In this research, advanced cancer refers to cancer that is metastatic and incurable. This definition reflects the focus of this work on the community of people living with cancer as a long-term condition. It acknowledges and seeks to include the range of potential primary disease types, states of progression, and prognoses.

1.2.2 Healthcare for people living with advanced cancer

The therapeutic goals of advanced cancer healthcare are to control symptoms, prevent complications and extend life-expectancy (Cortis et al., 2017; Howell et al., 2021). Clinical management of advanced cancer is based on a clinical assessment which considers symptoms and quality of life. Care plans reflect a collaborative decision made between clinicians and individuals living with advanced cancer (Browner and Carducci, 2005; Neugut and Prigerson, 2017). Tailoring care to people's changing holistic needs during advanced cancer is imperative in supporting them to live and die as well as possible (National Institute for Health and Care Excellence (NICE), 2004; Howell, 2012; Beernaert et al., 2016; Haun et al., 2017; Calman and Campling, 2019). Treatments for cancer have been the focus of much innovation and medicines can be administered more quickly, and with limited monitoring needed, thus negating the need for admissions and inpatient stays; or self-administered by people independently. Consequently, there has been a general move towards ambulatory provision of care and remote clinical services across disease groups. This also reflects the expansion of the population, and the need to manage care within available resources. People living with advanced cancer therefore are routinely cared for as outpatients and attend a specialist setting for consultation, investigation, and administration of some therapies.

Contemporary advanced cancer healthcare, consequently, is multi-faceted and represents the intersection and integration of oncological, supportive, palliative, and end-of-life services across numerous services and settings (Hui et al, 2012; 2013; 2015; Vanbutsele et al., 2018). This comprises frequent disease monitoring, intermittent or continuous treatment with anti-cancer and supportive therapy, and the management of symptoms and acute illness consequent to disease or treatment complications and care during death. Routinely, advanced cancer care is organised into pathways determined by primary cancer site and led by a multi-disciplinary team (MDT) comprising medical, nursing, pharmacy and allied healthcare professionals (HCPs) (Taplin et al., 2015; Cortis et al., 2017). In the UK, cancer care is routinely provided by the NHS via a specialist department in secondary care and generalists in primary care, whose roles and responsibilities vary during the disease trajectory (Cortis et al., 2017). The complex needs and network of services that advanced cancer both creates and exists alongside, particularly as people undertake increasing amounts of care independently at home, demands effective collaboration between healthcare providers. Healthcare for advanced cancer is adapting to clinical innovations and improvements in outcomes. In facing this challenge, it has been suggested that healthcare should be designed and structured to meet the needs of people living with cancer (White at al., 2021).

Despite recognition as a distinct phase in the disease trajectory, advanced cancer has not received the same attention as other stages of malignancy, such as post-cure survivorship or the end-of-life (Nekhylodov et al., 2017). Arantzamendi et al. (2020) highlight that available research in this area suggests that living well with advanced cancer is possible, but more work is needed to understand how people can be supported to achieve this. In addition to the changing trajectory of cancer and

the complexity of advanced cancer care, people experience cancer in the context of their overall health and their independent life. Identifying and addressing the multi-faceted, fluctuating needs of the growing population of people is essential for modern cancer healthcare, particularly in this era of people taking on self-management roles (NICE, 2004; DH, Macmillan Cancer Support, NHS Improvement, 2013; Howell, 2012; Harley et al., 2016).

1.2.3 Understanding the experiences and support needs of people living with advanced cancer

People's individual experiences during advanced cancer differ vastly due to biomedical and socioeconomic variables, and changes over the course of their illness trajectory. Trying to neatly summarise the diverse and complicated reality of living with advanced cancer is inappropriate. However, identifying commonalities between people's experiences is a valuable starting point to establishing a broad understanding of the key issues. Harley et al. (2012) adapted the Generic Choice Model for long-term conditions (Team DoHCP, 2007) to provide a framework for defining the experiences and needs of people living with advanced cancer. The modified GCM acknowledges the embedded complexity and variation across core themes of 'clinical services', 'self-care and self-management', 'living independently', 'finances', 'psychological wellbeing', and 'support pathways'. These insights have been developed and are reflected in the wider literature (Carter, 2011; Willis et al., 2015; Garcia-Rueda et al., 2016; Wang et al., 2018; Boele et al., 2019; Arantzamendi et al., 2020). Examining the core themes of the GCM provides a helpful overview of current understanding about experiences. Self-management needs are complex and vary across all these domains. The use of medicines by people living with advanced cancer potentially intersects multiple domains of GCM, so considering the detail is helpful when embarking on new research.

Engagement with clinical services is central to living with advanced cancer. Most people experience multiple appointments for clinical consultations, tests, and procedures. Whilst regular hospital appointments can be reassuring, waiting times are burdensome, especially for those in employment, who are older, have caring responsibilities, or a long distance to travel. Harley et al., (2012) also found that people routinely engage in complicated and demanding treatment schedules for radiotherapy, surgery, systemic anti-cancer therapy (SACT) and supportive therapies. These vary depending on people's diagnosis and within diagnostic groups depending on people's disease stage, performance status and past medical history. Despite these complexities, care is often poorly coordinated and there are disparities in perception of continuity between people from different primary diagnostic speciality groups. A variation in GP involvement is also reported, which depends on people's clinical circumstances and the level of community intervention needed. Some people choose to have limited GP input, due to a negative association related to their cancer diagnosis or perception about inadequate clinical knowledge (Harley et al., 2012).

Self-care and self-management responsibility incurred with living with advanced cancer are primarily associated with monitoring and responding to a complex profile of physical symptoms (Harley et al, 2012). The study found that self-management entails learning to recognise and react to symptoms by using medicines, reporting symptoms, and adjusting activities. Pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, diarrhoea, and anorexia are all common and their prevalence and severity vary according to cancer type, stage, treatment, and comorbidity (Solano et al., 2006; Henson et al., 2020). Symptoms are often more complicated and unpredictable in advanced disease, where people have widespread cancer, encounter multiple treatments, and have more comorbid medical conditions (Bluethmann et al., 2016). People must also develop vigilance for addressing symptoms of acute, potential-life-threatening complications, whose risk is elevated by advanced cancer disease processes and cancer treatments (Gibson and Keefe, 2006; Bell et al., 2009; Andreyev et al., 2014; Mason et al, 2016; Bluethmann, et al, 2016; Farmer et al., 2018). Chronic symptoms or the debilitating consequences of previous cancer treatment can also affect people's ability to engage in activity and lead to the loss of role and enjoyment. Reluctance to report the full extent of symptoms or side-effects is thought to be due to concern that treatment will be discontinued, a misunderstanding about the significance of symptoms or preference to not use medicines (DH, Macmillan Cancer Support, NHS Improvement 2013; Harley et al., 2016; Garcia-Reuda et al., 2016; Calman and Campling, 2019).

Needs for independent living during advanced cancer were reported by Harley et al. (2012) to change over time and be influenced by people's individual condition and its treatment. Whilst independent with personal activities, people need support with instrumental tasks such as shopping and housework and most ask family for support. Barriers to the uptake of formal support are linked to concerns about eligibility, the stigma of needing help, the paperwork required, and the difficulty engaging HCPs in discussions about it. People try to sustain normality by living as they always have and modify their involvement in activities that are personally important. However, their ability to do work and hobbies is impacted by physical limitations. Garcia-Rueda et al. (2016) call this 'normalcy' and describe it as the adjustment to new reality and living the nearest version one can to one's previous life before diagnosis.

Work, finances, and benefits is another key area of consideration for Harley et al. (2012). Those working at the time of diagnosis often reduce their working hours or take early retirement. Greater financial security is observed amongst people retired prior to diagnosis. For those who desire to return to work the instability of physical symptoms, and the time-commitment of hospital appointments, can cause difficulty. Though people are entitled to financial support, they experience variable pathways to the benefits application process. It can be difficult to get advice and people do not claim benefits due to the (possibly incorrect) assumption they are not entitled.

Psychological experiences relating to advanced cancer are incontrovertible. Harley et al., (2012) reported that people routinely live with a constant uncertainty posed by their unpredictable response to treatment and indefinite prognosis. This can cause worry about the impact on their loved-ones and anxiety in the wait for the results of staging investigations. People do not always disclose their worries and anxieties, out of concern about burdening others, which can lead to isolation. Coping strategies to maintain or regain control of day-to-day psychological wellbeing include being realistic, support, learning from others, remaining positive, maintaining as normal a life as possible (Bai et al., 2015; Lobb et al., 2015; Walshe et al., 2017). Though strategies are available to restrict thoughts about illness, any physical change can trigger concerns about disease progression. A greater psychological burden is also found to come about compared to surviving with cancer from which others have either died or have been cured (Bluethmann, et al., 2016). The diagnosis of and support for psychological distress can be concealed by people's relative clinical stability (Petrillo et al., 2021). Sand et al., (2009a) found that by developing strategies grounded in togetherness, hope, involvement and continuance of everyday life, people can cope with impending death. In 2019, after the commencement of this research Le Boutillier et al. proposed the ARC Framework to describe the lived experience of living with and beyond cancer. This summarises Adversity, Restoration, and Compatibility, as phases for how people make sense of their cancer experience, which highlights the personalised coping strategy to manage the situation. Subsequently, Arantzamendi et al. (2020) have articulated the challenges faced and resilience demonstrated by people who try to live fully as an iterative process revisited over time, which needs deep engagement, time, and effort, to live well even if it is in moments.

Support pathways are the last item in the modified GCM for chronic cancer (Harley et al., 2012). Whilst people do receive information about available support, help seeking is inconsistent. Often, people feel well supported and included in decisions about their care by cancer teams. However, there are discrepancies in the amount of support on offer based on primary diagnosis, disease stage or current treatment status. People who are not currently receiving treatment might have more difficulty accessing appropriate support. People who are not imminently dying, are unclear if they are unwell enough for support for 'terminal' cancer. Harley et al. (2012) found that uncertainty about the appropriate point of contact for symptom management advice hindered self-management. Those in receipt of support do so via unsystematic, chaotic processes. Clinical nurse specialist (CNS) support is consistently viewed as highly valuable and people with a named CNS are routinely reported to cope better. However, some do not have a named keyperson, which can be detrimental to the coordination of their care. Poor communication and lack of collaboration between care providers can lead to inadequacies in disease management and failure to address concerns (McDowell et al., 2010; Snyder et al., 2015). There is also known variation in the support people receive in primary care from their GP across different diagnostic groups (Rainbird et al., 2009; Boele et al., 2019). Earlier integration of palliative care has been suggested as a means of improving support in cancer care (Greer et al., 2013; Ferrell et al., 2017; Vanbutsele et al., 2018).

1.2.4 Approaches for supporting people living with advanced cancer

The potential physical, emotional, practical, social, spiritual, economic, and existential implications of advanced cancer are devastating (Howell, 2012; Harley et al., 2012; Howell et al., 2021). The change in disease trajectory, altered service delivery, and increasing population, justify effort to improving understanding about people's experiences of living with advanced cancer to help identify areas of unmet need and inform support provisions (Higginson & Constantini 2008; Rainbird et al., 2009; Garcia-Rueda et al., 2016; Moghaddam et al., 2016). The transformation of support for people living with and beyond cancer is a key priority of the National Cancer Strategy (NHS England, 2016). The National Cancer Survivorship Initiative (NCSI) focussed on the need to understand specific support needs for people living beyond a cancer diagnosis, bringing new emphasis on evaluating experiences rather than measuring only clinical outcomes (DH, Macmillan Cancer Support, NHS Improvement, 2013).

The concept of 'Survivorship' was created to communicate the unique experience of living beyond a diagnosis of cancer (Mullan, 1985). Different interpretations have emerged, but survivorship has come to represent the shared desire to get on with life, amongst those undergoing primary cancer treatment, in remission following treatment, cured, or with active or advanced disease (Feuerstein, 2007). Over time it been recognised that this categorisation of people living with metastatic and incurable cancer as 'cancer survivors' alongside those living cancer-free is potentially unhelpful (Khan et al., 2012; Plage, 2020). It has been argued that the breadth of the survivorship definition insufficiently attends to specific consequences associated with living with secondary cancer, such as fragile health, convoluted treatment pathways and complex support needs (Nekhyludov et al., 2017; Arantzamendi, et al., 2020).

In clinical practice survivorship strategy has driven the prioritisation of person-centred services, tailored care-planning, and a focus on supported self-management. The Recovery Package is a UK survivorship initiative comprising key interventions designed to improve outcomes for people living with and beyond cancer (Macmillan Cancer Support, NHS Improvement, 2013; Macmillan Cancer Support, 2013). The Recovery Package recommended clinical practice interventions are:

1. Holistic Needs Assessment (HNA) which facilitates specialist HCPs to assess needs, plan care, and re-evaluate.
2. Treatment Summary, as a means of communicating a summary of care at conclusion of cancer treatment.
3. The Cancer Care Review, a GP review tool for use within six months of a new diagnosis of cancer and a quality marker.
4. Education and support events, to support the development of self-management skills.

The core aim of this initiative is to encourage a personalised approach to enable people to live healthy and active lives, through the provision of information and support which promotes autonomy and independence, in a more integrated system where care is coordinated between providers (Richards et al., 2011; DH, Macmillan Cancer Support, NHS Improvement, 2013; Macmillan Cancer Support, 2013; Doyle and Henry, 2014; Greenfield and Proctor, 2021). The Recovery Package is a relevant initiative to this thesis because it both signals the previously discussed shift toward more person-centred care and illustrates the growing importance of self-management given the new trajectories of care for advanced cancer within people's lives and independent living. A model for the Recovery Package is shown in figure 1.
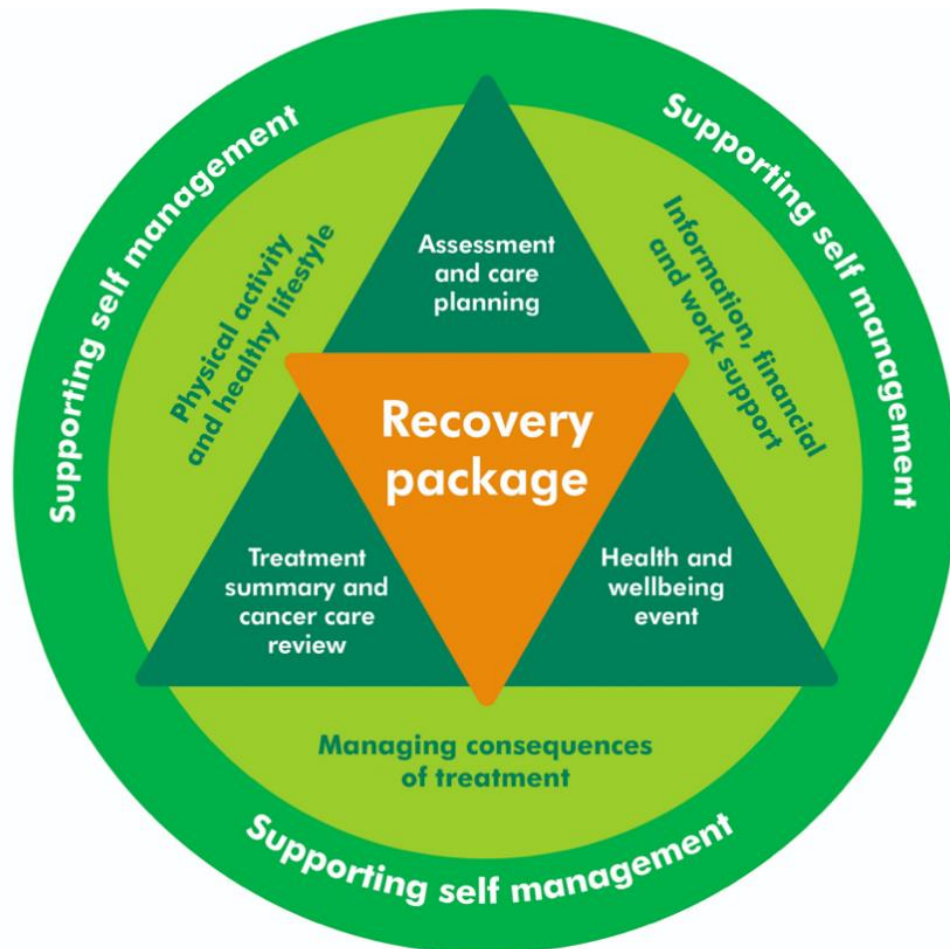
Figure 1. The Recovery Package model (Macmillan Cancer Support, 2013)

1.2.5 Supporting self-management during advanced cancer

Self-management is defined as the ability to manage the symptoms, treatment regimes, physical and psychosocial consequences, and lifestyle changes, consequent to living with a chronic condition (Barlow et al., 2002). Self-management has been proposed to be enacted via behavioural domains relating to self-care maintenance, monitoring, management, and confidence (Riegel et al., 2019). Supported self-management refers to the endeavour in helping people to develop the skills and confidence to adjust and manage their situation (Corbin and Strauss, 1988; Bodenheimer et al, 2002; Chodosh et al, 2005). However, the self-management goals of people living with chronic illness often do not align with the HCPs involved in their care, which is perhaps associated with the tentative continuation of normal life and simultaneous engagement with treatment (Thorne, 2006).

Self-management has come to be understood as a core pillar of living with advanced cancer. Recently, van Dongen et al. (2020) found that self-management strategies in advanced cancer varied widely, covering many domains, which are personal and divergent. The research recommended that individualised programmes that re-evaluate people's needs and wishes should be embedded into existing models of care. The priority for HCPs to help people access relevant services and develop self-management skills is imperative (McCorkle et al., 2011; Harley et al., 2012) and supporting self-management is a central component of The Recovery Package approach to empowering people who are living with and beyond cancer (DH, Macmillan Cancer Support, NHS Improvement, 2013). Promoting self-care among people living with and beyond cancer has been described as the essence of nurse-led interventions across the cancer spectrum (Charalambous et al., 2018). However, elsewhere, evidence indicates that oncology HCPs do not feel adequately skilled to support people and families with self-management (Howell, 2012; van Dongen et al., 2021). In applying Riegel et al.'s (2019) theory of self-care in chronic illness to people living with advanced cancer, Biagioli et al (2021) identified that the acute needs demonstrated by people living with advanced cancer may be a barrier to the promotion of self-care by clinicians, as they instead prioritise direct symptom management. In the time since the start of this research, interest in advanced cancer self-management has escalated. Recent work has outlined the need to prioritise preparing those living with and beyond cancer for what to expect, management of common symptoms and problems; and the development of health services and support to minimise the disruption to people's everyday lives (Foster et al., 2018). These authors explain that it is essential that healthcare providers, researchers and policy makers work together with people living with cancer to understand how to effect financial, practical and cultural changes in clinical services.

Section 1.2 has outlined the central ideas relating to advanced cancer and its care. The nature of advanced cancer has changed and it is now regarded as a long-term condition. Understanding people's complex experiences and considering how they are supported to self-manage is essential for future advanced cancer care. This insight is helpful before specifically exploring how people living with advanced cancer manage their use of medicines at home.

1.3 Using medicines at home

1.3.1 Living with advanced cancer entails many medicines

Medicines are substances which prevent or treat disease by correcting, restoring, or modifying physiological function. They are the most common therapeutic intervention in healthcare (Lehane and McCarthy, 2007; Sabate et al, 2003; NICE, 2009; Royal Pharmaceutical Society (RPS) 2016; MHRA 2020). Medicines are vital for people living with chronic conditions, who routinely require multiple medicines to maintain health (DH, 2012). Medicines, too, are integral to advanced cancer healthcare. They treat underlying disease processes, relieve cancer symptoms, prevent complications, address comorbidities and acute illness, plus mitigate the side-effects of medicines themselves (Lees and Chan, 2011; Fede et al., 2011, LeBlanc et al., 2015). This commonly results in the use of multiple medicines concurrently, or polypharmacy. Though there are numerous definitions for polypharmacy, it most commonly refers to the use of five or more medicines (Mason et al., 2017). Polypharmacy is well understood to potentially cause harm, through the inappropriate provision of medicines which is linked to increased likelihood of drug-related toxicity, medicine errors and non-adherence (Dodd, 2001; Riechelmann et al., 2007; Duerden et al., 2013; RPS 2013). However, polypharmacy can also be appropriate when medicines are beneficial in the context of managing multiple health conditions. The medicines people living with advanced cancer receive are usually essential to sustain life; or to correct or restore physiological function following the use of highly toxic cancer treatments; or hold back distressing and debilitating physical impacts of disease; and prevent the acute complications of cancer itself (Fede et al., 2011; Kotlinska-Lemieszek et al., 2014; LeBlanc et al., 2015; McNeil et al, 2015; Paque et al., 2019).

The complexity of the medicines regimen in advanced cancer care is unique. Unlike other long-term conditions (LTCs) people living with cancer do not always start using a medicine and continue indefinitely. Some medicines may be administered as ongoing therapies, but often medicines may be used intermittently or in rotation. The doses and durations of these treatments change according to clinical assessment. Supportive medicines too are variable in response to people's overall condition, regardless of the use of SACT. The acute disease processes of advanced cancer also routinely require intervention with medicines, which can sometimes transfer into ongoing use of medicine for a long-term mitigating effect. The symptoms associated with cancer disease and treatment result in a plethora of medicines for their management. For example, cancer itself and some SACTs increase the risk of thrombus. In this event, following acute treatment, anti-coagulation therapy is recommended. The use of this medicine however, requires use of another medicine, to prevent gastric damage. Medicines also promote quality of life; by, for example, inducing an appetite, or providing the energy to walk to the kitchen to make a slice of toast, or the ability to digest that toast without vomiting and for it not to cause constipation. The medicines used by people living with advanced cancer are integral to their complex health and wellbeing.

Simply stopping medicines is not necessarily possible. Living with advanced cancer therefore entails self-management responsibility for multiple concurrent essential medicines at home.

1.3.2 The medicines use process and advanced cancer care

Medicines use is best summarised as a process, beginning with the interaction between a potential medicines-user and a prescriber, and followed by transcription of a prescription, dispensing of medicines, administration of medicine and monitoring outcomes of medicines use (Moore et al., 2015). In considering medicines use in advanced cancer, it is valuable to reflect on this process. In the NHS, medicines are prescribed across clinical settings by specially trained HCPs, who comprise doctors and non-medical prescribers (NMPs). Prescribing interactions take place both in person during clinical consultations and remotely. Prescriptions are transcribed both physically and electronically. Prescriptions are checked in pharmacies within clinical care settings or in the community. Medicines are dispensed by pharmacists for collection as individual items. Alternatively, some medicines are dispensed in pre-filled compliance aids. Medicines administration in the home is undertaken independently by people themselves or with support from lay or professional care givers. The monitoring phase of the medicines use process depends on the prescriber, clinical context, and duration of therapy.

Consequent to the unique complexity of medicines use in advanced cancer, the medicines use process as outlined above, is not a linear transaction. Procedures are not uniform and divergences occur for different medicines within a single regimen. For example, an oral SACT is usually prescribed in a specialist oncology setting. This interaction will routinely take place in person and the prescription is transcribed. The medicines may then be dispensed in the clinical setting and handed to the recipient by a clinician. Alternatively, medicines may be collected from a central pharmacy or be delivered directly to people at home. This is just one scenario for one type of medicine in one setting. Another example is the use of oral calcium carbonate supplement to prevent or correct calcium deficiency, which is often a consequence of bisphosphonate treatment for cancer bone metastases. The supply of this medicine though initiated by an oncology prescriber may continue at oncology outpatient appointments or be taken over by the GP, as it is a long-term supplement and not a specialist cancer therapy. In this instance a routine prescribing interaction will not necessarily take place; people may obtain their repeat supply of this medicine by filing a request with their GP who will issue the prescription to a local pharmacy, again for collection or delivery. Just these two very common examples demonstrate how the medicines use process, though in principle straightforward, is complex when multiple prescribers and different types of medicines are involved. There are multiple other permutations for people who engage in this process. These scenarios offered here indicate how the ongoing monitoring of medicines use can become ambiguous due to the shared care of people living with advanced cancer.

1.3.3 Problems using medicine at home

In 2003, the World Health Organisation (WHO) estimated that between 30-50% of medicines prescribed for long-term conditions were not taken as intended (Sabate et al., 2003). Adherence is the widely accepted term for medicine 'taking' behaviour, which describes the extent to which people's medicine use matches the prescriber's recommendations (Barofsky, 1978). Following the WHO report a considerable field of research has been undertaken to enhance knowledge about the drivers of, and potential antidotes for, non-adherence. The breadth of this work and its findings indicate the complex nature of the entire process of medicines use. The focus of this research is on understanding the medicines-related experiences of people living with advanced cancer, rather than the extent to which people's medicine 'taking' corresponds with suggested directions. However, for a long time adherence has been the central focus of medicines research. Understanding this work is important in highlighting current knowledge and the complexity of the field of evidence.

Adherence replaced the term compliance, which instead infers passive following of clinical instruction and lack of involvement (Haynes et al, 2008; Horne et al., 2005). The emphasis of compliance on medicines-taking only implicitly suggests that anything other than this is deviance. Adherence accommodates people's freedom to decide whether to follow recommendations and emphasises the prescribing agreement itself (Sabate et al., 2003; Horne et al., 2005). The importance of using medicines as intended is to ensure their safety and efficacy (NICE 2105). Not doing so can cause harm and poor clinical outcomes. The economic implications of wasted medicines and the additional healthcare associated with re-medicating, extra treatments and tests, plus preventable unplanned hospital admissions are also great (Horne and Weinman 1999; Osterburg and Blaschke, 2005; Howard et al., 2007). Many variables have been shown to influence medicines use (Vermiere et al., 2001; DiMatteo, 2004; Kardas et al., 2013). The WHO classified the determinants of non-adherence into five dimensions: social and economic, heath system, therapy, condition, and patient related (Sabate et al., 2003). Social and economic factors concern inequitable access to information about medicines, due to language or illiteracy, and physical access to prescribers of medicines themselves, due to distances or financial costs. Lack of confidence to seek medical support, lack of support from peers or family, and lack of health insurance are all considered prohibitive of medicines use. Health system determinants refer to the availability of therapeutic relationships which enable people to disclose medicines-related issues, and the adequate training and resourcing of HCPs to facilitate such discussions and education. Therapy-related issues include regimen complexity, medicines side-effects or medicines being ineffective. Issues that are health condition related, relate to any stigma that impacts on engagement with medicines or mental illness. Patient-related factors concern people's individual medicines-taking ability, which encompasses knowing and remembering what medicines to take, when, and how. Beliefs about medicines necessity and concerns about potential adverse effects are central in this domain.

One accepted way of categorising non-adherent behaviour is as intentional and unintentional. These labels delineate between people's deliberate decision to not take advice of the prescriber due to their own perceptions; or their passive failure to follow recommendations due to practicalities beyond their control (Cameron, 1996; Atkins and Fallowfield, 2006; Lehane and McCarthy, 2007). Non-adherence has also been summarised as primary, secondary, and tertiary. Primary non-adherence refers to a non-fulfilment act, where people do not collect or initiate prescriptions; secondary describes the non-persistence enacted by discontinuing a prescription; and tertiary non-adherence explains people's non-conforming by doing something other than that recommended, such as missing or altering doses (Jimm and Jose, 2011). Each WHO determinant includes aspects of both intentional and unintentional non-adherent behaviour, and examples of primary secondary and tertiary non-adherence. It is important to recognise that these categorisations are not concrete. Seemingly unintentional behaviours, such as forgetting to take medicines can in fact be the result of illness perceptions or health beliefs, which cause people forget because they do not consider the medicine important (Easthall and Barnett, 2017). In the UK, guidance about supporting adherence by people receiving NHS care has informed frameworks of practice for HCPs. This focusses on the involvement of people in decisions, taking action to support adherence, reviewing medicines and effective communication between HCPs to prevent fragmentation of medicines care (NICE, 2015).

1.3.4 Approaches to supporting medicines use

A huge effort has been made to develop knowledge and interventions to address safe and effective medicines use. These approaches have consistently focussed on targeting different adherence determinants. Historically, strategies have been classified as educational, focussing on what people know about their medicines using include personalised or group counselling from HCPs and AHPs, using a range of audio-visual and documentary resources; and behavioural, seeking to impact on how people interact with their medicines. These are compliance focused such as reminders via alarms, diaries, charts, telephone calls or email alerts, and compliance aids. More recently a considerable amount of work has focused on people's thoughts, feelings, illness perceptions regarding medicines use, using approaches like motivational interviewing and health coaching (Easthall and Barnett, 2017). Interventions include targeting the prescribing agreement, contracts, adherence monitoring, simplification or tailoring of regimens. Other supportive approaches focussing on the practicality of medicines use such as skill building, regimen routinisation or tailoring and follow-up via pharmacy review have been explored. Systematic research evaluating these interventions consistently reports that the research quality is low, that interventions are complex and that most are ineffective. No single strategy has emerged as beneficial. These evidence reviews consistently conclude that approaches need to be tailored to individual need and that more rigorous research, incorporating more robust adherence measures, testing better interventions is needed (George et al, 2008; Neiwlaat et al., 2014; Ryan et al., 2014; Cross et al., 2020). Moreover, people with complex co-morbidities are not proportionally represented in these studies (Costa et al., 2015).

A range of studies have also considered interventions to target the impacts of polypharmacy, focussing on support for prescribers initiating both necessary and potentially unnecessary medicines. However, the effectiveness of this work is also inconclusive (Patterson, 2014). One approach is criteria to guide deprescribing decisions and ensure people do not receive treatment which may cause harm or provide no benefit (Alldred, 2014; Todd et al., 2017). Other research has attempted to address resistance to medicines discontinuation by the people using them (Reeves et al., 2008). These approaches include tackling the process of the prescribing cascade (Rochon and Gurwitz 1995; 1997), where prescribing occurs to treat the adverse effects of previously inappropriately prescribed medicine. Routine medicines reconciliation, which is defined as the accurate recording of current medicines for comparison against prescribing instructions, has also been proposed as one measure to prevent inappropriate or unsafe medicines use. Another recommendation is regular medicines reviews, which include a screen for medicine interactions and the opportunity to de-prescribe (Cashman et al., 2010; Fede et al., 2012; Todd et al., 2016).

The concept of concordance is also prominent in improving understanding about medicines use. Originally defined as the agreement reached between medicines users and prescribers, concordance is the recognition and negotiation of people's beliefs and wishes to determine how and when medicine will be taken (Marinker 1997; Carter et al, 2005). It emphasises the role of the person using medicines as a decision-maker in the prescribing interaction (Vermiere et al., 2001). This means that some 'non-compliance' may be rational and preferrable, in the case that a prescription is inappropriate or does not accommodate changes in clinical condition or circumstances. In this meaning, the not-taking aspect of medicines use is no longer fitting with deviance and instead meets the true definition of adherence. Such acknowledgement of people's autonomy had not previously been considered part of prescribing interactions (Horne, 1993; Dickinson et al., 1999; Chewning and Wiederholt, 2003; Pound et al., 2005; Cushing and Metcalfe, 2007). In examining the prescriber-patient interaction, Cushing and Metcalfe (2007) make recommendations about achieving concordance by exploring people's understanding of the diagnosis and options for treatment; their beliefs and concerns about the condition and the options for treatment; the challenges they anticipate in trying to adhere to a particular therapeutic regime and the practical ways of helping them with these difficulties. In the cancer context the concept of concordance has provided a framework to recognise the relevance of people's unvoiced agendas, quality of life, symptom monitoring, and involvement with MDT decisions regarding medicine use (Chewning and Wiederholt, 2003). It has been suggested that more attention is needed to apply measures which detect the extent and nature of people's participation in decisions about their medicines and other aspects of shared decisions. It is also noted that to directly improve people's quality of life, the research agenda around medicines in use in cancer must evaluate interventions and study the impact of the individual and organisational factors which affect communication between people living with cancer and their HCPs, throughout the care trajectory (Chewning and Wiederholt, 2003). It is important to note that despite the acknowledgement of people's experience offered by

concordance, it still refers only to the agreement made in the prescribing interaction, and adherence otherwise covers all the other parts of the medicines use process (Dickinson et al., 1999 Horne et al. 2005). Despite such significant interest in the use of medicines in healthcare, a definitive solution to helping people to take their medicines as intended is lacking and the picture about what works is vague. This raises questions about the value of focussing solely on the outcome of medicines-use.

1.3.5 Medicines Optimisation

Medicines Optimisation is a strategic approach to supporting medicines use which spans clinical and academic disciplines (Royal Pharmaceutical Society (RPS), 2013). It considers the entire process of medicines use and places importance on supporting people to get the most out of their medicines, even if that means not taking them. This represents a departure from a biomedical perspective, which has previously focussed on the indication for medicines and the clinical outcome of effective medicines administration. Instead Medicines Optimisation considers the meaning attributed to becoming a medicines-user and the long-term burden of multiple medicine use. Medicines Optimisation places value on HCPs being equipped to understanding people's experiences with their medicines and acknowledges that interactions and actions throughout the medicines-use process influence people's attitudes towards and approaches with their medicines (RPS, 2013; NICE, 2015). Medicines Optimisation good practice guidance specifically aimed at NHS HCPs, advocates for a holistic approach to supporting people to use appropriate medicines safely to achieve the best possible outcome (RPS, 2013). The guidance is organised around four guiding principles:

Principle 1. Aim to understand the patient's experience: focusses on understanding people's perspectives of using medicines. A criticism of prior work relating to medicines use has been the absence of specific insight into people's own experiences of medicines use (Vermiere, 2001; Mohammed et al., 2016). It is increasingly evident that people find taking medicines to be complicated and have negative experiences with medicines, which include poor disease control, inconvenience, adverse events, and inappropriate therapy (Mohammed et al., 2016). HCPs need to understand people's experiences of medicines in care planning in order to help identify burdens and help people in relation to their own life.

Principle 2. Evidence based choice of medicines: describes how medicines selection is informed by the evidence base, and is the most clinically and cost effective. This is to ensure that people use medicines that will give them optimal clinical outcomes and that the use of medicines with little clinical benefit is limited and ideally stopped. This principle also facilitates transparent decision making about access to medicines.

*Principle 3. Ensure medicines use is as safe as possible: r*efers to the responsibility of all HCPs, healthcare organisations and people using medicines to guarantee safe medicines use. This encompasses

adverse effects, interactions, safe processes and systems, and effective communication between professionals. This means avoiding preventable harms, giving people the confidence to use medicines, making it easier for people to discuss their medicines with HCPs, minimising medicines-related unplanned healthcare, reporting adverse events, and the safe disposal of unwanted medicines in local pharmacies.

Principle 4. Make medicine optimisation part of routine practice: concerns the integration of medicines optimisation into everyday healthcare, through the routine discussion between HCPs and medicines-users about getting the best out of medicines use. This incorporates opportunities for people to discuss their medicines with all their HCPs, so that they receive consistency in information about medicines. This fourth principle should also ensure that help with medicines is offered and is available and economic waste is reduced. The model for these recommendations is shown in figure 2.
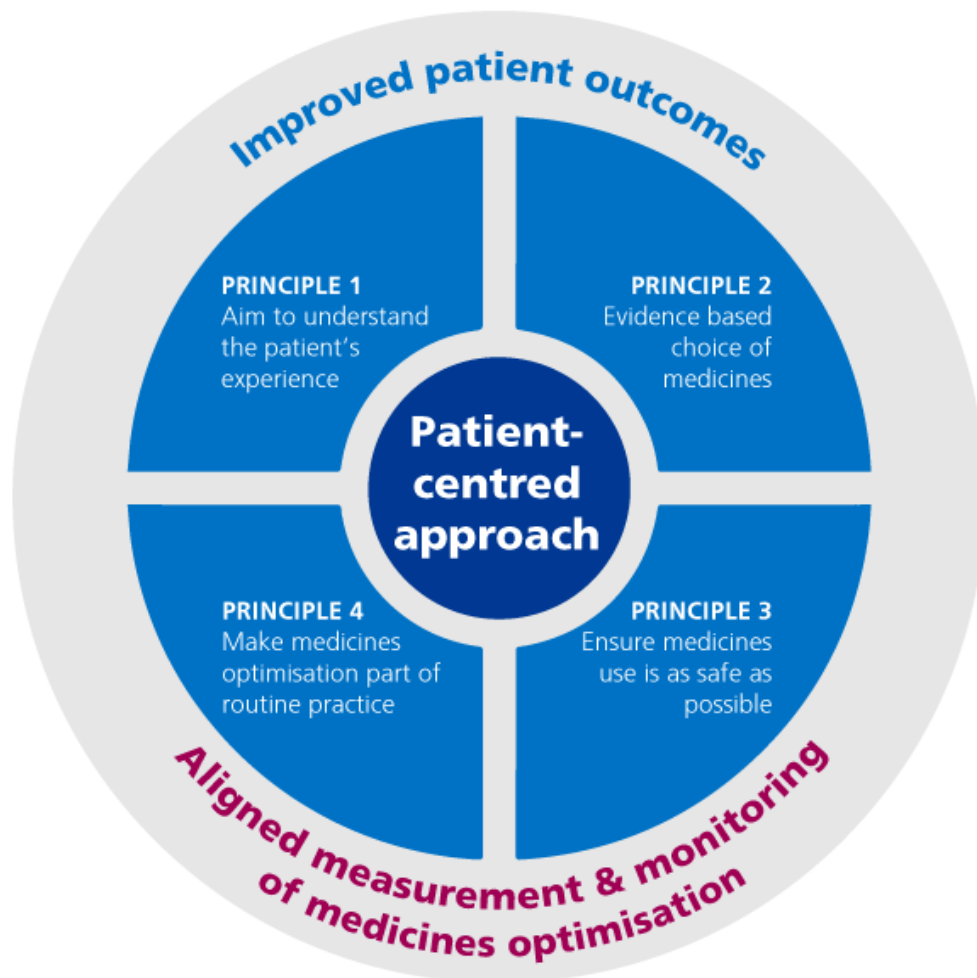
Figure 2. The Medicines Optimisation model (RPS, 2013)

The principles for Medicines Optimisation are intended for use in practice by the whole MDT, but also to inform development of services that ensure that opportunities to support people with their medicines are available throughout the healthcare trajectory. Undoubtedly, individuals' experiences of medicines use are varied and complex. Medicines use involves multiple stages and interactions, which take place in the context of changing health. Shifting the emphasis of interest onto people's experiences can enhance understanding about this complicated medicine use process. As previously identified, attempts to solve non-adherence reveal the many, often indistinguishable, associated factors. Moreover, the focus on adherence ignored the perspective of people who do use medicines as agreed, regardless of their experiences. This approach importantly allows the experiences of people who are adherent to be included in the narrative about medicines use. Considering how people feel about aspects of medicines use, and where they could be supported, might be an alternative way to provide benefit to a larger population.

Medicines Optimisation prioritises helping people make the most of medicines by thinking about their perspectives, which is particularly resonant in relation to advanced cancer medicines use. As discussed, contemporary care for advanced cancer is multifaceted, sprawling and likely long-lasting. Initiatives for people living with and beyond cancer focus on enabling people to have heathy and active lives, through support which is tailored to individual circumstances and goals (Macmillan Cancer Support, 2013). Given the likelihood that people living with advanced cancer will encounter multiple medicines during their complex chronic illness, medicines optimisation and specifically consideration for people's experiences with medicines seems a far more suitable standpoint for exploring and supporting medicines use, than does the isolated outcome of adherence.

1.3.6 Understanding experiences with medicines

The emphasis of existing research has possibly limited knowledge generation about people's overall experiences during the medicine use process and about what they do, or want to do, with their medicines. Shoemaker and Ramalho de Oliveira (2008) have defined the 'medication experience' as people's individual subjective understanding of taking medicines in their daily life. This encompasses not only the act of administering medicines, but the entire medicines encounter. It acknowledges that the meaning people attribute to their medicines, is symbolic of why they are required and their impact on the body. It also considers the everyday context that medicines are used in, which affects people's perspective and behaviour with medicines. These insights about what is required and what it means to people to use medicines are important. They complement other evidence regarding the social element of medicines use, recognises that when people use medicines at home, it represents an intersection between their healthcare and their everyday lives.

One area where this has been investigated in interventional work relates to people's beliefs about medicines. This includes people's perceptions about their need for medicines and benefit of taking medicines, concerns about their negative impact and their impact on self-identity (Horne, 1997;

Pound et al., 2005). Research indicates that adherence is directly connected to people's beliefs about medicines. This includes the assessment of medicines benefit, and concerns they harbour about potential harms. Concerns include fear of dependency and addiction, masking of symptoms, long-term harms of accumulation, and worry about immediate side effects (Horne et al., 1999; Todd et al., 2016). Evidence also indicates people's risk benefit evaluation changes over time and that inconsistencies exist in values and belief between different types of medicines (Horne and Weinman 1999; Clifford et al., 2008). The Necessity Beliefs Framework asserts that implicit judgements of the need for treatment and concerns about potential adverse consequences influence adherence and is suggested as a conceptual model for understanding people's perspectives and supporting prescribing decisions (Horne et al., 2013). In a synthesis of evidence from studies exploring medicine taking amongst people with chronic illness Pound et al., (2005) reported widespread caution regarding medicines use which they describe as resistance. In addition to concerns about physical consequences, people were worried about stigma and negative self-identity. Mohammed et al., (2016) contributed the notion that people do not necessarily harbour existing negative beliefs about medicines, instead they adapt to and tolerate their medicines until the cumulative burden overwhelms their ability to maintain control. Some people experiment and stop taking their medicines, only to re-start medicines-use in the event of adverse consequences. People commonly make trade-offs measuring the sacrifices associated with their health and wellbeing against the benefit of the prescription. Shoemaker and Ramalho de Oliveira (2008; 2011), too, say that the sense of control gained by altering medicines according to the impact that they have on the body is a pragmatic ongoing response to using medicines in the long-term. They emphasise the importance of continual patient education in the context of chronic illness medicines self-management.

Webster et al. (2009) developed the term 'lay pharmacology' to capture how people make sense of their medicines. People receiving long term anti-coagulation therapy constructed a meaning about their medicines which both aligned with, and diverged from, conventional clinical perspective. People in this study thought tablets to be the primary representation of illness and clinical treatment in the home, and their lay constructed understanding of medicines influenced their conduct with medicines. The authors argue this social embedding of medicines use is worthy of greater prominence in research and policy, particularly given the increasing transference of responsibility to people who use medicines via self-management. More recently, Rathbone et al. (2017) defined the phenomenon of people 'getting to know' their medicines, in a review of studies examining non-cancer chronic illness medicines use. The authors identified dislike of medicines, survival, perceived need, and routine, to be key in both enabling medicines use and allowing deviation if preferred. Consequently, they recommend reframing adherence as a social interaction, where the relationship between people's self-identity and their medicines is mediated by interaction with family, friends, health care professionals, the media and the medicine (Rathbone et al., 2017). Future interventions could therefore exploit interactions so that people 'get to know' their

medicines and how to use them. This research challenges NICE adherence guidance (2015), for not recognising medicines as social objects withing the social phenomenon of medicines adherence.

The complex practicality associated with implementing regimens of medicines from multiple sources during chronic illness affects people's quality of life (Chewning and Wiederholt, 2003; Mohammed et al., 2016). Haslbeck and Schaeffer (2009) observed people to be overwhelmed with regimen-related difficulties. The dynamism of the chronic illness trajectory was linked to this, due to the need for continual readjustment to manage illness, which is reflected in medicines and the medicines management routine. The authors state that decision making and cognitive models about medicines use might not fully capture these practical experiences and the range of issues that arise over long-term medicines use. They propose people underestimate the challenge of establishing a medicines management routine at the outset of illness and are determined to maintain autonomy through self-management. Yet over time medicines management requires realistic appraisal. They also identify 'stressed adherers' as people who maintain adherence despite the enormous associated challenges, and recommend that people living with chronic conditions need long-term, individualised self-management support to develop, maintain, and adjust medicines routines. Bytheway (2001) observed that the routines used by older people gave crucial independence and control with medicines use. Wolf et al. (2011; 2016) found that addressing inefficient consolidation of regimens by implementing standardized instructions could potentially help people routinise and take their medicines. May et al. (2009) propose that the problems people experience with their medicines are often induced by the healthcare system and argue that the complexity and workload associated with chronic illness means that difficulties with long-term medicines use are entrenched. They suggest that making medicines as minimally disruptive as possible via efforts to establish the weight of medicines burden, better coordinate care, acknowledge comorbidity in clinical evidence and prioritise individual perspectives is imperative. These principles can support implementation of medicines use and, in turn, enhance their clinical impact.

People living with advanced cancer receive advice about medicines from a range of sources. Macmillan Cancer Support (2021) explain the importance of taking medicines exactly as advised by the healthcare provider and also recommend keeping an up-to-date list of medicines at home. Advice stresses the importance of taking this medicines list to all healthcare-related appointments so that HCPs are aware of all medicines taken. It also suggests that family, friends, or carers know where to find this medicines list, so that key information can be conveyed to the HCP in instances of someone being too unwell to do this themselves. The emphasis of this advice on remembering to take medicines demonstrates a narrow perspective on medicines use and the associated processes. Evidence from broader chronic illness and adherence literature indicates that using medicines comprises multiple factors related to embedding in routine. Further, the impetus placed on individuals to take responsibility for accurate records of their medicines, highlights that accurate medicines information may not be readily available to HCPs at the point of care.

Specific research about medicines experiences during advanced cancer has focussed on the use of certain types of medicines, namely systemic anti-cancer therapy (SACT) and analgesia. A significant amount of work has concerned beliefs about and adherence to adjuvant treatments following cures for primary cancer. Amongst women with breast cancer, Harrow et al. (2014) reported women to endure a range of side effects, often without seeking help and in the absence of the offer of help at routine follow-up. Wells et al. (2016) noted that side effects are the most frequently reported barrier to anti-hormonal medication adherence. Likewise, Spencer et al. (2020) reported the need to improve provider communication, particularly around the benefit of adjuvants in recurrence risk reduction and the need to help people to better manage potential side effect of endocrine therapies. Efforts to support adherence have been focused on educational interventions and have shown little success (Atkins and Fallowfield, 2006; Weaver et al., 2013; Wheeler et al., 2019). In a review of medicines use amongst people receiving oral SACT, Marshall and Given (2018) identified that beliefs are multi-faceted and connected to symptoms, relations with the prescriber, previous experiences, the context of cancer treatment, fear of recurrence, emotional well-being, and information and education.

A vast amount of research has also focussed on the effective implementation of pain medicine regimens at home. Barriers to use of pain medicines relate to the inadequate assessment of pain, fear of addiction, worries about side effects, tolerance to opioids and a lack of shared language (Bennett et al., 2009: Bennett et al., 2011; Bennett et al., 2012; McPherson et al., 2014; Liu et al., 2018). Effective pain control relates to whether people are able to do their activities, fulfil tasks and sustain relationships (Gibbins et al., 2014). Pain is a dynamic self-management task and whilst attitudes and beliefs towards analgesics vary, they do not drive behaviour. Rather, experiences of pain severity and its meaning impact on how pain was managed (Hackett et al., 2016). Studies recommend individual goal setting to establish what people want from the management of pain (Bennett et al., 2009; 2011; 2012; Gibbins et al., 2014; McPherson et al., 2014; Erol et al., 2018; Liu et al., 2018; Hackett et al., 2016; Makhlouf et al., 2020).

The insights provided by this evidence enhance understanding about the complexity of people's medicines use, particularly around the use of specific medicines in advanced cancer. They support the idea that the binary distinction of intentional and unintentional medicines use is inaccurate and that a focus on understanding people's experiences of living and using medicines has greater utility than purely considering whether they take them as prescribed. Behaviour which appears to be unintentional non-adherence, such as forgetting to take a medicine, may relate to intentional factor of not valuing the necessity of the medicine so it is not prioritised, even if not conscious (Easthall, 2019). There is a strong focus on supporting self-management in pain, and specialist pain services are well-developed. However, pain, especially in advanced cancer, does not exist in isolation, and people experience a complex myriad of symptoms, illness and side effects which are managed by a multiple medicines. These insights available about the experiences people living with advanced

cancer have managing medicines in their own home are limited and reflect only a fraction of the issue, representing a failure to deliver the first principle of Medicines Optimisation (RPS, 2013). Despite a wealth of adherence-based research and selected research concerning people's experience, little is known about how people living with advanced experience their whole cohort of medicines; this constitutes a notable gap in existing literature and knowledge.

Section 1.3 has provided an outline of central ideas relating to medicines use at home. It has explained the complex nature of medicines use in advanced cancer, which likely involves multiple medicines, from numerous providers, supplied across a range of systems. People's encounters with medicines have persistently been investigated from the point of view of adherence. Whilst being important and elucidating useful insights, this offers only part of the picture and neglects exploration of people's experiences in the context of their health, healthcare and everyday life. Medicines optimisation has brought about a renewed focus, which has influenced the approach in this research. Rather than thinking about whether people's medicines-use is 'right' this research is instead concerned with what it is like to try.

1.4 Summary, research aims and plan

This chapter has provided background information about advanced cancer care and medicines use in the context of the UK NHS. Advanced cancer is increasingly regarded as a long-term condition, during which people experience complicated and precarious health and wellbeing. There is increased expectation for self-management. There is an essential obligation to use medicines at home. The enduring aim of advanced cancer care is to balance the quality and length of life. Optimising medicines management during this period therefore constitutes a central part of this evaluation. This chapter has discussed how improving understanding about people's experiences and supportive and self-management needs during advanced cancer is a priority, which is mirrored by a drive within healthcare to understand people's own perspectives about their use of medicines. This research aimed to develop understanding about how people living with advanced cancer manage their whole regimen of medicines at home; and to identify opportunities to support Medicines Optimisation within NHS healthcare for advanced cancer. The specific research objectives were therefore to:

- Establish existing knowledge about the experiences that people living with advanced cancer have managing domiciliary medicines
- Explore how people living with advanced cancer manage medicines use at home
- Explore healthcare professional perspectives about the experiences people living with advanced cancer have managing medicines
- Identify the priorities for Medicines Optimisation within NHS healthcare for advanced cancer

Figure 3 summarises the four key stages of work undertaken in this research. First, a literature review was conducted to address the absence of a comprehensive critical synthesis of research evidence about people's experiences with their regimen of medicines at this stage of cancer. The findings of this review informed the design of two empirical research studies: Research Study One to explore people's individual everyday experiences with their medicines and Research Study Two to examine the healthcare system within which medicines use takes place. The final piece of work engaged with stakeholder communities to disseminate and progress research findings.

Literature Review

Examine and synthesise existing evidence

Chapter 2

Research Study One

Explore people's experiences

Chapter 4

Research Study Two

Explore HCP Perspectives

Chapter 5

Stakeholder Engagement

Disseminate findings and set agenda
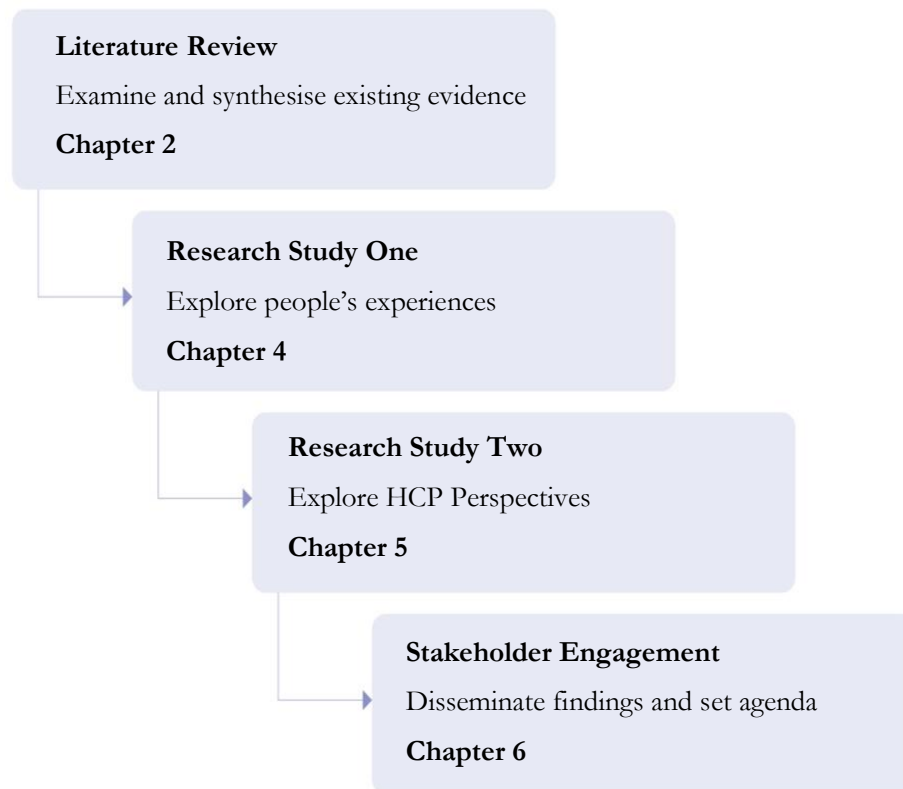
Chapter 6

Figure 3. Plan of PhD research

Chapter 2. Systematic literature review and narrative synthesis

2.1 Introduction

The introductory chapter highlighted how, despite the rising prevalence of advanced cancer and its increasingly long-term nature, there is insufficient understanding about the experiences that people living with advanced cancer have with their many medicines. Knowledge growth in the field has been siloed, focussing on the use of medicines for specific clinical indications such as pain and disease control; and at specific stages in the cancer care trajectory, such as the treatment of non-invasive primary cancer and cured disease (Bennett et al., 2012; Harrow et al., 2014; Marshall and Given, 2018; Makhlouf et al., 2020). The wider field of research about medicines use in chronic illness is dominated by the interest in improving adherence, which has primarily served to reveal the inherent complexity of medicines use (Ryan et al., 2014). Medicines optimisation represents a shift in concern towards person-centred outcomes. The Medicines Optimisation good practice guidance (RPS, 2013) specifically identifies how important it is that healthcare professionals understand people's perspectives of medicines use. This mirrors the endeavour to better support self-management in advanced cancer, by improved intelligence about people's individual experiences (DH, Macmillan Cancer Support, NHS Improvement, 2013). The convergence of these priorities formed the basis for this literature review and narrative synthesis. The review sought to provide an overview of current understanding about the experiences people living with advanced cancer have using prescribed medicines at home and identify gaps in knowledge to inform the design of new research needed to contribute meaningful new understanding to this field.

2.2 Review methodology

2.2.1 Methodologies and selection of narrative synthesis

The purpose of the review was to summarise current understanding about people's experiences of living with advanced cancer and using medicines at home. This demanded a focus on qualitative research, whose evidence would include people's individual perspectives, attitudes, ideas and beliefs and contextual information about their actions and interactions with medicines in everyday life (Green and Britten, 1998; Mason, 1996). The merits and limitations of available methodologies for qualitative evidence synthesis were initially considered, in relation to the review aim and the previous results of preliminary literature mapping (Snyder, 2019; Aveyard, 2014; Mays, et al., 2005; Badger et al., 2000; Moher et al., 2015; Arskey and O'Malley, 2005; Levac et al., 2010; Tricco et al., 2016). However, the small and varied field of research recovered by the initial scoping literature searches indicated that available findings were unlikely to have sufficiently consistent methodological specificity and uniformity to undertake a qualitative evidence synthesis. These approaches of meta-synthesis, meta-ethnography, or thematic synthesis rigorously combine the findings of qualitative research to demonstrate their collective meaning. Such integration of

available evidence can consolidate knowledge and enable rich interpretation, facilitating a deeper understanding of phenomena (Flemming and Noyes., 2021; Sandelowski and Barroso, 2003, 2007; Popay et al., 1998; Bearman and Dawson, 2013). Synthesising evidence from variable sources is complex and presents the challenge of maintaining the integrity of contextualised findings from methodologically dissimilar studies, whilst generating overall depth of conclusions (Sandelowski and Barroso, 2002a, 2002b; Dixon-Woods et al., 2005; Dixon-Woods 2011; Bearman and Dawson 2013). An approach which could collate the findings of studies with different philosophical and theoretical foundations, methods and analytical strategies was needed.

Narrative synthesis is a methodology suitable for coherently summarising evidence from methodologically diverse research sources. The approach uses textual methods to generate a story about the predominant issues and insights of phenomena (Popay et al., 2006). It facilitates collation of highly conceptualised findings alongside evidence with limited interpretive reframing. In this review, narrative synthesis was preferred due to its versatility in accommodating evidence from research studies of disparate aim, approach, quality, and outcome. A systematic literature review and narrative synthesis was devised using guidance for conducting systematic narrative syntheses detailed by Popay et al. (2006). The six key stages outlined are identifying the review focus, searching for and mapping the available evidence, specifying the review question, identifying studies to include in the review, synthesising findings, and reporting and disseminating the results. Using this systematic process and the recommended methods promoted consistency, replicability, and transparency (Centre for Reviews and Dissemination (CRD), 2008; Dixon-Woods, 2005).

2.2.2 Considering Medicines Optimisation

Medicines Optimisation good practice guidance for HCPs (RPS, 2013) are recommendations for all NHS clinicians, which focus on supporting people to make the most of their medicines. In this literature review, given the absence of specific relevant theory, this guidance was used as a framework for the narrative synthesis of evidence. The first guiding principle, which relates to understanding people's experiences with medicines facilitated the examination and integration of the available evidence. This principle is intended to influence the following outcomes:

- Patients are more engaged, understand more about their medicines and are able to make choices, including choices about prevention and healthy living
- Patients' beliefs and preferences about medicines are understood to enable a shared decision about treatment
- Patients are able to take/use their medicines as agreed
- Patients feel confident enough to share openly their experiences of taking or not taking medicines, their views about what medicines mean to them, and how medicines impact on their daily life

2.3 Methods

2.3.1 Locating relevant evidence: literature search strategy and eligibility criteria

A search strategy was developed to find and filter relevant research evidence. This entailed articulating an answerable review question, listing comprehensive searchable terms and establishing the parameters for study inclusion. The SPIDER tool for qualitative evidence synthesis was used as an organising framework for the development of the search strategy (Cooke, et al., 2012). SPIDER prioritises the components, Sample, Phenomenon of Interest, Design, Evaluation and Research type. Other tools, favouring alternative conditions are available, such as Population, Intervention, Comparison, Outcome (PICO) (Higgins and Green, 2013). SPIDER was preferred as it avoided unnecessary focus on intervention trials, which were unlikely to explore experiences. It also maintained focus on qualitative research and contextual nuance (Methley et al., 2014; Cooke et al., 2012). Table 1 summarises SPIDER parameters of the review question and search strategy.

Criteria	Specification	Rationale
Sample	People living with metastatic incurable cancer	Recognises people have variable primary diagnoses and prognoses and are in different clinical speciality groups on different care pathways
Phenomenon of interest	Independent use of prescribed medicines at home	Focusses on capture of evidence about actions and interactions about medicines use. Open to exploring perspectives about the whole medicines process
Design	Interview, questionnaire, focus group, observation	Allows preferred research methods to be introduced. Seeking studies which applied techniques for talking to people and observing experiences.
Evaluation	Experiences	States outcome measure of interest is people's perspectives, experiences, attitudes, beliefs, and preferences, to aid understanding about the meaning of the phenomenon
Research type	Qualitative or mixed methods research studies published in peer-reviewed sources	Defines nature of desired findings as published peer-reviewed primary qualitative or mixed-methods evidence

Table 1. SPIDER specification and rationale

The literature review question was: 'What evidence is reported in peer-reviewed published literature about people's qualitative experiences of living with advanced cancer and using medicines regimens independently at home?'.

Eligibility criteria for studies in the review were established using the SPIDER parameters as follows:

Inclusion criteria:

- Involving people living with advanced cancer independently using medicines at home
- Available in full-text format and English
- Published in peer-reviewed Journals

Exclusion criteria:

- Involving people living in any health or social care setting
- Including use of healthcare-supplied compliance aids
- Involving people in receipt of informal or professional assistance with medicines
- Entirely quantitative
- Published in Book chapters, study protocols, conference abstracts and posters, grey literature, technical reports and editorials, theses and dissertations

Availability of research in full-text format was essential to facilitate in-depth complete reading. Sources other than published research articles were excluded due to the absence of peer-review, and the expectation that any key findings of sources such as theses and dissertations would be published. The criteria acknowledged the limited available research field and likely need to include studies not fully aligned with the research question, but whose evidence overlapped with the review focus. For example, research studies may involve people living with advanced cancer alongside those at other cancer stages. There is also the potential for discrepancy in advanced cancer definition, reflecting the clinical ambiguity and lay terminology discussed in Chapter One. To explore the domiciliary nature of medicine use, the eligibility criteria stipulated that people live independently. However, this accepted the likely variation in supportive care needs and that evidence may incorporate lay caregiving. Though the review sought to examine evidence about the use of all medicines as a collection, the review was also open to the possibility that whole regimen use could be presented in studies investigating the use of one particular type of medicine, for example, analgesics.

To develop the search strategy, the review question was separated into meaningful searchable concepts. These were then tested and refined to establish a balance between specificity of focus on the review question and sensitivity to available evidence. The resulting search strategy only included

the components Sample, advanced cancer; Phenomenon of interest, medicines use; and Evaluation, experiences. Design and Research type were eliminated following practice searches. SPIDER has been shown to have heightened specificity and, in these iterations, using a methodology component yielded very little published work (Cooke et al., 2012; Methley et al., 2014). The nature of the remaining search terms was inherently focussed on qualitative perspectives and ideas and so preserved the focus of the strategy to retrieve studies with suitable approach and content. Keywords and exact phrases for each search term were identified using clinical knowledge and observation of exemplar search strategies. Synonyms, exact phrases, and subject headings were combined using Boolean, wild card, proximity and truncation operators and were modified according to the indexing and command functions of individual databases. An Information Specialist from the University of Leeds Library Research Support team provided feedback on search strategies. An example search thread is listed in appendix 1.

To find published peer-reviewed research articles, comprehensive systematic searches of electronic databases Medline via OVIDSP, PsycINFO via OVIDSP, EMBASE, CINAHL via EBSCOhost and Cochrane database were undertaken. Databases were selected for their relevant content regarding medicine and healthcare, allied health and social care practices and behavioural health. Database searches were limited to English language and studies involving human participants. The same search terms were also applied to the peer-reviewed journals Psycho-Oncology, British Medical Journal: Supportive and Palliative Care and the European Journal of Cancer Care, whose specific focus on research involving the population of people living with advanced cancer was valuable. Google Scholar was searched using research question keywords and the first 100 results were screened for relevance. The management of located research articles was supported by use of Endnote (X9) reference managing software. All articles retrieved were exported into EndNote and duplicates were removed. Literature searches were conducted between November 2014 and March 2015 at the outset of the PhD project and were then repeated in December 2020 and updated again in November 2021.

The titles and abstracts of all articles identified via the search strategy were systematically screened according to the review eligibility criteria. Irrelevant articles were removed. Full-text copies of all retained articles were obtained and screened, and irrelevant articles removed. Forward and backward citation searches of included studies were then undertaken to locate any further studies not previously identified. Potentially relevant articles were obtained in full-text format and screened. Eligible additional articles were added to the existing collection of included research studies, resulting in a final group for the evidence synthesis.

2.3.2 Examining the evidence: data extraction, quality appraisal and findings classification

The evidence presented in included studies was systematically examined and key information was extracted to aid article summary and cross-comparison. This included:

- Article: author, year, country, title
- Study: objectives, design, inclusion/exclusion criteria, population, data collection and analysis methods
- Population: sample size, age, sex, ethnicity, household, employment, primary cancer, disease status, co-morbidities, types of medicines used, frequency of medicines used
- Study outcomes: results, key findings, conclusions

The methodological quality of each study was then critically appraised using the CASP (Critical Appraisal Skills Programme) tool for qualitative research (CASP, 2018). This is one of several standardised measures to assess studies' theoretical and procedural robustness in relation to their purpose. CASP provided a methodical process to comprehensively audit studies' content and assess for potential biases, which could support study comparison, and the communication of findings in the evidence synthesis (Aveyard, 2014; Greenhalgh 1997; Greenhalgh and Taylor, 1997; Centre for Reviews and Dissemination, (CRD), 2008; Long et al., 2020). The ten CASP checklist questions were applied to each study. A scoring system was created to grade the overall methodological quality of each article and distinguish between the relative quality of studies. One point was given when the CASP question could be answered 'yes'. Points were cumulated and studies described as high (CASP score 9-10), medium (CASP score 6-8) or low (CASP score 5 or less) quality.

Measuring the methodological integrity of research only partially aids a judgement of quality. The contextual nature of qualitative research means that the value of the research also depended on the nature of studies' contribution to knowledge (Sandelowski and Barroso, 2003). Therefore, rather than relying solely on the CASP assessment, the richness of study findings were also appraised (Sandelowski and Barroso, 2003; Sandelowski, 2015). Discerning between research studies' findings, regardless of their methodology can be particularly useful in narrative synthesis. It supports the fair representation of credible findings, which may be otherwise undermined by procedural discrepancies; and prevents over-confidence in the findings of methodologically faultless work, whose interpretive insight is minimal (Sandelowski and Barroso, 2002; 2007). Sandelowski and Barroso (2003), suggest a typology to designate the extent of data transformation of study findings. Topical Survey denotes findings which are minimally translated from original data and traditionally use author-labelled inventories and lists to summarise ideas. Thematic Surveys use concepts or themes from existing literature or empirical results to organise data, whilst maintaining emphasis on cataloguing and enumerating the data. Conceptual Description moves toward interpretively integrating parts of data and reframing ideas as concepts developed from the data to extend

understanding. Interpretive Explanation is when data are transformed to produce fully integrated explanations that represent the target phenomenon offering a new, coherent model.

In this review, the findings of each study were classified according to this suggested typology. This appraisal involved systematic, in-depth reading of each article and reference to key information previously tabulated. A textual summary of the interpretive characteristics of the findings in each study was produced, and the appropriate category identified. The results of the assessment were then tabulated alongside CASP scores, to visualise the relative contribution of each study. This combined assessment of the methodological quality and interpretive value of findings across research studies justified the emphasis on evidence within the synthesis.

2.3.3 Synthesising evidence: organising, analysing and integrating findings

Guidance for conducting narrative synthesis suggests four stages towards integrating study findings (Popay et al., 2006). These are developing a theory of how the intervention works, why and for whom; developing a preliminary synthesis; exploring relationships within and between studies; and assessing the robustness of the synthesis product. In this review, these synthesis stages were addressed in turn, and tools recommended by the guidance were selected accordingly.

No governing theory was identified at the outset of this work. The literature review was exploratory and consequently assumed an open and generative approach.

A preliminary synthesis was developed by methodically interrogating the content, process and findings of each included research study (Popay et al., 2006). First, study key information and results were tabulated. Then, to preserve individual study characteristics, a textual summary of each was developed. Studies were next grouped according to sample, disease stage or recruitment setting, and the type of medicines use investigated. This process helped to determine the studies with most relevance to the review question. Overall, these stages encouraged familiarisation with the included studies' research aims, methods and findings.

To explore the relationships within and between studies, research findings were analysed for themes using a framework approach. The four outcomes of the first guiding principle of the Medicines Optimisation good practice guidance for HCPs (RPS, 2013) previously outlined in section 2.2.2, were used as a broad analytical framework for the narrative synthesis providing an initial basis to organise study findings. This offered only one way of structuring analysis of study evidence. The approach was motivated by the absence of alternative theory, framework and policy about experiences of using medicines and long-term cancer. The outcomes offered a means to map existing knowledge about medicines use amongst people living with advanced cancer, according to clinical guidance about understanding their experiences. This meant that resulting recommendations about the nature of further research were context bound and applicable to

current best practice. During analysis, study evidence was systematically extracted and interrogated. Findings from different studies relating to the same idea about people's experiences were congregated as a potential theme. These developing themes were assigned a descriptive statement to articulate the interpretive position and provide analytical transparency. Findings from each study represented by the same theme were charted together as a collection of synthesised findings. Synthesised findings were organised according to the four outcomes suggested in the first principle of Medicines Optimisation good practice guidance (RPS, 2013). The relationships within and across the studies could be explored and patterns and variance throughout data observed. Throughout this process study authors' own terminology and phrasing was retained to preserve the contextual research perspective. Concept mapping facilitated visualisation of the outcomes and the newly generated themes and demonstrated their relationships with one another. The outcomes formed core nodes and were connected to analytical themes to show the associations between concepts.

To assess the robustness of the synthesis, appraisal of methodological and findings contribution was undertaken to assess the strength of evidence (Popay et al., 2006). This combined critique and classification aimed to enhance the trustworthiness of the synthesis by ensuring that appropriate weight be given to each piece of evidence. The table summarising studies' appraisal outcomes was used for reference throughout the development of the textual synthesis. Findings from studies executed with methodological excellence were judged more important than those with theoretical or procedural insufficiencies. Conceptually progressive findings from high quality studies took precedence over assertive interpretive contributions in lower quality research.

2.4 Results

2.4.1 Overview of search results

A total of 984 articles were retrieved, of which 955 came from subject databases and 29 came from key healthcare academic journals and Google Scholar. After title and abstract screening, 23 articles were selected for full-text review. Eight of these articles were assessed to be eligible for inclusion in the narrative synthesis of research evidence. Citation searches identified a further three eligible articles. Two of these articles were a two-part publication reporting findings from a single study. The research included therefore comprised 11 articles overall, reporting ten studies. Five of the included studies were previously identified through scoping searches undertaken in preparation for this literature review (Zeppetella, 1999; Stoner, et al., 2010; Schumacher et al., 2002; Sand, et al., 2009b; Klein et al., 2013). The additional six articles were identified during the original and updated searches proper (Yeager et al., 2012; Wickersham et al., 2014; Schumacher et al., 2014a and 2014b; Milic et al., 2016; Campling et al., (2017). The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009), were used to produce the PRISMA diagram in figure 4, to summarise search results and the article selection process.
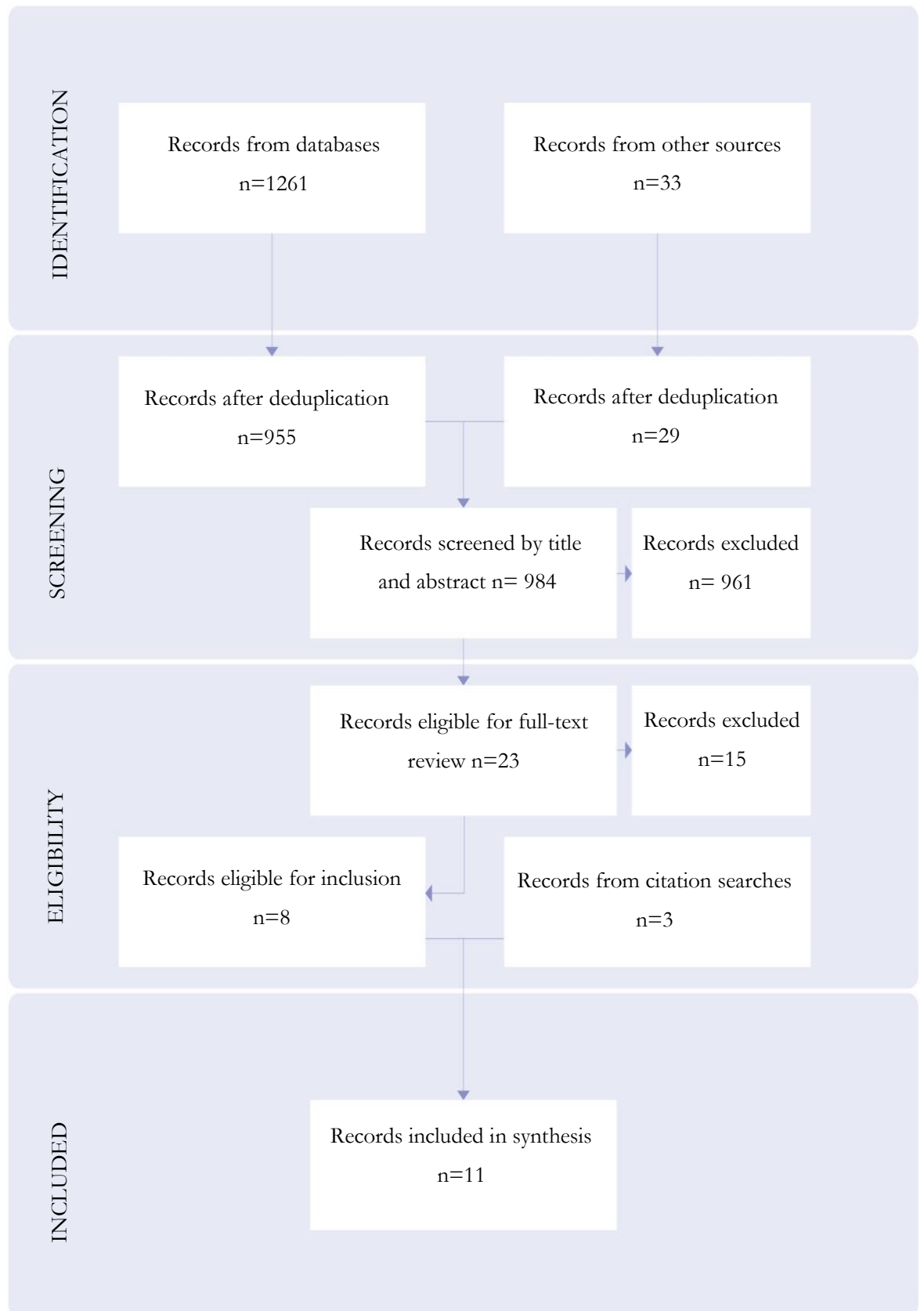
Figure 4. PRISMA diagram of inclusion and exclusion of research studies for literature review

2.4.2 Article screening and study selection

The title and abstract of 984 articles were systematically screened for eligibility. As anticipated, due to the broad scope of the search concepts much of this literature was not applicable to the focus of the review. The 961 irrelevant articles were excluded. Twenty-three articles which met the inclusion conditions or required clarification were progressed for full-text reading. The full text screening group included articles reporting research studies about medicines adherence, adherence interventions, polypharmacy, pain-management, medicines discontinuation and the use of medicines at the end-of-life. There was a notable abundance of research investigating whether people take their medicines as directed or not and the reasons why. Evidence about people's experience of medicines in the context of their condition, their healthcare and their homes was scant. Study samples all included people living with advanced cancer. Some studies additionally included other people at various stages in the trajectory of care, receiving curative treatment, those in follow-up after effective cancer treatment and people with a short life expectancy receiving end-of-life care.

Each article was read carefully and considered in relation to the review aims and eligibility criteria. Full-text reading revealed limited research with precise relevance to the review question. Eligible studies used a range of methodological approaches. This confirmed the suitability of a narrative synthesis. Rather than attempting to represent the field and provide a cumulative record of evidence, the methodology would incorporate different types of evidence to produce a contextually rich overview of the story of current knowledge. After full-text screening, twelve articles were rejected as they reported evidence of insufficient overlap with the review focus. Most were investigations about analgesia only and focused on identifying and overcoming the perceived barriers to adherence, rather than exploring people's experiences with pain medicines management or their integration with a broader medicine regimen. Other excluded studies focussed on people's use of a specific cancer therapy or self-management generally during advanced cancer. Ten studies were eligible for inclusion in the review, one of which was reported across a two-part publication.

2.4.3 Included studies

The ten research studies included in the narrative synthesis of evidence are summarised in Table 2. This was a small collection of research studies. Studies used a range of qualitative techniques to collect data of varying relevance to this review question. Notably, the research was conducted over a long period, during which cancer care and treatment, and the concept of advanced cancer chronicity, have been rapidly developing. The lack of more recent exploration in this field is surprising, particularly due to the increasing domiciliary nature of advanced cancer care delivery. The evidence synthesis can therefore not reflect or evaluate the impact of pathways and processes in current advanced cancer care.

Included articles used a range of overlapping terminology. Some refer to participants and others, patients. In this chapter the collective term people will be used. This choice reflects the fact that whilst in the context of a study individuals are participants and in the context of healthcare, they are patients, the overarching premise of this thesis is to explore the experiences of people, beyond their capacity as a participant or patient. Similarly, research articles used different vocabulary to denote prescribed medicines, such as drugs, pharmaceuticals and medications. As is consistent throughout this thesis, the term medicines is used in the evidence synthesis to reflect the Royal Pharmaceutical Society (RPS) accepted term (RPS, 2019). All studies reported findings about the experiences of medicines use amongst people living with advanced cancer. There was remarkable variation in the terminology used to report disease stage, which was anticipated for the reasons previously identified in Chapter One. These discrepancies have been retained in discussion about the research evidence to assist in judgement regarding its relevance to the review purpose.

Three studies presented qualitative findings on people's approaches and feelings about use of a whole regime during advanced cancer (Klein et al., 2013; Stoner et al., 2010; Sand et al., 2009b). Klein et al., (2013) involved people living with cancer attending an outpatient clinic, three-quarters of whom were reported to have 'incurable' disease. Stoner et al., (2010) included eleven people with late-stage cancer identified at an oncology clinic. Sand et al., (2009b) sampled fifteen people living with advanced incurable cancer with multiple metastases and short life-expectancy, from a palliative care day centre. All conducted interviews in the clinic. Two further studies specifically explored people's adherence and satisfaction with the use of their whole collection of medicines (Zeppetella, 1999; Milic et al., 2016). Zeppetella (1999) used face-to face semi-structured interviews alongside pill-counting, to assess compliance with prescribed medicines at home. Ninety-two percent of the 111 people in the study had terminal cancer of various origin. Milic et al., (2016) used a written questionnaire to collect qualitative data about tablet-taking preferences amongst 100 women with metastatic breast cancer. Both presented mixed statistical and qualitative data.

The remaining studies used in-depth qualitative methods to gain richer insights into issues but lacked the same overlap of focus with the review question. Three concerned the management of cancer-pain (Campling et al., 2017; Schumacher et al., 2002; Schumacher et al., 2014a; Schumacher et al., 2014b). Unlike other cancer-pain research located in the searches, these provided detailed evidence about people's implementation of analgesic regimens and the processes of medicines management and integration of pain-relief regimens with their other medicines. Campling et al., (2017) included fifteen people in the last year of their life, thirteen of whom were reported to have cancer, plus healthcare professionals and carers. Campling et al., (2017) used qualitative methods of in-depth interviewing and focus groups to develop understanding about roles and transitions of engagement with pain relief medicines management at the end-of life. Two studies, Schumacher et al., (2002) and Schumacher et al., (2014a; 2014b), assessed nurse-led pain management interventions for people with cancer pain, which were both embedded in a larger Randomised-Control Trial

(RCT). Schumacher et al., (2002) included adults with varied cancer diagnosis all with bone metastases and described the stages of a pain management medicine regimen implementation process. Schumacher et al., (2014a; 2014b) sampled people with an unreported disease status, whose prognosis was judged greater than six months and sought to categorise and contextualise pain-management practices. Both studies used observational methods analysing clinical interactions, alongside pain diaries and nurse memos and also included carer perspectives. The study by Yeager et al., (2012) used interviews to explore symptom self-management approaches in people living with advanced cancer and reported evidence regarding people's medicines experiences. Similarly, Wickersham et al., (2014) undertook multiple face-to-face and telephone semi-structured interviews to explore the use of oral-SACT, to develop a grounded theory to explain surviving with non-small cell lung cancer (NSCLC). Of the thirteen people diagnosed with NSCLC in the study, eleven were Stage IIIb or IV. Though specific to a diagnosis and treatment, findings presented potentially valuable insights about people's other medicines.

Of the ten studies, five were conducted in the USA, three in the UK, one in Norway, and one in Switzerland, meaning the research provides only a Western perspective. This dominance prevents a broader scope of knowledge and cross-comparison between people, healthcare and systems globally. Overall, the research samples lacked insight into the impact of ethnicity. There was some effort to represent diversity, but many studies did not adequately report sociodemographic variables. Rather than stating cultural identity, Klein et al., (2013) reported on immigration status and Zeppetella (1999) identified people for whom English was not their first language. By contrast, in both 2002 and 2014 studies, Schumacher and colleagues reported the ethnicity of all involved. Samples comprised mainly Caucasians, with small numbers of people of African American, Hispanic, Asian or mixed ethnicity. Yeager et al., (2012) specifically selected a sample of low-income African Americans. As only three studies were conducted in the UK (Campling et al., 2017; Milic et al., 2016; and Zeppetella, 1999), the depth of perspective about the NHS healthcare context and the impact of Medicines Optimisation strategy on people's experiences is also restricted

Authors	Year	Country	Title	Aim	Design	Participants and setting	Methods
Campling, N., Richardson, A., Mulvey, M., Bennett, M., Johnston, B., and Latter, S.	2017	UK	Self-management support at the end of life: Patients', carers' and professionals' perspectives on managing medicines	To describe, characterise and understand the concept of self-management support as the end-of-life approaches, in the specific context of managing analgesia and related treatments	Qualitative	n=38 people in the last year of life (n=15) carers (n=4) HCPs from Palliative Care (n=19) Primary diagnosis: bile duct (1) breast (1) colon (1) lung (3) melanoma (1) mesothelioma (1) oesophagus (1) pancreas (1) prostate (2) uterus (1) non-cancer (2) male (8) female (7) mean age 66 (range 47-84)	Focus group at hospice (4) interviews at home (11) Verbatim transcription Framework analysis
Milic, M., Foster, A., Rihawi, K., Anthoney A., and Twelves C.	2016	UK	Tablet burden in patents with metastatic breast cancer (MBC)	To define tablet burden experienced by women with MBC, establish which groups of drugs contribute to that burden, gain insight into	Mixed methods	n=100 Women with advanced breast cancer (100) Primary diagnosis: breast (100) Disease status:	Questionnaire given to people attending outpatients, day-unit or inpatient ward Statistical analysis

				patients' attitudes towards oral cancer treatments and determine to what extent patients perceive tablet burden as a problem		metastatic Female (100)	
Schumacher, K.L., Plano Clark, V.L., West, C.M., Dodd, M,J., Rabow, M.W., & Miaskowski. C.	2014 a & b	USA	Pain medication Management Processes Used by Oncology Outpatients and family caregivers Part I: Health Systems Contexts Part II: Home and Lifestyle	To describe day-to-day pain medication management from the perspectives of oncology outpatients and their family caregivers who participated in a randomized clinical trial of a psychoeducational intervention	Qualitative	n=62 people with cancer (42) family care givers (20) Primary diagnoses: breast (14) lung (6) prostate (17) Other (5) Disease status: life expectancy at least 6 months Male (25) female (17) Mean age 64 (range 40-88)	Observation of clinical intervention interaction Interpretive analysis

Wickersham, K.E., Happ, M.B., Bender, C.M., Engberg, S.J., Tarhini, A., Erlen J.A.	2014	USA	Surviving with Lung Cancer: Medication Taking and oral targeted therapy	To explore process of medication-taking for adults with non-small cell lung cancer (NSCLC) receiving Erlotinib, an oral epidermal growth factor receptor inhibitor (EGFRI) therapy. To develop a grounded theory that described and explained the process of medication-taking for adults in this patient population	Qualitative Grounded theory	n=13 outpatients with NSCLC all receiving Erlotinib Primary diagnosis: Lung (13) Disease status: stage II/IIa (2) stage IIIb/IV (11) Male (5), female (8) Mean age 70.5 (range 52-83)	In-depth semi structured interview at home or convenient other location (13) follow-up at home or convenient other location (14) follow-up telephone interview (5)
Klein, M., Geschwindner, H., and Spichiger, E.	2013	Switzerland	Life with a multitude of medications A qualitative study of experiences	To investigate in the Swiss context, how patients with cancer experience a complex drug therapy in everyday life and how they deal with it at home	Qualitative	n=12 people with cancer Primary diagnoses: Gastrointestinal (5) haematological (4) lung (2) breast (1)	semi-structured interviews at home (10) at outpatient clinic (2) Content analysis

			of patients with cancer			disease status: remission (2), metastatic palliative (7) metastatic chronic (2), unknown (1) Male (4) Female (8) Mean age 69 (range 61-78)	
Yeager, K.A., Bauer-Wu, S., Dilorio, C., Quest, T.E., Sterk,C.E., Vena C.	2012	USA	Managing One's Symptoms: A Qualitative Study of Low-Income African Americans with Advanced Cancer	To discover what individuals do day-to-day, to relieve and manage symptoms. To learn about strategies used to manage symptoms directly from African American individuals, experiencing the symptoms not just what prescribers had prescribed	Qualitative Descriptive	n=27 low-income African Americans with advanced cancer Primary diagnosis: Breast (9) lung (8) prostate (3) Ovarian (3) Cervical (1) leiomyosarcoma (1) renal (1) vocal chord (1) Female (18) male (9) Mean age 57 (30-79)	semi-structured interview at clinic (11) semi-structured interview at home (16) Content analysis
Stoner , M. , Hand M.W., Foley, R.	2010		Patients With Cancer: Experiences of Medication Management	to understand the process of medication management in patients with late-stage cancer	Qualitative (descriptive phenomeno logy)	N=11 People with late-stage cancer Female (6) male (5) Mean age 75.4 (range 65-88)	Semi-structured interviews at community-based oncology practice (11)

							Thematic analysis
				from the perspective of the patient.			
Sand, A.M., Harris, J., and Rosland, J.H.	2009	Norway	Living with Advanced Cancer and Short Life Expectancy: Patients' experiences with managing medication	To explore patients' experiences of using medicines when they are living with far advanced cancer and short life expectancy	Qualitative	n=15 people with advanced cancer Primary diagnosis: gastrointestinal (6), breast (3), lung (3), renal (1), skin (1), gynaecological (1) Disease status: incurable, end-of-life (15) Male (5) female (10) Mean age 62.4 (range 39—92)	Semi-structured interviews at palliative care unit (15) Thematic analysis
Schumacher, K. L., Koresawa, S., , West, C., Hawkins, C.,Johnson, C., Wais, E., Dodd, M.,	2002	USA	Putting Cancer Pain Management Regimens into Practice at Home	To describe the difficulties with pain management that patients and family caregivers bring to a nurse's attention during a teaching and coaching intervention	Qualitative	n=85 people with advanced cancer (52) family caregivers (33) Primary diagnosis: Breast 56% Lung 12% Prostate 10%, other 25% Primary disease:	Semi-structured clinical encounters implementing intervention Telephone follow-up at 2,4 and 5 weeks Inductive Analysis

Paul, S M., Tripathy, D., Koo, P. & Miaskowski, C.						Breast (29) lung (6) prostate (5) other (12) Disease status: bone metastases (52) female (36) Male (16) Mean age 58.9 (range	
Zeppetella, G.	1999	UK	How do terminally ill patients at home take their medication?	To identify the drugs prescribed to terminally ill patients living at home and to assess their compliance with treatment	Mixed methods	n=111 terminally-ill people	Semi-structured interviews and pill counting At home (106) Statistical analysis

Table 2. Literature review data extraction table

2.4.4 Critical appraisal of methodological quality and findings classification

The methodological quality of each study was evaluated using the CASP tool for qualitative research (CASP, 2018). All studies were considered focussed, had clearly stated aims and used suitable qualitative methods. However, the level of detail provided, acknowledgment of integral limitations and transparency of reporting varied. Five studies were rated as high quality (Campling et al., 2017; Schumacher et al., 2002; Schumacher et al., 2014a and Schumacher et al., 2014b; Wickersham et al., 2014; Yeager et al., 2012).

Camping et al., (2017) clearly articulated the aim to understand self-management roles and describe, characterise and explain self-management practises at the end-of-life care and analgesic use. The authors used theoretical concepts to guide the study through conception, data collection, and the subsequent interpretation of findings using a framework approach. The study appropriately applied focus groups to explore role definitions and interviews to explore depth about the nature of self-manage experiences. Transparent procedural detail is provided about the predetermined themes and the deductive data analysis, incorporating inductive ideas. A conceptual model for self-management of pain-management at the end-of-life concisely summarises new understanding, as a dynamic process involving people living with cancer, carers and HCPs. The authors discuss the development of ideas and contextualise implications for academic understanding and clinical practice, all of which enhance the dependability and extend the transferability of findings.

Schumacher et al., (2002) report key evidence about the difficulties of practical management of pain control regimens, generated from observation of interactions between people and their HCPs at home, during a broader RCT. The authors identify the necessity to not influence RCT outcomes and resultant limits of the method in exploring individual concepts further. Audio-data were supplemented by annotation. Comprehensive details of a rigorous analytical process describe an inductive approach which included coding and categorisation practices. The authors refer to co-analysts and category testing of participant data, indicating a rigorous focus on delivering credible results. The study findings also attend to transferability, by contextualising the impact of the intervention being tested in the RCT, and identifying how these qualitative data are so vital in identifying the dynamic and ongoing nature of the process of pain medicine-management. Later, Schumacher et al (2014a; 2014b) report day-to-day pain-medicine management from the perspective of people living with cancer and their family caregivers. The authors give detailed explanation of the processes of interrogating overall data enriching the trustworthiness of results. There is reference to co-analysts and use of verbatim quotations. Findings are clearly stated as being divided across a two-part publication and are extensively discussed in relation to the existing body of evidence and their contribution towards developing new understanding. The authors clearly articulate the context of their conclusions and the implications for clinical practice facilitating the accurate transferability of findings. Wickersham et al., (2014) suitably apply Grounded Theory to explore the process of medicine-taking for adults with NSCLC using oral treatment and describe a

theory of surviving with lung cancer. They clearly articulate sampling procedures and attrition, demonstrating transparency which enhances the article quality. Analytical detail is thorough with a detailed description of constant comparative analysis, and the use of co-analysts to enhance credibility. Similarly, Yeager et al., (2012) use a descriptive qualitative approach, to explore symptom-management during advanced cancer. Measures to promote rigour, of both process and analysis are articulated, demonstrating reflexivity and transparency. There is sound justification for the use of interviewing, and the interview topic guide is included. Close attention is paid to maintaining ethical integrity. Multiple coders are involved in data analysis. The authors explain that during the research all processes, collaborations, and data decisions were documented, which consolidated the trustworthiness of the study.

Three studies were assessed as medium quality (Klein et al., 2013; Milic et al., 2016; and Sand et al., 2009b). Both Klein et al., (2013) and Sand et al., (2009b) provided a detailed overview of their rationale and methods of accessing people's perspectives of medicines use during advanced cancer. The method of recruitment used by Sand et al., (2009b) at a palliative care day hospice is appropriate; however, the article indicates that a researcher approaches people directly, which raises questions about ethical sample selection and undermines the integrity of the research sample. Study eligibility criteria are not pre-specified, which further weakens the credibility of findings. Both Sand et al., (2009b) and Klein et al., (2014) consider the ethical impact of research and effort to eliminate potential sources of bias yet omitted methodological process detail. Sand et al., (2009b) reported transparency of analysis, clearly described as a two-stage process involving co-analysts. Findings are clearly presented as four overarching themes. Whilst the summary discussion is brief, the broad implications for clinical practice and contextual limitations are recognised. Klein et al., (2013) reported limited detail about their data collection process, with minimal information about the interview topic guide and procedure, which limits the transferability of methods. The description of the content analysis method is vague, and systematic procedures therein not clearly articulated, restricting the extent to which findings can be securely attributed with the study aim to understand people's behaviour with their medicines. Milic et al., (2016) clearly state their aims to quantify tablet burden in women with metastatic breast cancer and establish which drugs contribute to tablet burden and enhance insight into patient attitudes about oral SACT. They explicitly justified and appropriately used a questionnaire and inventory to assess the research aims. Inclusion criteria relevant to the aims of the study are used. However, no attempt to achieve demographic variation is articulated. The authors state that the convenience sample of 100 people is likely to be representative; however, because no clear process for recruitment is provided, the robustness of this claim and the replicability of the study are undermined. The survey collected predetermined answers which are numerical or based on a Likert Scale to determine adherence and convenience. Results are represented with limited analytical insight. This article reported the essential study detail but did not address researcher bias or ethical considerations, again minimising confidence in rigour.

Two studies rated as low quality both specifically focussed on understanding people's experiences with medicines during advanced cancer. Stoner et al., (2010) stated using descriptive phenomenology to understand the perspective of medicines-management experience in people with late-stage cancer. However, the report lacked essential information about sampling, data collection, and analytic techniques and only a limited description of findings was presented. Extensive ramifications of findings were discussed. However, the extent to which the findings are believable in relation to the evidence presented and authors' assertions, and that they can be transferred to other contexts, is dubious. The lack of transparency in reporting and lack of reflexivity further lessens the methodological integrity of this work. Finally, Zeppetella (1999), combined interview with pill-counting in a study assessing compliance. Data collection procedures and analytical process were not described, and qualitative findings from the participant responses were not systematically discussed. That no acknowledgement of potential bias is provided, is particularly relevant in this single-author study, where the research is undertaken by the treating clinician who recruited people during their routine clinical interaction and appears to have conducted the data collection and involved no co-analysts. The avoidance of discussion about the possible limitations of these technical processes harms the credibility and dependability of the research findings.

The classification guide for assessing and comparing qualitative data proposed by Sandelowski and Barroso (2003) was applied to each study to consider the interpretive contribution of findings. Two studies demonstrating the highest degree of conceptualisation, Campling et al., (2017) and Wickersham et al., (2014), were classified as 'interpretive explanation'. Campling et al., (2017) developed understanding about self-management engagement, building on existing theory about support roles at the end-of-life and pain medicines-management processes, to elucidate findings as a conceptual model of self-management support of analgesia and related treatments at the end-of-life. The carefully detailed explanations give insight into the roles of people living with cancer and carers, plus the need for skilled, ongoing assessment to detect changes in competencies and preferences around opioid use. In-so doing, the authors make a valuable new contribution to this specific area of care. The findings are used to develop a feasibility trial for a supportive intervention. Wickersham et al., (2014), present similarly transformative findings. The authors develop a grounded theory for 'Surviving with Lung Cancer', from the conceptualisation of key themes identified through interview analysis. Detailed explanation and contextualised quotations for three concepts are supplied and variance within the sample is reported. The relationship between these themes and their integration is provided and represented as an illuminating conceptual model, which includes context regarding the healthcare process of medicines use and the actions and attitudes of people living with NSCLC relating to using oral medicines to stay alive.

Studies whose findings were categorised as 'conceptual description' were Schumacher et al., (2014 a and b),Yeager et al., (2012), and Sand et al., (2009b). Schumacher et al., (2014 a and b) integrated data about people's experiences of the different procedural stages of pain medicines-management

to develop understanding about the overall phenomenon as a framework of contexts and processes. This delineates aspects of people's experiences in order to report high levels of detail and variation and are supported by rich descriptions. The authors explain the significance of the relationships between these concepts and people's co-experiencing of multiple themes, within the complex systems involved. Yeager et al., (2012) present findings as themes developed from the data to extend understanding about the experience of managing symptoms of advanced cancer amongst low-income African Americans. The organisational hierarchy of these concepts is diagrammed through the interaction between concepts. However, this is not discussed in detail and this representation of concepts is not critically examined in relation to other self-management theory. Sand et al., (2009b) present four key themes to represent their findings about the experiences that people with 'end-stage' cancer have with their medicines during cancer. The themes are used to reframe the ideas introduced. Findings are summarised beyond the *a priori* ideas stated in the article introduction. Authors describe variation in the sample and example quotations accurately supplement thematic descriptions and the relationship between themes is briefly described.

Klein et al., (2013) and Schumacher et al., (2002) offer findings characteristic of 'thematic survey'. Schumacher et al., (2002) present seven stages of 'putting pain management into practice', describing experiences as an ongoing problem-solving process. Data are interpreted topically around the processes identified, using *in vivo* descriptions and explanation and examples are consistent and supportive. Klein et al. (2013) use three themes to label and categorise people's experiences. These are supported by subthemes which use *in vivo* description to report relatively brief detail, context and variation between cases with quotations. Findings do highlight people's experience and a diagram representing these experiences is presented. However, ideas from the data are not reframed conceptually. Because the relationships between categories are not explained, and the model is not related to theory, the interpretive contribution of the study is reduced.

One article, by Stoner et al., (2010) bordered 'thematic survey' and 'topical survey'. The quality of the presentation of results is low, so it is difficult to make an accurate judgement about the degree of interpretation undertaken. Findings are summarised as a list of categories and presented in a table as four key themes. Quotations are provided alongside each of these sub-themes. However, no information is provided about the interview or participant context within which the individual comments were made. The process of generating these four categories is not described. Discussion about categories is unsystematic and broad. The quotations themselves are valuable and could, with different treatment in the report, have illuminated vital meaning around people's experiences. It is possible that the thematic categories are indeed generated from the data but that is not transparent.

Finally, studies by Milic et al., (2016) and by Zeppetella (1999), are classified as 'topical surveys'. The reports about these studies are informative, using predominantly nominal and categorical ways of representing findings. Milic et al., (2016) provide useful context about numbers of medicines,

types of medicines, and relevant data about women's perception of inconvenience with tablets. Likewise, Zeppetella (1999) categorise medicines and the reasons why people are non-compliant with medicines at home. Yet, neither study offers further insight and depth of understanding into people's experiences and self-articulated attitudes.

To facilitate assessment and comparison of the overall strength of evidence across the studies, the results of the critical appraisals of methodological quality (CASP, 2018) and findings classification (Sandelowski and Barroso, 2003) were considered together. Table 3 summarises critical appraisal outcomes for each study. Studies are listed according to their relative rating for procedural and analytical quality and interpretive contribution; higher rated studies are in darker shading. This allows studies' comparative overall value to be visualised as a hierarchy. This process supported the weighting of evidence included in the synthesis, enhancing the accuracy of reporting about findings, and ensuring the robustness of the synthesis.

Study authors (date)	Methodological quality (CASP, 2018)	Findings classification (Sandelowski & Barroso, 2003)
Campling et al., (2017)	High	Interpretive explanation
Wickersham et al., (2014)	High	Interpretive explanation
Schumacher et al., (2014 a&b)	High	Conceptual description
Yeager et al., (2012)	High	Conceptual description
Sand et al., (2009b)	Medium	Conceptual description
Schumacher et al., (2002)	High	Thematic survey
Klein et al., (2013)	Medium	Thematic survey
Milic et al., (2016)	Medium	Topical survey
Stoner et al., (2010)	Low	Thematic survey/ Topical survey
Zeppetella, (1999)	Low	Topical survey

Table 3. Research quality and classification appraisal outcomes for included studies

2.5 Literature review findings: a narrative synthesis

2.5.1 Narrative synthesis themes

Research findings from each study were examined in the context of the four outcomes of the first guiding principle of the Medicines Optimisation good practice guidance (RPS, 2013). The themes developed during the synthesis of research evidence are presented in Table 4. Whilst multiple themes were mapped to each of the four outcomes, the table highlights that the first outcome, about engagement, understanding and choice about medicines had the greatest number of related themes. Though the same number of themes were mapped to remaining outcomes, a notably limited amount of evidence was identified about the final outcome, which refers to interactions with HCPs about medicines.

Medicine Optimisation Outcome	Themes
Patients are more engaged, understand more about their medicines and are able to make choices, including choices about prevention and healthy living.	Having many medicines
	The hard work of medicine management
	Taking responsibility for medicines
	Knowing medicines
	Source, quality and timeliness of information about medicines
Patients' beliefs and preferences about medicines are understood to enable a shared decision about treatment.	Preferring to take as few medicines as possible
	Fearing what medicine will do
	Having a choice
Patients are able to take/use their medicine as agreed	Accessing medicines
	Strategies to manage medicines
	Making unintentional changes to the regime
	Making intentional changes to the regime
Patients feel confident enough to share openly their experiences of taking or not taking medicines, their views about what medicines mean to them, and how medicines impact on their daily life.	Experiencing complex and simultaneous symptoms and side-effects
	Having doubts, worries and unanswered questions
	Having opportunities to talk about medicines

Table 4. Narrative synthesis themes and subthemes mapped to outcomes of the first principle of Medicines Optimisation good practice guidance (RPS, 2013)

Medicine Optimisation Outcome: Patients are more engaged, understand more about their medicines and are able to make choices, including choices about prevention and healthy living.

The first outcome refers to involvement with and understanding of their medicines and how this relates to their choices. Research findings highlighted the extent of people's responsibility for medicines and the practical knowledge and expertise necessary to interact with them at home.

Having many medicines

People living with advanced cancer were prescribed many medicines for multiple indications. The extent of medicines ranged from one to 16 different medicines every day amongst studies which specifically detailed this evidence (Zeppetella, 1999; Sand et al., 2009b; Klein et al., 2013). People living with advanced cancer were found to have on average between 6.5 and 8 different daily medicines (Sand et al., 2009b; Klein et al., 2013). Zeppetella (1999) reported that terminally ill people had on average 5.5 different daily medicines. Milic et al., (2016) reported the number of tablets taken, rather than different medicines, and reported that people living with MBC were prescribed a median of eight and in some cases up to 31 tablets daily. Medicines were prescribed to treat cancer as well as manage side-effects and symptoms, prevent complications, and treat comorbidities. Across studies, people used oral cancer treatments including chemotherapy, endocrine treatment and targeted agents. Other medicines primarily included analgesia, anti-emetics, gastro-protectants, steroids, laxatives, bisphosphonates, and calcium supplements as well as endocrine, anti-coagulant, anti-hypertensive, and mood-stabilising medicines (Zeppetella et al., 1999; Yeager et al., 2012; Milic et al., 2016). Zeppetella (1999), found that 39 different drugs were involved amongst the 111 terminally ill people surveyed. Klein et al., (2013) reported that six people took medicines twice daily, two took them three times a day, and four took their medicines more frequently than three times a day. Zeppetella (1999) did not explicitly report the dosing schedules of everyone's regimens; however, the study did present a sub-set of results relating to the forty-seven people who omitted medicine. Of this group, medicines of all daily frequencies were omitted, but particularly those required four times daily when compared with once daily medicines. Several studies additionally reported use of over-the-counter medicines mainly for pain, constipation or dietary supplementation (Zeppetella, 1999; Yeager et al., 2012; Milic et al., 2016), which was shown to compound regimen complexity. Medicines were prescribed by multiple HCPs and consequently supplied from different sources.

The hard work of medicines management

Engaging with medicines translated to considerable work. Authors specifically exploring pain-relief (Schumacher et al., 2002; Schumacher et al., 2014a and 2014b; Campling et al., 2017) provided highly detailed insights into the processes associated with implementing medicine-regimens at home. This is not only the act of medicines-taking, but wider medicines management practices

including accessing medicines and symptom assessment. Schumacher (2002) described pain medicine self-management as an "ongoing-problem solving" exercise and attributed people's difficulties with pain-management to seven sub-processes of putting pain-management regimens into practice. These are defined as: obtaining medicines, accessing information, tailoring the prescribed regimen to meet individual needs, managing side effects, cognitively processing and remembering complex information, managing new or unusual pain, and managing multiple symptoms simultaneously. Schumacher et al (2014a; 2014b) later described what was perceived as the "unending" work of people living with advanced cancer using analgesia at home. Both healthcare plus home and lifestyle contexts accounted for a huge amount of participant effort to navigate the multi-dimensional process of getting prescriptions, obtaining medicines and then understanding, organising, storing, scheduling, remembering, and taking pain-medicines. Campling et al., (2017) subsequently showed these processes to fit within the broader conceptualisation of pain self-management during the end of life.

Taking responsibility for medicines

Varying degrees of personal responsibility for medicines management were demonstrated. Explaining people's pain self-management roles in the end-of-life, Campling et al., (2017) build on a typology initially developed for nurses by Johnston et al., (2012), which describes the distinct roles of advocate, educator, facilitator, problem-solver, communicator, goal-setter, monitor, and reporter, whose resulting behaviours support medicines use. Campling et al., (2017) went on to find that people's autonomous work was merged with the work of their HCPs in a continuum of self-management. Here, role variation contributed to a dynamic process from full engagement where individuals chose responsibility, accepted risks, and made complex decisions, to no engagement where deterioration is accompanied by the transfer of responsibility. This model accommodates for overall decline and day-to-day fluctuations in wellbeing, where the enactment of self-management behaviours is affected by people's competency, engagement, and acceptance of responsibility.

Elsewhere, amongst participants with advanced cancer, various levels of participation with medicines were observed. Studies described people being completely independent, the involvement of a caregiver, or relying on HCPs, which was all also susceptible to change over the course of the advanced cancer illness. Wickersham et al., (2014) observed the rigorous preparation and ongoing self-assessment and maintenance undertaken prior to commencing and when using medicines for NSCLC. Milic et al., (2016) found that women's preference for oral systemic anti-cancer therapy (SACT) rather than intra-venous (IV) therapy for metastatic Breast Cancer (MBC), was sometimes governed by the sense of control and personal responsibility it afforded. Some interviews with people living with advanced cancer indicated high degree of engagement with their whole regimen; this included altering and adjusting medicines according to personal preference (Sand et al., 2009b; Yeager et al., 2012). Stoner et al., (2010) on the other hand, described the notion of people's

surrender to their medicines burden and resultant reliance on nursing and medical care providers to manage practical issues related to medicines.

Knowing medicines

The connection between knowing medicines and being able to use them effectively was widely discussed. Studies found that people's knowledge about the indication for their medicines varied. Some found that people knew well the reasons for taking their medicines and were able to name their diagnoses, diseased organs, symptoms, principles of medicines action, and rationale for one medicine in preference to another (Yeager et al., 2012; Klein et al., 2013; Wickersham et al., 2014). Others were unclear about or unsure about their different medicines and lost track of their purpose over time (Zeppetella 1999; Sand et al., 2009b; Stoner et al., 2010). Poor understanding was cited as a reason for medicines omission or use of additional medicines (Zeppetella, 1999). Klein et al., (2013) recommended that HCPs should regularly check people's knowledge about their medicines and encourage medicine adherence.

However, knowledge about medicines was not limited to the rationale for medicines use. It also encompassed practical familiarity, where people made a connection between their medicines' purpose and their physical appearance, which enabled them to interact with and about their medicines. Schumacher et al (2014) defined this 'understanding' as a specific element of the multi-dimensional process of medicines use. Evidence highlighted barriers to this link between knowing and distinguishing between medicines, prohibiting use and talk about medicines. Campling et al., (2017), Klein et al., (2013), Sand et al., (2009b) and Schumacher et al., (2002; 20014a; 2014b) all demonstrated that whilst people knew why medicines were prescribed, they had trouble pronouncing or recalling medicines names due to their long, polysyllabic form, or niche abbreviations, which were not intuitively linked to their purpose. This was exacerbated by medicines being renamed or replaced with different brands or formulations. People used their own techniques to get to know their medicines and had developed reference systems to orientate themselves to the drug, by knowing the packaging, tablet appearance, and referring to a nick name, function, or dose. Campling et al., (2017) found that in the context of pain management, these obstacles to knowing medicines impacted on people's role as a facilitator in implementing their pain management strategy. This could lead to uncontrolled pain and mismanagement of analgesic side-effects. These barriers also affected their roles as educator, advocate, and communicator by generally obstructing meaningful communication with prescribing clinicians, which caused confusion and posed safety risks.

Sources, quality and timeliness of information about medicines

The sources of information about medicines available to people, and value of that information, were often reported as variable. A range of formats for information provision existed, depending upon the medicines supplier, including verbal from the prescriber and other HCPs, and textual on the medicines label, Patient Information Leaflets (PILs) in medicines packets, local written

guidance, and digital resources. Despite the amount of information available, people did not always have access to (or know how to) discern specific, reliable information that could be applied to their situation. People were dependent upon the medicines prescriber for what they perceived to be accurate information (Klein et al., 2013). Contact with other expert HCPs could be useful, for example with a Specialist in Palliative Care or Pain (Schumacher, et al., 2014b; Campling et al., 2017). However, individual HCPs could not always provide personally relevant answers upfront (Schumacher et al., 2002; Schumacher et al., 2014; Klein et al., 2017). Information about medicines from HCPs was rarely accompanied by instructions about their practical use at home (Schumacher et al., 2002). It was perceived that some HCPs withhold certain details, particularly around adverse effects, which drives suspicion about whether people are truly informed (Klein et al., 2013). People appreciated written materials, but unhelpful presentation or indistinct content could be obstructive to accessing necessary information. The information printed on medicines labels was sometimes too small, poorly worded, and lacked essential detail about the medicines, or its administration, which was particularly problematic for those in receipt of multiple prescriptions (Stoner et al., 2010; Schumacher et al., 2014b; Campling et al., 2017). Patient information leaflets (PILs) inside the medicines packet were sometimes difficult to understand or contained extensive information about medicines risks which provoked hesitancy (Stoner et al., 2012; Klein et al., 2013; Schumacher 2014b; Campling et al., 2017). Schumacher et al., (2014b) observed this to be exacerbated by the limited opportunity to talk things over with a knowledgeable clinician. The internet was helpful, but people again required supplementary input from HCPs to decipher relevant facts (Campling et al., 2017). More generally they needed to speak to someone to consolidate understanding and retain information. The timeliness of education about medicines was sometimes unsuitable or inconsistent. People felt they received lots of information at the commencement of medicines but that subsequent discussions occurred only if problems arose with medicines (Sand et al., 2009b; Klein et al., 2013). The absence of an ongoing and open dialogue about medicines left a gap in support provision and the HCPs that people were in contact with were not necessarily well-informed about medicines (Sand et al., 2009b; Stoner et al., 2010; Klein et al., 2013). In the clinical context of pain-management, people were found to need information at different stages for different reasons, as ongoing support for their medicines use (Campling et al., 2017; Schumacher et al., 2014a).

The emphasis of information provision was considered by some to be skewed towards anti-cancer treatments (Klein, et al., 2013). Conversations about the benefits, risks, and toxicities of these medicines were consistently reported but this was not the case for other types of medicines. This supported people's preliminary work of information-seeking when considering therapeutic options (Wickersham et al., 2014). However, the inadequacy of information at other stages in the treatment pathway was stated as a reason for not using medicines as prescribed and seeking alternatives (Zeppetella, 1999).

Medicine Optimisation Outcome: Patients' beliefs and preferences about medicines are understood to enable a shared decision about treatment.

This second outcome refers to the acknowledgement and involvement of medicines users' personal views and values in making joint decisions. The evidence highlighted the personal negotiation people make between the clinical importance of medicines versus their concerns about what their use will do to them. These factors impact on their decision-making around medicines. Minimal evidence focussed on the involvement of HCPs in this negotiation or the dialogue of shared decision-making.

Preferring to take as few medicines as possible

People commonly harboured a dislike of medicines (Sand et al., 2009b; Yeager et al., 2012; Klein et al., 2013; Wickersham et al., 2014). Even those who had taken medicines for years preceding their cancer diagnosis still expressed their preference to take as few medicines as possible and ideally none (Klein et al., 2013). For many people, medicines signified illness and therefore any dose reduction or cancellation was a victory and perceived as a step towards improved health (Sand et al., 2009b; Klein, et al., 2013). Having medicines in the home was a constant reminder of cancer and people were also concerned about the prospect of side-effects, the inconvenience associated with tablet size, taste, quantity, or the complexity of medicines regimens, all of which contributed to their desire to take fewer medicines (Zeppetella, 1999; Yeager, et al., 2012; Klein et al., 2013; Schumacher et al., 2014a; Wickersham et al., 2014; Milic et al. 2016; Campling et al., 2017).

Fearing what medicines will do

All studies reported people's concerns about the consequence of medicines use. This included both immediate and long-term physical and psychological impacts. People were afraid of side-effects, either due to previous encounters, or those that they had been warned about or observed in other people. Wickersham et al., (2014) discussed this in the context of weighing up harms and benefits of starting Erlotinib, a SACT which blocks lung cancer cell growth. People reported the toxicities, which include rash, diarrhoea, colic, and hair changes, to be frightening. Yeager et al., (2012) described people's dislike of the drowsiness caused by some analgesics. In the context of analgesia, constipation was a severely troubling side-effect of opiates, which people feared to the point of reducing their doses and having more pain (Schumacher et al., 2002). Several studies found people to be particularly worried about developing tolerance and needing increasing amounts of medicine to achieve the same therapeutic effect (Zeppetella, 1999; Sand et al., 2009b; Yeager et al., 2012; Klein et al., 2013). People also expressed concern about losing control due to medicines via developing dependency and addiction (Schumacher et al., 2002; Sand et al., 2009b; Yeager et al., 2012; Campling et al., 2017). Studies specifically exploring pain control identified consistently that people intentionally experience suffering to limit their intake of medicines to mitigate their concerns (Schumacher, 2002; Yeager et al., 2012; Schumacher, 2014a; 2014b; Campling et al., 2017).

Having a choice

All the included studies highlighted how worries about medicines were commonplace, but so too was the acceptance of their necessity and the notion of having limited choice about whether to use them. Some people viewed medicines as a barrier to the deterioration of their health due to cancer and its consequences. Medicines provided an opportunity to protect themselves and prevent disease sequelae, complications, or further invasive and aggressive treatment, for which people were grateful (Sand et al., 2009b; Yeager et al., 2012; Klein et al., 2013; Wickersham et al., 2014). This was challenged though, by feelings about the possible negative effects of medicines. People evaluated wanting not to die or be in pain, against their underlying reluctance to take medicines. Wickersham (et al., 2014) reported that people commencing new treatment weighed up concerns about the side-effects of treatment against the possible benefits. Yeager et al., (2012) defined people's internal conflict about not taking medicines but knowing it was necessary.

Sharing decisions with HCPs about medicines varied. Wickersham at al. (2014) explained how people considering Erlotinib therapy sought advice from others such as a family member and trusted doctor recommendations. This research offered a theory of surviving with lung cancer, which was articulated as a continuum of advocacy-negotiation to reflect potential decision points and degrees of autonomy throughout the treatment pathway. Campling et al., (2017) offer a self-management model, which similarly demonstrates how people's preference to engage in decision-making about their medicines is dynamic and malleable over the course of the end-of-life phase. Also, coordinating multiple HCPs involved in care to make a shared decision about pain management was found to be difficult. Klein et al., (2013) reported that people living with advanced cancer worked with their doctor to negotiate dose reductions or discontinuation and felt that deviating from the prescription would be deceptive. Stoner et al., (2010) conversely interpreted people's general lack of involvement with their medicines as surrender and disempowerment.

Choices around medicines were connected to the idea of being in control. People were fearful of losing agency and so some made deliberate modification of medicines regimes as a means of retaining or regaining autonomy. Zeppetella (1999) found that the least compliant people cited medicines infectivity, avoidance of side-effects, and distrust in the drug or the prescriber as reasons for non-adherence. Sand et al., (2009b) and Yeager et al., (2012) both described how people consciously adjust medicines beyond the prescription to suit their personal needs. By 'listening to their bodies', people experimented and titrated medicines according to their tolerance of certain symptoms, side-effects and preferred activities.

Medicine Optimisation Outcome: Patients are able to use their medicine as agreed

This outcome refers to the administration of medicines in accordance with prescribers' recommendations. Research evidence focussed on adherence, the processes which enable people to use medicines effectively and the perceived drivers of non-adherent behaviour.

Accessing medicines

Physically obtaining medicines was an important aspect of medicine use. People referred to the processes associated with medicines supply or prescription renewal. Schumacher et al., (2014a) outlined the health systems contexts of getting prescriptions and obtaining the medicines, within their wider multi-dimensional framework of cancer pain-medicine. This could be convoluted, with medicines coming from different places with no standardised reordering process. People needed to first get relevant authorisations and then follow the specific requirements of each supplier, which was time consuming and exhausting, causing effort, worry and frustration (Schumacher et al., 2002; Schumacher 2014a; Campling et al., 2017). Some people were found to experience significant difficulties with the ongoing supply of medicine (Schumacher et al., 2002). Obtaining refills could be chaotic; people sometimes ran out and some were tempted to stockpile medicines at home in case their circumstances changed, and medicines were needed in the future (Stoner, 2010). Zeppetella (1999) observed an association with multiple excess supplies amongst people who had many different prescribers.

In the context of pain, obtaining medicines required in-person trips to the pharmacy, which were tiring and created additional burden on top of already attending existing appointments. Direct supply of medicines from the hospice or hospital was advantageous because it was convenient, but also because a clinician would be present to explain and demonstrate. Other people received medicines by post, which was helpful but required forward planning (Campling et al., 2017). Repeat medicines prescriptions generated other problems. The timing of renewal was crucial to make requests with enough time to avoid a gap in supply. People with multiple concurrent repeat prescriptions found the lack of syncing of supplies particularly difficult. Electronic reordering platforms were slow and unusable. Problems could also occur at the pharmacy itself, as some medicines might be out of stock, delayed, or provided in the incorrect preparation. This all amounted to stress and frustration (Schumacher, et al., 2002; Campling et al., 2017). Klein et al., (2013), exploring overall medicines use in advanced cancer, observed that people's actions for obtaining medicine were ritualised in a similar way to the routines associated with medicines administration. Studies from the USA all made numerous references to the cost of prescriptions and how this affected the ability or choice to obtain prescribed medicines (Schumacher et al., 2002; Schumacher et al., 2014a; 2014b: Stoner, 2010; Yeager et al., 2012; Wickersham, et al., 2017).

Strategies to manage medicines

Effective medicines-taking was underpinned by shared practises. People's approaches involved integrating medicines-taking into everyday life and activities in the home to routinise their regimen. Schumacher et al., (2014a) outlined the home and lifestyle processes of organising, scheduling, remembering, and taking medicines within their wider multi-dimensional framework of cancer pain medicines management. These were later confirmed in pain-medicines self-management towards the end of life (Campling et al., 2017). Though other studies exploring people's experiences with their whole collection of medicines at home did not explicitly delineate the stages of regimen management, they too described people's application of interdependent, strategic moves. Organising medicines required arranging them in certain permanent locations associated with specific times of the day, activities and habits. Medicines were lined up on kitchen counters, bedside tables and bathroom cabinets (Sand et al., 2009b; Schumacher et al., 2014a; 2014b; Wickersham et al., 2014; Campling et al., 2017). The sheer quantity and form of medicines prescribed within analgesic regimes, including patches, liquids and tablets, could preclude orderly arrangement (Campling et al., 2017). Scheduling involved identifying routine fixed times and procedures and linking medicines taking to activities like waking up or mealtimes (Klein et al., 2013; Wickersham et al., 2014; Schumacher et al., 2014a; 2014b; Campling et al., 2017). This was a unique challenge with medicine for pain-relief, which demanded tailoring according to people's individual daily routine and wellbeing (Schumacher et al., 2014a; 2014b; Campling et al., 2017). Remembering to use medicines was often facilitated by use of an alarm, a family member, or an alternative prompt. The use of visual or active cues, where medicines were strategically positioned or placed were also useful reminders (Klein et al., 2013; Wickersham et al., 2014). Taking medicines involved dispensing them straight from the packaging, using a home-made receptacle, or medical compliance aid. Their specific placement was thoughtful, to consider the presence of children, pets or visitors (Schumacher et al., 2014b; Campling et al., 2017). Compliance aids were, in some cases, a helpful means of organising, scheduling and remembering pain medicines doses. However, for many they were inadequate; compartments were not large enough for all the pills, the medicine schedule did not match the number of compartments, or the medicines were supplied in an alternative preparation that was unsuitable for dispensing into the compliance aid (Schumacher et al., 2014a; 2014b; Campling et al., 2017). Separating medicines from their original containers, to populate a compliance aid, was also a source of confusion as people were no longer sure what the medicines were or how they should be taken.

Schumacher et al., (2002) recognised that these highly personalised strategies came about from people's trial and error attempts at medicines-management because of a lack of practical guidance about how to deal with them. In contrast to these highly ordered approaches. Stoner et al., (2010) specifically found people to lack a management system and be entirely reliant on recall, which resulted in chaos. Zeppetella (1999) observed that some people had compliance aids or medicines charts; however, their use was not explored.

Making unintentional changes

Several studies presented evidence related to the causes of people's unintentional non-adherence. Forgetting was commonly reported, particularly if routines were interrupted in any way. Certain dose timings or schedules were more vulnerable to being forgotten, such as at periods of the day without ritual, or when routines were disrupted in the event of visitors or a trip out (Klein et al., 2013). Zeppetella (1999) found that people were most likely to not take medicine as prescribed when they were required multiple times throughout the day, most commonly QDS. Milic et al., (2015) did not comment directly on adherence but observed that over a third of women with MBC forgot their tablets at least once, and some up to five times weekly.

Remembering to take medicines was complicated by a mindset of only taking medicine in response to a symptom, which was particularly relevant in the use of pain medicine. This undermined a fundamental principle of effective analgesia, which aims to maintain a continuous pain-free duration (Schumacher et al., 2002; Campling, et al., 2017;). Physical factors such as drowsiness, fatigue, and memory loss exacerbated difficulties with remembering, which led people to miss doses or be uncertain of whether they had already taken medicines (Schumacher et al., 2002; Campling et al., 2017). Unintentional non-adherence was also associated with being confused about medicines in some way. Changes to medicines appearance and labelling discrepancies were disruptive and a source of anxiety (Sand et al., 2009b; Stoner et al., 2010; Klein et al., 2013; Schumacher et al., 2014b; Campling et al., 2017). Types of medicines caused more confusion, such as analgesic patches due to their unique administration method and schedules. Practical and organisational problems also caused non-adherence. Swallowing large tablets or getting medicine out of fiddly or impenetrable blister-packs or heavy glass bottles all make medicines-taking harder. These issues were exacerbated by the physical symptoms associated with cancer and its treatment such as poor appetite, nausea, peripheral neuropathy, and fatigue (Schumacher et al., 2014b; Campling et al., 2017). In the context of pain management Schumacher et al., (2002) found that people had problems titrating doses, combining analgesia and using medicines 'as required' optimally.

Making intentional changes

Evidence also demonstrated deliberate non-adherence. Several studies exemplified self-regulatory tactics which entailed contradicting their prescription to modify medicine doses and timings, titrate, or omit medicine to see what happened. People adjusted their medicines to avoid persistent unwanted side-effects in the hope of achieving some respite and even to participate in otherwise unfeasible activities (Zeppetella, 1999; Yeager et al., 2012; Sand et al., 2009b;). People assessed if they could take fewer medicines without feeling worse and reintroduced doses as symptoms returned (Sand et al., 2009b; Yeager et al., 2012). Some deviation was driven by concern about intangible effects, such as the fear of opiate-dependence or addiction (Sand et al., 2009b). In both cases, people were found to experience symptomatic suffering in their attempt to avoid these unwanted consequences.

Intentional non-adherence in people living with advanced cancer at home was found to sometimes be associated by a lack of trust in medicines benefit (Zeppetella, 1999). Other people in this study avoided taking medicines out of a consciousness that they already took so many tablets. In the context of end-of-life care, people intentionally stopped using medicines, because they encountered obstacles which prevented the optimal implementation of their regimen and meant they did not achieve therapeutic benefit of the medicines (Campling et al., 2017). Their resultant dissatisfaction with the outcome caused them to lose faith in the medicine and then stop taking them altogether. Medicines omission was also shown to be grounded in the desire of people living with advanced cancer to forget their disease. Not taking tablets maintained an illusion of health (Sand et al., 2009b; Yeager et al., 2012).

Medicine Optimisation Outcome: Patients feel confident enough to share openly their experiences of taking or not taking medicines, their views about what medicines mean to them, and how medicines impact on their daily life.

This outcome refers to people's assurance in sharing their experiences of medicines administration and their opinions and ideas about medicines use and impact. Findings provided insight into people's perspectives of being a medicines user, the consequences of medicines use, and their current opportunities to share these experiences with HCPs involved in their care.

Experiencing complex or simultaneous symptoms or side-effects

People living with advanced cancer encountered a plethora of physical symptoms, which they were required to monitor and medicate. This was complicated because symptoms were caused both by disease, the side-effects of cancer treatment, comorbidities, and the side-effects of other medicines. Consequently, people had trouble identifying and articulating their symptoms and attributing them to a specific physiological or pharmacological cause (Schumacher et al., 2002; Sand et al., 2009b; Yeager et al., 2012; Klein et al., 2013; Schumacher 2014b; Campling et al., 2017). Common problems arose associated with analgesia. Schumacher et al., (2002) described the snowballing effect that occurs through attempting to manage side-effects with one medicine, which then causes a new side-effect also requiring management with another medicine. Side-effects became a barrier not only to initiating medicines but also continuing medicine use. Symptoms associated with the toxicities of SACT could be frightening, unpleasant, and socially inhibiting because of their impact on physical appearance. Despite the severity of side effects people were committed to therapy and even perceived side-effects as an indication of treatment effectiveness (Wickersham et al., 2014).

Having doubts, worries and unanswered questions

People in several studies were found to have unresolved concerns about their medicines. People questioned whether their drugs were appropriate, if others were available, whether side-effects would occur, and how medicines information related to their specific circumstances (Schumacher et

al., 2002; Sand et al., 2009b; Yeager et al., 2012; Klein et al., 2013; Schumacher et al., 2014b; Campling et al., 2017). These worries were often inadequately addressed. People wanted HCPs to listen to them, talk to them about medicines, and present them with options (Sand et al., 2009b; Klein et al., 2013). Uncertainty resulting from unanswered questions translated to doubts about medicines and perception of medicines lack of effectiveness or inadequacy and non-compliance (Zeppetella, 1999). In the context of the implementation of a pain-management intervention, Schumacher et al., (2002) found that common misconceptions about opioids, for example, were often overcome through structured education. Similarly, Schumacher et al., (2014b) found that people's doubts and uncertainties could be addressed by bespoke nurse coaching. However, these findings exposed the absence of assistance with medicines via routine clinician contact.

Having opportunities to talk about medicines, concordance

People had limited opportunities to share their experiences regarding their medicines (Schumacher et al., 2002; Sand et al., 2009b; Stoner, et al., 2010; Klein et al., 2013; Campling, et al., 2017). Whilst they were consistently informed about their medicines upon initiation, there was variable ongoing interaction with the prescriber depending on how well the medicine was tolerated. People wanted additional information or further continuing dialogue about their medicines. Stoner et al., (2010); Schumacher et al., (2002), and Schumacher et al., (2014a; 2014b), all importantly noted that the structure of routine advanced cancer care might preclude people from having regular opportunities to discuss their medicines. People who are not receiving active treatment and so are not attending hospital regularly have no reason to visit their GP, and with no continuing care needs are not being seen routinely in the community but are seen intermittently for follow-up. Campling et al. (2017) too found that a lack of continuous review could lead to sub-optimal medicine taking and poor symptom control. Some people saved discussions about medicines until their next contact with the doctor, who was seen as the competent professional (Sand et al., 2009b). Zeppetella (1999) reported that people who saw their GP, rather than the hospital doctor, as their main prescriber were more likely to adhere to their prescribed medicine, implying the benefit of a level of trust. Some advanced cancer people questioned why they did not receive Specialist Palliative Care earlier (Sand et al., 2009b). Schumacher et al., (2014a) observed logistical barriers associated with the accumulation of prescriptions from multiple clinicians located in sprawling geographic locations. Their use of different health-care networks and prescribing practises encroached on a collaborative approach and some people opted to wait until their next face-to-face appointment, rather than tackle these challenges of coordinating care.

Few references were made to pharmacist input across the research studies. Stoner et al., (2010) and Campling et al., (2017) both noted people's limited interaction with pharmacists but highlighted the benefit of a personal relationship when it did happen (Campling et al., 2017). Klein et al., (2013) reported that the relationship between people living with advanced cancer and their prescribing doctor was a decisive factor in their medicine-taking. Trust in the doctor's diagnostic and treating

skills facilitated this. People worked with the doctor, were satisfied with the information provided and suspended outstanding concerns to take medicine. Authors consistently concluded that people would benefit from person-centred information, tailored to their specific preferences and concerns (Sand et al., 2009b; Stoner et al., 2010; Schumacher, et al., 2014a and 2014b; Campling, et al., 2017).

2.6 Discussion

2.6.1 Summary of findings

The synthesis demonstrates that using medicines at home during advanced cancer involves significant self-management responsibility. People receive many medicines for various clinical indications, which come from a range of sources, are used differently in the home and have an array of impacts. For people to be able to use their medicines safely and effectively in the context of their everyday life entails proficiency and expertise at a cognitive, practical, and emotional level. How different people engage with their medicines varies in relation to these areas and is individual, dynamic and complicated. Medicines use indeed involves medicines-taking, but also requires multiple associated stages and obligations.

This description of the labour associated with being a medicines user in this evidence synthesis resonates with the findings of other studies exploring long-term medicines use. Other research has conceptualised medicines management as a type of work, amongst people living with both HIV (McCoy et al., 2009), and in diabetes, arthritis and coronary heart disease (Cheraghi-Sohi et al., 2015). These studies add strength to the concept of medicines use as a multifaceted workload. Evidence in this review explained that people develop strategies for dealing with the many necessary actions and interactions of medicines use. Studies reporting the experiences of people using pain medicines specifically provide highly detailed insight into medicines-management processes (Campling et al., 2017; Schumacher et al., 2002; Schumacher et al., 2014a; 2014b). Findings were confirmed elsewhere in studies exploring use of a whole medicines regimen during advanced cancer (Klein et al., 2013; Sand et al., 2009b; Milic et all., 2016).

The review highlighted variation across the literature in the interpretation of people's understanding about medicines. Research disagrees about whether people living with advanced cancer largely know what their medicines are for. Research reliably identifies how people face barriers to their familiarisation with medicines due to impenetrable pharmaceutical terminology. Some of the research studies explained how this prompts people to develop their own relevant reference points to identify medicines and communicate with others about them. These are alternative to those used in the clinical setting. Several studies acknowledged how people's awareness of medicine indication is only part of the consideration towards their understanding them to facilitate their use (Schumacher et al., 2002; Schumacher et al., 2014a; Campling et al., 2017; Klein et al., 2013). Knowledge also encompasses practical and logistical factors, facilitated by familiarity with the

physical items themselves. Moreover, the evidence in pain studies indicates that people's approaches to knowing their medicines in this way are undermined by practical barriers to this knowledge relating to prescribing changes and supply issues (Sand et al., 2009b; Stoner et al., 2010; Klein et al., 2013; Schumacher 2014a; Campling et al., 2017).

Another key area of evidence regarded people's opinions about types of medicines. The review highlighted that unaddressed concerns about medicines prevail and are compounded by the limited opportunities to seek support within the care pathway. People face real dilemmas about using their medicines. They are fearful about what medicines will do and often have already had bad experiences to support these concerns. They are worried about losing control, medicines becoming ineffective, or acquiring stigmatising habits. People feel that they have little choice but to take medicines, due to the fragility of the health condition, although they would prefer to take fewer medicines and ideally none. Some consequently enter unsupported negotiations with themselves about their medicines use. This evidence has some commonality with the findings of Pound et al., (2005), reviewing medicines use in chronic illness, who suggest 'resistance' best captures how people try to minimise their intake at the same time as taking them. Given the concerns and challenges reported by people across this evidence, it is likely that this same concept can apply to people living with advanced cancer. Intentionally taking less medicine than prescribed might provide a way of exerting some control. This is not driven by a fundamental attempt to avoid medicines, but due to legitimate concerns about the effects and the practical use of medicines use.

The review highlighted how medicines use itself entails a range of discretional strategies and considerations. Non-adherence to a prescribed regimen may be due to stressors on a part of that process, as well as in reaction to worries about consequences. Mohammed et al., (2016) highlight how interference with everyday life attributed to medicine use in chronic illness was also connected to ineffective medicines use. This review showed that the intensity of the burden of people's experiences, was related to individual capacity to manage. Over time, some people respond by changing their medicines regimens, whereas others continue to shoulder burdens at the expense of their physical, social or psychological wellbeing (Mohammed et al., 2016). The review findings indicate that opportunities to talk to healthcare professionals about the complex and difficult symptoms and side-effects are limited. There was evidence to suggest a complacency from HCPs around the discussions about everyday medicines, as opposed to those regarding the toxic and potentially life-changing medicines used to target cancer, about which clinicians readily provide counselling.

2.6.2 Strengths and limitations

The narrative synthesis presented provides a comprehensive summary of the research evidence about people's experiences with medicines during advanced cancer. The thorough examination of the research literature and thoughtful scrutiny of available studies supports the reliability of the

findings of this review. This review applied systematic methods recommended by tailored guidance to carefully search for, and identify, research from a sparce and disparate field (Popay et al., 2006). The searches were updated several times indicating that these results correctly summarise the nature and state of the current evidence base. The research studies included in the review were cautiously assessed using two different appraisal tools (CASP, 2018; Sandelowski & Barroso, 2003), which evaluated their methodological quality and the depth of their conceptual insight. The resulting grading of the relative value of evidence justifies the weight conveyed in the narrative synthesis. Mapping available evidence to the outcomes of Medicines Optimisation good practice guidance (RPS, 2013), assured that research was examined in a way meaningful to the review focus, and with applicability to clinical recommendations about understanding people's medicines experiences.

Despite this robust and rigorous approach to identifying relevant high-quality evidence the findings of this review are limited by the amount, value and type of research evidence available. Only a very small group of studies were identified as relevant to this review and consequently the available evidence is limited. The studies that were deemed relevant vary in their specificity to the review aim and the value of their evidence. These factors all restrict development of a broad understanding about the experiences people living with advanced cancer have at home with all their medicines.

A cluster of the highest quality studies reported important evidence about medicines management and people's experiences in the home. However, these studies are highly specific and overlap only partially with the focus of this review. Campling et al., (2017), involved people approaching the end-of-life, transitioning to a phase of increased dependence and support with medicines. This support from healthcare professionals and carers in the home, does not necessarily reflect that of people living independently with advanced cancer and earlier, albeit less easily defined, disease stage. The study also only considers the use of analgesia, rather than the whole collection of medicines. Schumacher et al., (2002) and Schumacher et al., (2014a; 2014b), usefully highlight how people's practical experiences are closely connected to clinical practice. However, they again only consider pain, in isolation of a likely complex regimen of other medicines. That these studies took place during an active undertaking of coaching around medicines also prevents the evidence realistically demonstrated everyday medicine use. The wider connotations of medicines use can be ignored, and particularly the roles of other healthcare teams and other settings of care. In exploring the experiences of people living with lung cancer and their medicine Wickersham et al., (2014) present highly insightful understanding about cancer medicines decision-making. Yet, again, this study's focus is not well aligned with the concerns of this review, about practical engagement and the broader healthcare context. Similarly, Yeager et al., (2012) concentrated on general advanced cancer symptom self-management, rather than the whole process and experience of medicines management. The evidence presented by Milic et al., (2016) about perspectives about oral medicines approaches in a specific cancer diagnostic cohort does not offer rich insight into the reality of everyday medicine use.

Three studies specifically explored the meaning of people's experiences of using all their medicines at home in the context of their life with advanced cancer (Sand et al., 2009b; Stoner e al., 2010; Klein et al., 2013). However, these studies were of lower quality involving less appropriately matched samples and used less in-depth methods of data collection and analysis. A proportion of interviews in the study by Klein, et al. (2013) took place at home and offer some insight into practical medicines management. However there is no insight into the UK healthcare context of medicines use. Sand et al. (2009b) involved people from a palliative clinic whose stage of disease, plan of care and needs are likely different from the focus of this current work. Stoner, et al. (2010) present a very low-quality study, and again, involve a poorly defined sample whose relevance to this review is difficult to judge. None of these research studies provided observational qualitative data about what people are doing at home with all their medicines and what their experience means. The problem about the population is important because they offered little exploration of medicines responsibility and the practicalities of medicines use in relation to the variety of care settings and healthcare professionals encountered during chronic cancer. One study considered medicines use at home, and involved a healthcare professional researcher, however focussed specifically on compliance (Zeppetella, 1999). This study used methods which were limited to only answer the question of if, rather than how, people use their medicines. In addition to relevance and quality of execution and insight, a significant limitation of this synthesis is that much of the evidence identified is old. In view of how much cancer care, therapy and understanding of the field has changed the application of evidence into current clinical practice locally and globally is limited.

A key limitation of this review is that it was conducted by a single reviewer. Whilst the academic supervisors provided support during the development of the review methods, the systematic searching, screening and study quality appraisal, data extraction and analysis were all undertaken independently by the researcher. The inclusion of a second reviewer to confirm the inclusion of all relevant evidence and minimise the risk of bias would have enhanced the robustness of this review

2.6.3 Summary and implications for this research

This literature review aimed to systematically locate and summarise published peer-reviewed research evidence about the experiences that people living with advanced cancer have using their medicines independently at home. This chapter has explained the methods used to find research and integrate its evidence using narrative synthesis techniques. The results highlight a lack of high quality, qualitative research sharing this focus. The small amount of relevant research has varied purpose and methodological quality and provides limited in-depth insight into the meaning of people's experience of living with advanced cancer and using of a whole regimen of medicine. Findings were extracted, analysed and synthesised narratively in the context of the first principle of the Medicines Optimisation good practice guidance (RPS, 2013). The evidence synthesis offered

collective understanding about people's perspectives of medicine use in the context of medicine optimisation outcomes.

The research included in this synthesis focusses on people's knowledge about why their medicines have been prescribed and some of the factors determining whether they choose to use them. Far less frequently reported is rich, detailed evidence about how people manage their medicines practically and what their specific approaches and attitudes are toward this practical and clearly significant work. The populations that are the focus of existing research, routinely fail to represent people living independently, who are not approaching the end-of-life and remain engaged in active cancer treatment. Nor does research consider their use of a whole regimen of medicines. In focussing on specific aspects of a medicine regimen, many of these studies likely avoid attending to the complexity and issues of organisation that are relevant when considering a complex regimen delivered across multi-dimensional healthcare. Also unavailable in this evidence is clear insight into how people's medicines use fits with the complex system of advanced cancer healthcare.

As discussed in the thesis introduction, advanced cancer requires input and involvement from an various different HCPs. The research to date lacks attention to possible explanations for why people have certain experiences, and insight into the relationship between those experiences and the structural issues of the medicines use process. Most of the studies included in this review were international and none of those exploring general medicines management and advanced cancer were conducted in the UK The results do not provide the depth of insight into NHS healthcare service necessary for considering how best to support people in this vital aspect of their cancer care. There is also an absence of evidence addressing how people can best be supported with their medicines experiences by the HCPs involved in their care pathway. There is also little mapping of the opportunities within advanced cancer care for people to talk about their medicines and access MDT expertise and guidance with medicines management.

Such limited understanding about how people manage is surprising given the growing population of people living with advanced cancer and the reliance on domiciliary medicines in cancer healthcare. The Royal Pharmaceutical Society has identified a clear agenda to bring understanding about people's experience of medicines to the forefront of clinical practice (RPS, 2013). The shortfall in evidence about advanced cancer medicines management identified by this literature review demonstrates clear need for new research. This needs to focus on deeper, richer exploration about how people living with advanced cancer manage their various medicines as a whole regime, in the context of their cancer as a long-term condition; the construct of healthcare in terms of people's medicines management, and how their pathways through advanced cancer can deepen the understanding about their experiences; and identification of priorities to support people within these areas of medicines management to make the most of their medicines.

Chapter 3. Research Methodology

3.1 Introduction

The literature review demonstrated a paucity of evidence about the experiences people living with advanced cancer have using domiciliary medicines. The relevant studies were sparse, inconsistent in quality and offered limited overlap with the specific focus of this research. Despite the major shift in emphasis recommended by medicines optimisation policy to place understanding about medicines use from the perspective of medicines users at the foreground of healthcare (RPS, 2013; NICE 2015), the findings showed that this evidence has not yet been captured for people living with advanced cancer. Also apparent was the absence of evidence about the clinical context for people's medicines experiences and regarding support for medicines optimisation in this population. An Interpretive Description (Thorne et al., 1997) methodology was used to guide the design of qualitative research to generate clinically relevant knowledge to address these gaps. Research was organised into two interconnected studies; firstly, to provide richer insight into the everyday experiences that people living with cancer have managing a whole regimen of medicines at home; then to contextualise and progress this insight in a meaningful way by examining evidence in the context of NHS healthcare for advanced cancer. Finally, to identify from the wider community what future support for medicines use should and could look like stakeholder engagement was carried out.

3.2 Designing the research

3.2.1 Research Paradigms

Philosophical principles of ontology, epistemology and methodology form the interpretive paradigm that underpins research decisions. Considering the fundamental beliefs about the nature of the reality of medicines use by people living with advanced cancer, what it is possible to know about it, and the best way to get that knowledge, informed the design of this research (Ritchie and Lewis, 2003; Denzin and Lincoln, 2017; Patton, 2002; Creswell, 2014). The ontology was guided by a relativist stance. This nuanced version of idealism is grounded in the belief that reality is entirely dependent on the individual mind and cannot exist without socially constructed meanings. Relativism here assumes that people living with advanced cancer have subjective individual experiences of their disease, medicines, and healthcare and that these experiences occur in the context of their own diverse social worlds. Establishing understanding about medicines use requires joint construction with those numerous individual versions of the experience. This is unlike Realism, which is grounded in the idea that reality is distinct from people's interpretations and meanings about it. In the context of prescribed medicines use by people living with advanced cancer, this translates to the assumption that immutable facts of medicines management exist, independently of people's own perceptions (Ritchie et al., 2013). Research in this perspective,

presented in the narrative synthesis, included quantitative measures of pill counting to monitor if participants took their medicines (Zeppetella, 1999). These methods demonstrate some facts of medicines use, but do not allow opportunity to explain why people do what they do. This position was avoided in the current research, out of interest in the dynamism and diversity of subjective experience. Materialism is a variant of realism, based on the idea that only physical features hold reality. Other elements like beliefs, are 'epiphenomena' which arise from the material world and though acknowledged, do not shape the knowledge of interest (Ritchie and Lewis, 2003). This position was rejected in this exploration of medicines experiences, due to the interest in the involvement of human actions and interactions throughout the medicines use process. These are here considered integral to the meanings constructed about medicines use.

Epistemologically, the research asserts that understanding the phenomenon of medicines use during advanced cancer is only possible through the inductive interpretation of the meaning people attach to their own experiences. Induction is when observations about people's experiences of using medicines are used to build knowledge about the phenomena. This is appropriate in research, like this, which is exploratory in nature and not governed by an established theoretical argument. An alternative epistemology is deduction, where a hypothesis is applied to the data. Deductive reasoning moves from the general to the specific to confirm or reject theory (Patton, 2002). Whilst qualitative research is inductive in principle, the influence of the researcher perspective and interaction with the interpretive process is inevitable (Ritchie et al, 2013). Interpretivism maintains that complete objectivity cannot be possible (Ritchie and Lewis, 2003; Lincoln and Guba 1985); such is the case in this research where, engaging with the research field and generating data about people and their medicines, the researcher becomes an intangible part of the research itself.

3.2.2 Qualitative Methodologies

Qualitative approaches are entirely appropriate for illuminating and enhancing meaning about poorly understood, complicated and specialist health phenomena and were well suited to the aims of this research (Creswell, 2014; Ritchie and Lewis, 2003; Pope and Mays, 2006; Patton, 2002; Morse, 2007). Immersive qualitative methods could help create knowledge about the nuanced personal experience of managing medicines when living with advanced cancer. The techniques could also facilitate development of contextual explanations about the complex healthcare system within which multiple services and professionals deliver medicines-related input to people living with advanced cancer. A qualitative approach could also support the transformation of research findings beyond the description of problems, into knowledge applicable to healthcare practice. The qualitative methodologies most traditionally associated with applied healthcare research in the naturalistic paradigm are Ethnography, Phenomenology and Grounded Theory; these were each considered as a potential primary approach, prior to the selection of Interpretive Description.

Phenomenology is the philosophical perspective guiding research whose purpose is to understand the essential nature and uniqueness of people's 'lived-experience' of a phenomenon (Dowling, 2007; Creswell, 2014). Phenomenological approaches are popular in research in healthcare where clinical roles value person-centredness and afford proximity to people's experiences (Converse, 2012; Balls, 2009). Phenomenological studies typically use in-depth interviewing to collect data. Data analysis aims to generate textual description. In applied health research the use of phenomenology has received disapproval for inadequately addressing the critical first-person experience of phenomena and instead serving as a general descriptor of health events (Caelli, 2000; Crotty, 1996; Dowling, 2007). Phenomenology was rejected as an approach for this research. Though it does offer a means to describe individuals' perspectives about their medicines use, this research sought to explore medicines management from a wide range of perspectives to understand a complex process. Phenomenology was thought inadequate to the broader research objectives and potentially prohibitive of the practical application of research findings (Holloway and Galvin, 2015).

Grounded Theory is a systematic strategy for research, also common in nursing research, which aims to generate explanatory theory of social phenomena (Creswell, 2014; Charmaz 2006; Corbin and Strauss 2008). Methods of in-depth interviewing and constant comparative analysis are applied to facilitate co-construction of meaning. The constructivist perspective of Grounded Theory is a flexible and interactive interpretation of the traditional approach, which accepts the relationships between research data and the researcher and does offer a structure for constructing the meaning about the phenomenon of medicines use during advanced cancer (Charmaz, 2006). However, the aim of this research was not restricted to the production of abstract theory, so an alternative to Grounded Theory was required.

Ethnography is an approach that seeks to understand shared cultural meaning including patterns of behaviour, language use, and social arrangements (Creswell, 2014). Ethnographic research typically involves the researcher embedding themselves in the research field and uses interviews, observations, and reflexive analysis to generate subjective and contextual findings (Mason, 1996; Ritchie and Lewis, 2003; Denzin and Lincoln, 2017). Whilst the qualitative methods of observation, associated with ethnography are helpful in relation to the practical behaviours associated with medicines, the methodological process was not appropriate for the purpose of this research. Ethnography was rejected based on the absence of a specific location or culture for the researcher to embed themselves to obtain adequate understanding of medicine use that could inform medicines optimisation principles across diagnostic groups and clinical disciplines.

Though these qualitative approaches included valuable methods, none could address the aims of the current research exclusively. The methodology needed to facilitate access to individuals accounts of their experiences with medicines and physical, visual data about the nature of their medicines and medicines management; contextualize people's experiences within available NHS healthcare; and develop understanding applicable to current clinical practice. An approach was

sought which could coherently connect the goals of the inquiry and uphold the guiding epistemological principles.

Generic qualitative approaches combine qualitative methods from different traditions to explore phenomena and develop descriptions about what is observed (Sandelowski, 2000; Smith et al., 2011; Merriam, 2002; Caelli et al., 2003). Such designs intentionally avoid commitment to a particular methodology, which permits some freedom from the constraints of traditional procedural rules. Studies may continue to draw on aspects of approaches, but legitimately deviate from other principles. Consequently, generic approaches have been criticised for blurring methodological boundaries and lacking rigour (Caelli et al., 2003; Reeves, 2008; Rolfe, 1998). One generic approach is Qualitative Description (Sandelowski, 2000), which aims to remain close to the data by formulating low inference findings (Kahlke, 2014). Qualitative description is most appropriate when the research purpose is to describe a phenomenon (Sandelowski, 2000; Kahlke, 2014). Whilst the versatility offered by a generic design was potentially helpful in this research, a methodology was needed which could facilitate the creation of conceptual, clinically relevant findings.

Interpretive Description is an alternative generic research methodology which specifically aims to generate meanings and explanations of people's subjective experiences about complex health phenomena (Thorne et al, 1997; 2004; Hunt 2009). It too advocates the use of different qualitative research methods, addressing the question of rigour by recommending explicit acknowledgment of epistemological positioning and the clinical integrity informing the research aim (Thorne, 1997; 2004; 2010). Interpretive Description research is based on constructivist, naturalistic principles (Thorne, 2016; Kahlke, 2014; Lincoln and Guba 1985). The approach is committed to making research which generates contextual data from multiple subjective experiences and creates socially constructed understanding, which is directly relevant and applicable to clinical practice. In valuing the hermeneutic circle, the methodology functions not simply to produce findings which describe what is there but identify patterns and connections within a phenomenon which interpret what the evidence might mean (Thorne, 2016; Kahlke, 2014; Hunt, 2009). In this research, Interpretive Description offered an iterative approach which could acknowledge the theoretical foundation and address the need for qualitative methods to explore the complex and contextual nature of medicines use during advanced cancer from multiple perspectives, to create clinically useful insight.

3.2.3 Theoretical Perspectives

Theories relating to this realm of inquiry were considered in the preparation of the methodology. Theory is the meaningful arranging of concepts about phenomena, which can support movement from description to explanation (Silverman, 2001). Theories are important in healthcare policy and practice because they can facilitate broader understanding of the underlying causes and influences of individual insights that arise about everyday clinical situations (Reeves et al., 2008; Kelly, 2010; Silverman, 2001). Due to the exploratory nature of the research, no governing theory was selected at the outset. As identified in the introductory chapter, and as the literature review has

demonstrated, the general research field is sprawling and there is a scarcity of knowledge about this research phenomenon. Theories exist regarding specific aspects of the medicines use process, such as shared decision-making and adherence. In some areas interest is rapidly accelerating, such as behaviour-change in prescribing. The application of theories in this context of probing and generative research is limiting and inappropriate. It is, however, valuable to consider the role and reach of these theories.

Adherence frameworks offer a means to guide the selection and interpretation of data to evaluate the outcome of medicines use (Patton et al., 2017; Munro et al., 2007). A whole range of these fit into the broad category of Social Cognition Models. The Health Belief Model (HBM) is one such model, used to explain level of engagement with health-promoting behaviour (Champion and Skinner, 2008). It consists of key constructs which explain why people will take action to prevent, to screen for, or to control illness conditions. The core concepts of the model are perceived susceptibility, perceived severity, perceived barriers, perceived benefits, cues to action and self-motivation. In medicines use the HBM has been used to interrogate and understand people's adherence behaviour and it was considered here, as it is one of the most well understood, and widely used of the Social Cognition Models. However, it was decided to be unsuitable for this work. As previously outlined, this research is focused on understanding people's experience and needs with medicines during life with advanced cancer, not simply about the success of the act of medicines-taking. Also, the HBM also assumes that individuals process information rationally and fails to account for the emotions they may experiences around medicines use, such as fear, which is a known driver of medicines-taking behaviour. In addition, the HBM has also received criticism for overly focussing on the individual, rather than the social and environmental factors that influence their behaviour. This research is grounded in the healthcare and social context for medicines use.

The Necessity Concerns Framework (NCF) (Horne et al., 2013) attends to people's conscious decision making around medicines use. It was developed from the Beliefs about Medicines Questionnaire (Horne et al., 1999) to provide insight into the relationship between people's beliefs, and their adherence. The NCF states that people who use medicines weigh-up the benefits and costs of medicines, when deciding whether to be adherent. When beliefs about necessity exceed concerns, then adherence is said to increase. This theory too was rejected in this research, as it does not help in the exploration of the broader medicines use process. Beyond understanding why medicines are needed and deciding whether to use them, this research was concerned with how people deal with the responsibility of medicines. Beliefs about the need for medicines and worries about their impact undoubtedly influence people's behaviour with medicines at home, but this is only part of the overall phenomenon of self-managing. This research was interested in the wider experience of medicines use, which involves multiple stages and interactions.

The inability of theories to adequately accommodate the nature and complexity of non-adherence has prompted the recommendation for the tailored use of psychological theory (Easthall and Barnett, 2017). Models which predict and explain human behaviour are increasingly applied in the health research field to support behaviour change interventions. One popular example is the Theoretical Domains Framework (TDF). The TDF is a composite framework of 128 constructs from 33 behaviour change theories designed to improve access to and utility of behaviour change theory (Michie et al., 2005). It can be used with other frameworks such as the COM-B model and Behaviour Change Wheel to support behaviour change interventions, specifically with healthcare professionals (Michie et al, 2011). However, the TDF has drawbacks. Particularly, that its inflexible operationalisation can force deduction and the potential to overlook important findings (McGowan et al., 2020). The TDF was rejected at this stage, for the more fundamental reason that the research was exploratory, and not concerned with designing or testing an intervention. The work sought to understand the nature of experiences, gaining insights into beliefs, attitudes, and behaviours.

Another area of healthcare theory relevant to this research considers the burden of treatment. Treatment burden describes the work of self-care people are required to undertake as a result of undergoing a healthcare regimen. This encompasses the responsibility for organising and coordinating care, and carrying out self-care work such as self-monitoring and self-administering treatment (Eton et al, 2012; Shippee et al, 2012; Gallacher et al, 2013; May et al, 2014; Sav et al., 2015). Evidence indicates that as treatment burden increases, adherence to self-care can diminish, which in turn is likely to cause worse health, ineffective use of available healthcare resources and increased dependence on others. Moreover, in response to poor outcomes, healthcare providers are more likely to intensify treatment, increasing burden further still. Consequently burden of treatment is dynamic, person-specific and influenced by multiple pre-disposing variables. Research about treatment burden observes that the accountability for undertaking self-care work has shifted onto patients in response to increased populations of people with long-term multimorbidity (Eton et al, 2012; Shippee et al, 2012; Gallacher et al, 2013; May et al, 2014; Sav et al., 2015).

Two conceptual models have been created to explain people's ability to effectively undertake self-care work associated with chronic illness. Both the Cumulative Complexity Model (Shippee et al., 2012) and the Burden of Treatment Theory (May et al., 2014) consider the influences of healthcare workload, patient capacity and the provision of health services on treatment burden. The Cumulative Complexity Model describes the relationship between workload, impact of work and individual capacity (Shippee et al., 2012). Workload refers to the time and energy required to manage a condition and may include tasks such as attending appointments, enacting lifestyle changes or using medicines. Impacts of work, include the effect of the work on relationships, activities, or physical or psychological function. Individual capacity denotes the personal emotional, financial and social resources required to undertake the work. The Burden of Treatment Theory builds on this understanding and explains the interaction between the work passed to people

receiving care and their relational networks, and people's individual's capacity for action (May et al., 2014). This theory states that people's engagement in treatment work depends on the extent they have agency to participate in the work; and their ability to exercise agency relates to their social networks, which also importantly includes the HCPs involved in their care. The theory also considers how control over the nature and delivery of healthcare services rests with providers; and that this provision is characterised by the opportunities made available locally, which can be unequally distributed. The theory goes on to suggest that capacity for self-care action is contingent on the qualities that people and their networks possess to be able to exploit healthcare opportunities. Consequently, Burden of Treatment Theory explains that individual capacity is not merely a property of people's functional performance but is also shaped by their social skills, ability to cooperate with others, and their social capital, which is the ability to access available resources.

Whilst theories can play a pivotal role in the contribution of new knowledge, using them uncritically, particularly in the context of research about individual behaviour, can exacerbate ignorance about the contextual nature of people's experiences (Burr, 2015; Leeming, 2018; Willig, 2017). Rather than revealing underrepresented ideas, theory can impose dominant meanings. Here, the research focus and aims did not fit well into one specific theoretical domain. Indeed, in Interpretive Description, Thorne (2016) suggested such a cautious approach to allegiance to a particular theory, warning how theory can impose criteria for understanding evidence. The theories and models discussed relate to predicting health behaviour or understanding why people do what they do. However, this research preceded such a stage of investigation. No theory can fit this research at present, because the whole field is uncharted and uncertain; the phenomenon of advanced cancer care and medicines use is ill-defined, with no clear framework of meaning, no accurate conceptual terminology and relates to multiple social, psychological and biomedical foundations. The literature review did not point to a particular theoretical argument. More broadly, there are silos of working and an outdated emphasis on adherence, which overlooks the widescale issue of the domiciliary medicines use process. The experiences people have with their medicines is a bigger, systems issue spanning the continuum of cancer and breadth of NHS services. Therefore a research design was required that could look at the multiple components rather than targeting one element with a specific model. In developing understanding about perspectives of people living with advanced cancer, and strategy to support them, the potential to develop theory about medicines use during advanced cancer would be available. However, the goal of the research was to develop conceptual description, which could describe commonalities and account for variations and ideally be relevant to the applied field. In the absence of substantive theory, conceptual frameworks provide means to organise ideas. The previously discussed Medicine Optimisation good practice guidance for HCPs (RPS, 2013) provided a relevant framework for exploring available evidence whilst being open, not prescriptive, about experiences. It offered a means to organise ideas about medicines use, with connection to the known factors established in the literature review and maintain a strong link to clinical practice.

3.2.4 Quality

Quality in qualitative research is achieved through conducting work with rigour and reporting it with transparency (Sandelowski, 2000; Silverman, 2010). Trustworthiness is a widely accepted measure for quality within which the key components of credibility, reliability, transferability, confirmability are evaluated (Lincoln & Guba, 1985; Green & Thorogood, 2014). Credibility is the accurate reflection of data in the findings generated, which demands adequately intense involvement with people to maintain proximity to their experience of the phenomenon; and robust clarity in the drawing of inference from data, using rich description with appropriate raw data (Lincoln & Guba, 1985). Transferability refers to the presentation of sufficiently detailed information about the people involved in research, the environmental circumstances, and the procedures undertaken to enable findings to be relevant in other contexts. Dependability is the clear demonstration of consistency in the approach, whereby the research procedures are replicable, even though it is accepted that the specific subjectivity of data cannot be. A clear audit trail renders this possible. Finally, confirmability is the likelihood that findings are accurate, and intentional biases arising from researcher motivation, or unintentional biases based in underlying assumptions, are identified.

In practice these measures are achieved by applying disciplined reflexivity throughout the research process and are proven through research writing which demonstrates conscious thought and conscientious method. Sometimes, quality reporting checklists are favoured, to standardise study reporting to demonstrate all the measures taken (Tong et al., 2007). However, there is disagreement about whether such tools are beneficial. Instead, they may reduce the considerations to a basic exercise, which might provide explanation or justification, but not ensure quality of research product (Barbour, 2001). Ensuring that work is performed rigorously and comprehensively reported is an imperative feature of trustworthy research. Interpretive Description recommends some specific measures for ensuring credibility which are discussed in section 3.3.1.

3.2.5 Disciplinary Insight and Reflexivity

Reflexivity is the means by which qualitative researchers are sensitive to, and negotiate how, predisposing conditions shape their approach to generating and interpreting data (Pope and Mays, 2006). Influences can include prior assumptions, disciplinary perspectives and proximity to the subject of the research (Finlay, 2002a; 2002b). This research was indeed impacted by the inseparable grounding values of nursing education and practice; and past exposure to the experiences of people living with advanced cancer. These factors guided the philosophical approach to this research problem, informed the goals of research, and underpinned the methodological obligations. Fundamental to the selection of Interpretive Description (Thorne et al., 1997), was the opportunity to appreciate and appropriately incorporate these influences.

Cancer nursing is grounded in the core values of person-centred, holistic care (UK Oncology Nursing Society (UKONS), 2017; European Oncology Nursing Society (EONS), 2018). This encompasses acknowledgement of the context in which people's individual health behaviour is enacted and the implications of complexity in their everyday lives. It also supports the idea that nurses can contribute to improving outcomes by jointly working with the public and professionals to enhance people's wellbeing (UKONS, 2017; EONS, 2018; Kearney and Richardson, 2006). The clinical nurse specialist (CNS) role is consistently identified as being key in the quality of individual experiences of cancer and cancer care. Core competencies for oncology CNSs are underpinned by the timely comprehensive assessment of people's unique physical, psychosocial, spiritual and emotional needs, plus care planning which promotes quality of life and independence (Doyle and Henry, 2014; DH, Macmillan Cancer Support, NHS Improvement, 2013).

My own oncology nursing practice has afforded a closeness to people living with advanced cancer, providing the opportunity to listen to their personal stories and witness their shared experiences. It has simultaneously facilitated insight into the operational reality of NHS cancer care. Cancer nursing has motivated my aim to improve support for people living with advanced disease and consolidated the principle that HCPs involved in the cancer care pathway have a clear role in supporting those improvements. Findings of the literature review resonated with some of my own in-practice observation about people's experiences. However, considering these results through a disciplinary lens highlighted glaring areas of evidential insufficiency. The absence of data about people's practical everyday medicines use, and about their medicines-related interactions throughout cancer care, is unhelpful. These gaps prevent genuine debate about what the experience of medicines use really is, and what solutions to support people who are living with advanced cancer should or could look like. Experience of close collaboration with people living with advanced cancer in clinical practice undoubtedly influenced a keenness that this research should directly place people at the heart of any dialogue about how best to improve their experience. The overall approach was also a response to the dominance of research concentrating on the discrete clinical outcomes or behaviour of people who use medicine, rather than examining the relationship between people's experiences and the systems within which medicines use takes place.

3.2.6 Involving People

Consulting with people about research which directly affects them is crucial in applied healthcare research. 'Patient and Public Involvement' (PPI) helps to focus research on the insights, questions and needs of those closest to the research issue, and can help research remain relevant, mitigate assumptions and bridge the gap between the researcher and people under study. These measures aim to give validity in developing robust and meaningful research findings (Hanley, et al., 2003). There are different ideas about what constitutes PPI and how best to undertake valuable work. Inherent tensions exist, which call into question the value of time-consuming involvement and the likelihood that neutrality is possible given that people who contribute to research too are influenced

by their own social and political values (Green and Thorogood, 2014; Hanley et al., 2003; NIHR 2014). The nature of PPI is also a pragmatic consideration relating to available resources.

In this research, communities with personal experience related to medicines use and advanced cancer were the involved public. This included people who have previously or are currently living with cancer, their relatives, friends, and informal caregivers; healthcare professionals involved in advanced cancer care and medicines related care; and strategic professionals, involved in the financial, educational and service delivery systems connected with cancer healthcare. Given the anticipated time frame for the empirical work a deliberate decision was made to not create a single advisory panel for this research. This would avoid asking people to contribute a long-term commitment and minimise potential burden for people living with advanced cancer and those working in the NHS. Instead, a variety of contributors were involved in this research at multiple stages,. As section 3.4.1 outlines, people were involved in shaping the research design, developing and testing study materials and ultimately shaping findings. Whilst involving others in research is not a research method, the specific activities that were undertaken in this research to promote inclusion of other perspectives and expertise are present alongside methods to assist reporting.

3.3 Research Design

3.3.1 Interpretive Description Research

Interpretive Description provided a guiding methodology for this research. Research was designed to illustrate the detail and complexity of people's experiences with medicines, explore those experiences specifically in relation to healthcare setting and consider how best to apply the findings to clinical practice. The methodology promoted focus on research methods to generate rich, naturalistic data and encouraged reflexive acknowledgement of pre-existing experience. This approach aimed not just to describe the phenomenon, but to develop understanding through collectively constructing meaning which could enhance clinical knowledge. Interpretive Description was developed within nursing research as an alternative to conventional qualitative methodologies (Thorne et al., 1997). The approach is aligned with the philosophical assumptions underpinning constructivism and naturalistic inquiry (Lincoln and Guba, 1985). Thorne (2016) states that "Interpretive Description studies:

- are conducted in as naturalistic context possible, in a manner that is respectful of the comfort and ethical rights of all participants,
- explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of applied practice insight,
- capitalise on human commonalities as well as individual expressions of variance within a shared focus of interest,

- reflect issues that are not bounded by time and context, but attend carefully to the time and context within which human expressions are enacted

- acknowledge a socially constructed element to human experience that cannot be meaningfully separated from its essential nature

- recognize that, in the world of human experience, 'reality' involves multiple constructed realities that may well at times be contradictory, and

- acknowledge an inseparable interaction between the knower and the known, such that the inquirer and the "object" of that inquiry influence one another in the production of the research outcomes."

Interpretive Description is distinctive in its acknowledgement of the multiple complex interactions between psychosocial and biomedical phenomena (Thorne, 2016; Thompson Burdine et al., 2021). It aims to construct knowledge about clinical issues which are experienced subjectively and contextually. The product is a coherent conceptual description that connects the themes characterising a phenomenon and reports the variation therein (Thorne et al., 1997; 2004; Thone, 2016; Thompson Burdine et al., 2021). A central tenet of Interpretive Description is the use of research questions which capture the research aims and seek to address the gap in knowledge specifically articulating the need to establish 'what is happening' in a phenomenon. Such disciplinary questions maintain clinical focus and extend the purpose of the work beyond generic qualitative describing and avoid terminology conventionally associated with specific methodological traditions such as causation or evaluation (Thorne, 2016).

Interpretive Description is also characterised by some specific considerations regarding quality beyond those standard criteria for trustworthiness. Thorne (2016) argues that quality standards for health research are different because findings may be subsequently applied clinically; and so there is consequently a disciplinary responsibility to extend the quality consideration to an appreciation of possible interpretation of research findings. Thorne (2016) is wary of the checklist venture as a means to demonstrating study quality. She instead suggests additional principles for engendering trust as, epistemological integrity, representative credibility, analytic logic and interpretive authority. Epistemological integrity is the clear statement of underpinning assumptions and the logical connection of a research strategy to that epistemology. This is possible through the articulation of research questions with rational connection to analytical methods. Representative integrity is the notion that research sampling is aligned with the interpretive paradigm upon which research is based; and large enough that recurrence of themes and introduction of new ideas are both possible. Analytic logic describes being explicit about interpretive decision-making. This is achieved, for example, by maintaining an analytical audit trail and illustrating interpretive ideas as thick description alongside verbatim data (Ponterotto, 2006). Interpretive authority refers to

interpretations being trustworthy and a fair illustration of reality via the presentation of sufficient substantiating information (Thorne, 2016).

3.3.2 Organising the research

The research questions summarised the need to first find and explore the richness and the detail of people's individual experiences; then to examine what those experiences mean in terms of the healthcare setting, and then identify what the focus of future strategy should be.

1. How do people living with advanced cancer independently manage their medicines at home?
2. What do healthcare professionals understand about people's experiences using medicines during advanced cancer and how they could be better supported?
3. What is stakeholder feedback on people's experiences and what are the priorities for supporting medicines optimisation in advanced cancer care?

The research was arranged into two empirical studies, which each used different qualitative methods to answer the first two research questions, followed by stakeholder engagement work to address the third (Thorne, 2016; Pope and Mays, 2006; Lincoln and Guba, 1985).

Research Study One aimed to explore how people living with advanced cancer manage all their medicines at home. The study integrated interviewing with the physical presence of medicines in people's homes to generate a range of perspectives about everyday medicines use. Purposive sampling was used to select a group of medicine-users with different primary diagnoses of metastatic incurable cancer at various stages of care. Face-to-face semi-structured interviews were conducted using an interview topic guide based on the identified gaps in knowledge. Interviews included opportunities to involve medicines. Audio-recording, photography and annotation were used to capture data. Data were transcribed, cross-referenced, and analysed for themes using a framework approach (Ritchie and Lewis, 2003). The themes generated were used to build a shared meaning of the experience of medicines self-management during advanced cancer. These findings were then used to inform the second study, which sought to contextualise people's medicines experiences in relation to the structure of NHS services and roles.

Research Study Two aimed to explore what NHS healthcare professionals understand about the experiences that people living with advanced cancer have using their medicines, and what potential opportunities they identify to improve support. The study used interviewing with a photo-elicitation component, using resources informed by findings of Research Study One. Purposive sampling was used to select a group of NHS HCPs from different clinical disciplines, responsible for the care of people living with advanced cancer at various stages of the care pathway. Semi-

structured, face-to-face or telephone interviews were conducted using a topic guide and photographs directly developed using evidence about people's experiences of medicines use at home. Audio-recording and annotation were used to capture data. Data were transcribed, cross-referenced, and analysed for themes using a framework approach. Findings related both to enhancing the meaning of medicines self-management in the context of UK NHS care, and to areas within clinical practice which could be addressed to improve medicines use experiences.

Stakeholder Engagement was designed to seek dialogue and feedback and identify priorities for future medicines optimisation support in this population. The study used evidence from Research Study One and Two, to open the research findings up to a wider audience to establish the best direction for the future.. Engagement was conducted at existing events attended by people from the cancer support and primary and secondary healthcare communities. Six core areas for improving support for people living with advanced cancer who use medicine at home grounded real-life experience were developed. Each 'medicines optimisation priority' distilled the central research concepts of the research into clinically relevant, tangible examples for change. Visual engagement resources were developed around each of the priorities and written evaluation tools were used to explore whether stakeholders agree that they are important and why, are there differences in opinion based on expertise, and could they integrate change in these priority areas in their own practice. Section 3.4 rationalises the selection of the specific research methods used these studies. Chapters four, five and six then present the methods and results of these studies in turn.

3.4 Research Methods

3.4.1 Involvement

PPI activities were undertaken during the planning of each research study. Individuals contributed during the development of the research questions, the selection and implementation of research methods and the preparation of study materials. These interactions sought to maintain the relevance and focus of the work, and to minimise the impact of unconscious researcher bias by enhancing insight into other clinical scenarios and exposure to other professional opinions and expertise.

Research Study One involved other people during the formulation of the research questions and development of the study protocol. Four cancer support groups were attended, and attendees informed the focus and format of this initial research about medicine use. Following presentations to each group, people shared their experiences and feedback about the need for the research and its essential purpose. One particularly impactful meeting was attended by people affected by pancreatic cancer. Their insights were strongly relevant, due to their experience of pancreaticoduodenectomy surgery, which results in multiple life-long medicines use; and their open and frank reflection on issues regarding medicines and quality of life brought about by their poor prognoses. Some group

attendees offered to remain in contact to review study materials as they were developed. As recommended, pilot interviews were also conducted to inform the development of the topic guide (Brédart et al., 2014; McNair et al., 2008). Three pilot interviews were undertaken with individuals known to the researcher. Notes and audio-recording were made with permission, which assisted in the development of study approach and resources. In addition, healthcare professionals (HCPs) at the study site, were engaged intermittently to advise on recruitment strategy and identify suitable host venues.

Research Study Two involved clinical and strategic HCPs in the development of the study protocol. Governance managers at participating organisations advised about operational feasibility and local permissions during the development of this study protocol. Individual advisors involved during the preparation of the research protocol and ethics application for research Study One suggested recruitment approaches and reviewed recruitment materials. Another PhD candidate who is also a senior Trust clinician facilitated introduction to a senior Trust manager, whose network and expertise strengthened the recruitment strategy and extended the reach of the effort.

Stakeholder Engagement involved the expertise and connections of representatives from key governance and advocacy organisations with whom relationships had previously been established at earlier stages of the research. These individuals provided access to contacts for existing events and guidance on the most suitable format for engagement materials. The involvement of participants in the first engagement event, also served as a pilot whereby evaluation materials were tested and then refined for future use (Wellcome Trust, 2021).

3.4.2 Sources of data

The sources of data for the research were governed by naturalistic principles, which advocate the importance of including a range of people most intricately experiencing and involved with the phenomenon of interest.

Research Study One, aimed to access the subjective individual accounts of people using medicines independently whilst living with metastatic incurable cancer. This encompassed people with different primary diagnoses, disease stages, care pathways and medicines responsibility. Interpretive Description values research conducted in the most natural conditions possible (Thorne et al., 1997). Previous research about medicines has traditionally been conducted in clinical environments of care. Whilst practically feasible and convenient, this precludes access to data associated people's homes, which are the physical location and social setting for medicines use. In this first study, exploring people's medicines use in their natural environment created the opportunity for people to draw upon relevance and meaning of the home. As Bowling and Ebrahim (2005) identify, conducting interviews at home allows the additional benefit of the comfort and privacy over the clinical setting. Embedding the research in the environment of medicines use, in the natural space,

promoted trustworthiness. Specific clinical information about medicines themselves, was not considered an important source of data. It was intentional that no medicines inventory was taken as part of the study, nor were medical records or prescription documents accessed during data collection. This was due to the focus of the research on people's everyday encounters with their medicines in the home. This is regardless of their indication. The literature is clear that people living with advanced cancer can have many medicines at home. This study did not need to count them. It needed to know how people manage them.

Research Study Two aimed to generate insight about the healthcare context of medicines use during advanced cancer, which was absent from existing literature. The focus of the study was to access HCPs perspectives to endorse and deepen insight into people's experiences, in terms of the healthcare system which fundamentally governs their medicines related care; and identify possible opportunities to support people with their medicines. In Interpretive Description, Thorne (2016) emphasises how clinicians' expert knowledge and experience can be a rich source of insight about otherwise inaccessible aspects of a phenomenon. A sample of HCPs were sought with specific proximity to the advanced cancer care pathways and medicines use process.

Stakeholder Engagement aimed to generate insight into the appropriate future direction for work about supporting medicine use during advanced cancer. A priority setting and feedback exercise offered the opportunity to move the research findings beyond their conceptualization and rather than staying entrenched in the problems of medicines use, consider shared ideas about potential strategy for innovation in this area. Priority setting is particularly beneficial in applied healthcare research for highlighting what issues are most important to the shared agenda of people who receive and deliver care and do research about it (James Lind Alliance (JLA), 2021). Priority setting can also ensure the focus of future research remains on developing practical information that people and healthcare professionals need, rather than just what researchers want to research (JLA, 2021). The study included a wider network of public and professionals, with personal, clinical, and strategic proficiency regarding medicines use and advanced cancer. This provided the chance to disseminate the knowledge generated by the previous studies and record stakeholders' interaction with the evidence and their joint priorities.

3.4.3 Sampling

Study sampling procedures were designed to identify and involve a subset of each population of interest most suitable to answer the research questions (Ritchie et al., 2013; Thorne, 2016). This process acknowledged that no sample can entirely represent a population and all the details and permutations that exist with phenomena. Instead, sampling aimed to consider groups interesting to the research aims (Thorne, 2016). Different strategies are available to locate sample participants. Interpretive Description suggests theoretical or purposive sampling approaches to access variations of the theme under study (Thorne, 2016). In a theoretical approach, a variant derived from the data

informs the search for cases (Strauss and Corbin 1998). This supports trying to refine the variable and finding maximal variation, though Thorne (2016) acknowledges that this approach is not always possible, particularly in small, or time constrained studies. Purposive sampling can increase the scope of the possible data through careful parameters of sample selection. This means recruiting people specifically because of their experiences. This allows the predictable key variables to be stated in advance to try and achieve satisfactory diversity. Prespecified sampling frames facilitated this. The first two studies overall sample size was stipulated by a minimum and maximum number of participants. This strategy acknowledged that it could not be possible to achieve 'saturation' of ideas and themes by a certain number of encounters. Such theoretical saturation argues that sufficient richness of data is achievable and there are no new variations (Ritchie and Lewis, 2013). Instead, the approach assumed that encounters with a small, carefully selected group which generate data for the basis of analysis is an appropriate way to gain knowledge. This aimed to address the representative credibility of research findings, by being large enough that recurrence of themes is possible and that new ideas can help construct meaning (Thorne, 2016).

Research Study One sought participants able to illuminate the breadth and variable nature of experiences for people living with advanced cancer. Prior literature focused on people at specific points in the cancer trajectory such as at the end-of -life, or during curative treatments. However, this does not reflect the many other people living with advanced cancer whose disease status and stage in the trajectory of cancer are harder to define. The sample also required participants with variation in cancer stage and medicines to enhance exposure to different experiences. The size of the participant sample of people living with advanced cancer in the first study was suitably small to allow the opportunity to gather deep insights about individual perspectives. A lower limit was set to reflect the fewest acceptable accounts.

Research Study Two similarly aimed to involve a variety of perspectives in this case from people with different relevant professional insight about the phenomenon. These were HCPs who encounter people living with advanced cancer in different clinical settings. Clinical professionals' input was considered highly valuable to the development of the conceptual description about people's experiences due to the unique closeness of specific HCPs to the phenomenon (Thorne, 2016). This group encompassed different HCP roles involved at different stages of the trajectory of cancer care, with different exposure by virtue of their clinical remit.

Stakeholder Engagement then required participants from the wider network of people involved in this area with insight and influence in various aspects of the medicines use process in advanced cancer care. This includes the HCPs involved in direct care, but also workforce personnel and strategy directorship. The sample sought to engage teams with experiences of the cancer specialty, but also pharmacy, higher education, and general healthcare, to recognise the broader positioning of people living with advanced cancer and their care, in the general healthcare landscape. Including a more

numerous and diverse population meant allowing additional perspectives from communities with experiences of receiving care, with direct clinical and implementation-focused and cross organisational expertise, to consider realistic enactment of future work. The number of people involved in the engagement was determined by the size of individual events. Events were specifically identified with large numbers of attendees from a range of roles and professional levels.

3.4.4 Generating data

Interpretive Description recommends methods of interviewing and observation as means to access data, but also suggests openness to a range of other data sources which can strengthen knowledge creation (Thorne 2016). Data generation methods were sought for the research which would allow comprehensive and contextual insight into the phenomenon.

Research Study One used interviews as an efficient and effective way to generate qualitative data which can enable understanding about different people's experiences and perspectives (Kirkevold and Bergland, 2007; McCracken, 1988). Interviewing people living with advanced cancer could encourage the sharing of rich description and provide access to meaning about otherwise unreachable areas of reality (DiCicco-Bloom and Crabtree, 2006; Warren and Karner, 2005). Focus groups offered means to investigate a communal meaning; however, interviews were preferred for the need to capture a breadth of experiences and variations in personal approach. Previous research had demonstrated a limited contextual basis about medicines use during advanced cancer. The interviews were therefore conducted at participants' homes, the natural setting for medicines use. This environment could encourage responses about participants' emotions, memories, practical happenings, beliefs, and preferences. This also provided more personalised dynamic surroundings for interviews and intentionally avoided simulation of a medical or pharmacological consultation which focuses on clinical outcomes and a physiological model of health. Instead, interviews aimed to explore people's practical approaches to medicines use and their attitudes towards those experiences. Pilot interviews conducted during the study development helped to establish the interview topic guide content, style and length.

The decision to involve medicines physically in the research interviews was influenced by the piloting process. Pilot interviewees often had difficulty recalling details about the medicines to which they were referring during discussion. One person brought a prescription, which listed their medicines, but this did not prove useful when trying to describe individual medicines use throughout the day. Involving medicines in the interview also supported access to naturally occurring data about people's physical and practical engagement with their medicines in situ (Lincoln and Guba, 1985; Silverman, 2001), which the literature review had found to be poorly documented. A semi-structured topic guide was developed to focus upon the research agenda, whilst allowing space for new meaning and the potential that dialogue may produce new knowledge (Britten 1995; Bredart et al., 2014; McCracken, 1998; Britten, in Pope and Mays, 2006; Denzin and

Lincoln, 2017). The topic guide questions were informed by the first principle of the Medicines Optimisation good practice guidance (RPS, 2013) previously detailed in the literature review, and the specific gaps in understanding identified. Physically incorporating medicines into interviews required a means of accurately recording observations. Photography was identified as a practically convenient means of administrating and cataloguing visual data, to supplement interview audio-recordings and fieldnotes and support data interpretation. The use of photography as an aide-memoire alone was re-evaluated when during the protocol development a friend shared her own photograph of her grandfather's medicines arriving home from pharmacy. This image shown in Figure 5 was strikingly effective in communicating an everyday reality of medicines use at home in chronic illness and provoked exploration of the benefits of photography as a research device itself.

Photography records complex visual representations of life and can capture and communicate highly detailed, nuanced and descriptive ideas with immediacy (Collier 1957, Bechky 2003; Rose, 2007; Killion, 2001). In research, photographs are particularly relevant when used to highlight phenomena from less visible groups, which may otherwise be unseen (Russell and Diaz, 2011; Loseke, 2001; Killion, 2001). Photography is also known to sometimes feel less intrusive to participants than audio-recording interviews, as some participants prefer showing the objects and spaces, rather than trying to explain them (Holliday, 2007; Pink, 2010). Moreover, the use of photography was considered a valuable tool in establishing the credibility of this research. By ensuring research findings were visually validated, photography here provided an opportunity to promote interpretive authority (Thorne, 2016).

Figure 5. Medicines arriving home from pharmacy, reconsidering photography

The array of techniques for integrating photography as a research method were appraised in this methodological design. Photovoice is a participant-led technique that provides the possibility to capture intimate data about private action elements of medicines use, longitudinal concepts, or related events outside of the home. Researcher-led photography, on the other hand, can ensure that the events of the research interview are accurately mapped. This technique is likened to the active interpretation required to develop descriptive accounts from research interviews (Holliday, 2007; Harper, 2000). In this research, researcher-led photography offered a means to capture the trajectory and content of research interviews and maintain the focus on the study purpose.

Research Study Two used interviews with HCPs to develop meaning about the evidence generated in Research Study One. The study specifically aimed to explore findings about people's experiences with their medicines in the context of available NHS healthcare. This was an essential means of linking the research findings from the previous study back to the clinical setting where medicines are supplied and monitored. Interviewing HCPs about these findings was a means to access their clinical knowledge and in-depth specialist understanding of healthcare infrastructure, protocols and process, and their own role in medicines optimisation. Interview topic guides were derived directly from the analytical interpretation of data generated in Research Study One. The topic guide used semi-structured questioning to allow research focus on key topics whilst allowing introduction of other ideas. The opportunity for free conversation was particularly valued because of the extent of evidence that warranted clarification, explanation and justification. Illuminating HCPs insights into people's experiences could offer essential depth of understanding about topics, but maintain study integrity, by adding HCPs input independent of researcher disciplinary knowledge.

In addition to questions, photographs taken in Research Study One were also incorporated as a photo-elicitation technique. Photo-elicitation describes the technique of introducing photographs into the research interview to probe and provoke data from participants and establish collaborative discussion around the meaning of a photograph (Collier & Collier 1986; Harper, 2002; Warren 2017; Mills and Hoeber, 2013). Photo-elicitation was used to illustrate key thematic concepts from Research Study One. Images were presented to participants to generate ideas and insights about real-life scenarios. Photographs were selected via cross-referencing with thematic codes, aligning with the HCP interview topic guide. For example, a photograph showing annotated packaging to support understanding names of medicines, was used alongside questions about how people know what things are. Photo-elicitation was integrated into the interviews. Using photographs that represent challenging concepts was also important in getting responses from participants about things that are potentially uncomfortable (Harper, 2002). Photos also helped to provide specific detail about the practical scenarios that people experience; this was particularly relevant for HCP participants who might only have insight from the healthcare setting, rather than seeing people at home (Harper, 2002; Warren, 2017). It also promoted trustworthiness in the accuracy of HCPs responses to specific scenarios.

Stakeholder Engagement used public engagement techniques to generate data from a range of people about support for medicines use during advanced cancer. The design of this work reflected a commitment to maintain closeness to people's accounts of their real experiences and on turning that knowledge into action. Engagement is a form of public involvement, which provides people from relevant communities with trustworthy information, and seeks their input into agenda-setting, decision-making, and policy development (Cohen et al., 2008; NCCPE, 2021). The use of engagement was conceived in reaction to the limited system-focus of existing research about medicines. It was a means to canvas a range of expert opinions about the best potential course of action for this research; to validate evidence; and tentatively test ideas. A participatory research method offered a way to share these research findings with others and consider the development of solutions that will better support people to manage their medicines. Using the original data from the previous empirical research studies maintained the focus of the exercise on peoples real life experiences. Textual and visual evidence provided a means of coherently presenting research comments when asking people to select their priority. There are some known barriers to undertaking engagement in setting health priorities. It has been suggested that the public involved in research are not objective and as they have their own agenda (Kapariri et al, 2003). Yet, this is potentially true for any stakeholder involved from any community involved in priority-setting, including HCPs, administrators, and researchers (Burgess, 2003).

Various approaches for this work were considered. A Delphi study could seek consensus (Barrett and Heale, 2020), which in this scenario could help as a method to reduce the complexity of the ideas and get agreement on perhaps one priority or a list of priorities. However, at this stage, there was a need to gain more feedback about the feasibility of these priorities going forwards. The study rather than achieving consensus, needed to ask if these areas are in fact priorities and if they could be taken forwards in practice, and if so, are there different priorities needed for different sectors. The public engagement fitted well as a smaller scale study to take stock of the findings, gain feedback, and seek a way forward for the research. Further, this work was not only about priority setting, it was also about sharing the complex findings with stakeholders to get their feedback. In addition to asking about priorities, the study explores why things were a priority to stakeholders and differences between sectors to see if one priority might work across areas or if priorities were clearly different for different people and practices. Other approaches only focus on achieving consensus on priority lists, rather than generating this insight about rationale and implementation. The chosen approach reflected the belief that the public have a genuine stake in the outcomes of research. Stakeholder engagement is grounded in the idea of mutual benefit, through a two-way process of sharing research findings and listening to stakeholder ideas.

A local organisational framework was used to guide the methods. The Strategic Plan for Public Engagement (STAR) (University of Leeds, 2016) underpins institutional public engagement.

STAR encompasses the following core aims:

- Social responsibility refers to the openness about research taking place, and contribution to societal evolution and social mobility.
- Trust accounts for how we strengthen the relationship with the wider community and listen to others to enhance partnerships and build foundations for future relationships for engaged and impactful research.
- Accountability to the public who fund institutional research whose impact and purpose serves and is valued by wider society.
- Relevance which seeks to ensure that research conducted is relevant to society's needs and has impact on society. Research outputs are easily accessible and widely used, innovation flourishes as ideas and insights are exchanged

Data from Research Study One was particularly appropriate for public engagement. Photographs were a useful tool for communicating ideas and the high-resolution of images meant that increasing their size was viable. Narrative exhibition content was developed using photographs, pen portraits, quotes and explanatory summaries to give more detailed descriptive information about each 'medicines optimisation priority.' The techniques were specifically selected to inform people about the findings, provide clinical context and encourage interaction with research evidence to gather opinions and identify opportunities for making 'medicines optimisation priorities' happen in the context of specific stakeholder roles and remits in clinical healthcare and research. The approach aimed to help shape the trajectory of future work, research, and clinical practice using creative and inclusive methods. Interactive resources were developed to communicate salient research messages, evaluate the extent and reach of dissemination and enable audiences to identify their 'medicines optimisation priority'.

3.4.5 Thematic analysis

Qualitative data analysis is the systematic process of transforming data into conceptual insights about research phenomena. Analysis entails exploring and identifying patterns and differences in data, and then grouping and labelling it into themes to support the generation of concepts (Miles et al., 2014, Smith and Firth, 2011; Morse, 2021). Methods share similar sequential strategies of immersion, sorting, coding, categorising and conceptualising to structure data management (Silverman 2001; Guba and Lincoln, 1982; Gale et al., 2013; Sandelowski, 2000). Interpretive Description is informed by a naturalistic paradigm and suggests themes are inductively generated from data to build conceptual descriptions. Interpretive Description recommends that analysis is a reflexive and ongoing process, ideally conducted alongside data collection. This can enable ongoing engagement with the data to explore the ideas and interpretations that occur once data collection

has started and allow iterative thoughtful interrogation of future data and constant comparison. The approach also proposes that analytical strategies can be borrowed from other methodologies to support a methodical, transparent process (Thorne 2016). Most crucial to analysis, Thorne argues, is the distinguishing between preconceptions that are socially constructed. In this research this included differentiating between assumptions about how people should or could manage medicines, from those that are fundamental, respect for people's autonomy in concordant decision making, or minimising distress in cancer care. This meant maintaining awareness to not be drawn into the assumption that all people should take all medicines as prescribed and instead hold a non-judgmental, open-minded approach to hearing and understanding people's perspectives of having medicines at home. Maintaining a clear and transparent documentation of the analytical decisions using reflective accounts, notes, memos and aligned with plentiful raw data, was central in this process to address Thorne's markers of analytic and interpretive credibility (2016).

Research Study One used no guiding theory. The interview topic guide was informed by the Medicines Optimisation good practice guidance (RPS, 2013) plus the findings of the evidence synthesis and was focused on generating new insights. An iterative approach to data analysis was needed, which favoured making concepts and recontextualising data, rather than simple sorting. This meant a tentative approach to coding through deep engagement with data and then classifying and connecting these interpretations into conceptual ideas (Silverman, 2001; Lincoln and Guba, 1985). A Framework approach to analysis was applied. Framework analysis is not aligned with a specific epistemological approach and is particularly well suited to thematic analysis of descriptive semi-structured interview data (Gale et al., 2013; Furber, 2010). The framework approach suggests that a series of discrete, interconnected stages are used and that movement through and between stages facilitates establishing a coherent account of the whole data (Pope, et al. 2000, Ritchie and Lewis, 2003). This approach allowed the RPS Medicines Optimisation outcomes (RPS, 2013) to influence initial analysis and the developing themes to be built from participants accounts.

Research Study Two also applied a framework approach for data analysis. The method was advantageous in accommodating inductive interpretation of healthcare professionals' accounts, alongside the use of a priori concepts transposed from the previous findings about people's experiences (Pope et al., 2000; Ritchie and Lewis, 2003). Applying this approach, meant the analysis could remain grounded in the experiential data generated previously and HCPs reactions to that. But it also enabled reframing of concepts and consider medicines use from the perspectives of those providing care to corroborate and provide alternate accounts and opinions about it.

Stakeholder Engagement used thematic analysis to examine the meaning of feedback responses of stakeholders who engaged with the research resources. Stakeholders provided responses as text on feedback card and made verbal comments during interactions, about their rationale for choosing a specific priority, and suggestions for the implementation of that priority. These responses were

collated and analysed for patterns and exceptions. Responses were labelled and grouped accordingly. Groups belonging to the same overall concepts were brought together to summarise an overarching theme. This process could facilitate the identification of key concepts in the data. In addition to this qualitative feedback, some non-qualitative data was also captured in this study. Alternative techniques were employed to handle and appraise that data. To examine the scope of engagement the size of delegations was approximated. To assess the extent of engagement the number of picture postcards selected, feedback cards returned and conversations with the researcher were all counted. The 'medicine optimisation priority' selected by participants was self-recorded on a written feedback card and these too were tallied. The professional role of participants was self-recorded on the feedback cards. The results were also analysed together to consider feedback selection by role-group.

3.5 Summary and next steps

The research methodology for this work was developed iteratively. Interpretive Description (Thorne et al., 1997) provided a guiding framework, to create qualitative research to address the gaps in knowledge outlined in the literature review. The approach was favoured for its grounding in naturalistic principles in keeping with the epistemological position (Lincoln and Guba, 1985) and for its focus on producing work based on generating evidence about people's everyday health experiences with direct relevance to the clinical environment of care. Research methods were selected to facilitate going into people's homes, to see what they did with medicines, link these findings back to practice and find out what to take forward and where best to focus future effort in this complicated area. The research was conducted across three coherently connected research studies. Carrying out research in people's homes provided a contextual basis about medicines use missing from existing literature. The use of photographs improved the accuracy and credibility of individual accounts of specific experiences. The findings from the first study provided a foundation for adding HCPs insights from clinical practice about people's experiences. Photo-elicitation ensured continuity and specificity when referring to examples and data. The and final piece of engagement work utilized personal accounts, themes, and photography from earlier studies to engage interactively with a wider and relevant audience to maintain the research's commitment to maintaining proximity to people's experiences, and prioritising research of practical and clinical significance. This research is presented in the following three chapters.

Chapter 4. Research Study One

How do people living with advanced cancer independently manage their medicines at home?

4.1 Introduction

This first empirical research study aimed to explore how people living with advanced cancer manage medicine use at home. As explained in Chapter Three, Interpretive Description (Thorne et al, 1997) was selected to guide the design of qualitative research to explore pertinent gaps in knowledge and generate clinically relevant evidence. The study specifically sought to illuminate people's individual perspectives of dealing with all their medicines in the context of everyday life, and advanced cancer, in the natural environment of their use, to develop a conceptual description of the experience of using medicines at home during advanced cancer.

4.2 Methods

4.2.1 Participants and setting

The study sample were adults over the age of 18 receiving standard NHS care for advanced / metastatic cancer. Primary cancer was not specified in the inclusion criteria; however, disease groups most prevalent in the UK were prioritised during recruitment. These were breast, kidney, lung, prostate, and lower gastrointestinal cancers. Inclusion criteria for primary diagnosis was limited to solid-tumour cancer due to differences in treatment protocol for haematological malignancy. People diagnosed with blood and lymphatic cancer routinely receive intensive inpatient therapy, so were excluded from the current study. Some specific solid-tumour diagnoses were also excluded: testicular cancer was excluded due to improved outcomes including cure for people living with advanced disease; upper gastrointestinal and head and neck cancers were excluded because of the likelihood that disease or treatment could induce oral dysfunction, and the need for alternative routes for nutrition and medicines. Inclusion criteria required participants to be prescribed a minimum of one medicine for regular use from an NHS provider and to be independently responsible for using it at home. People were not eligible if they received informal or professional support to use their medicines. All participants were required to be able to provide informed consent. Only English speakers were included, due to the absence of resources for translation services and therefore potential ethical issues regarding participant safety.

The following eligibility criteria were applied:

Inclusion criteria:

- Advanced / metastatic incurable cancer of solid tumour origin
- independently using prescribed medicines at home
- over 18 years of age
- able to provide informed consent
- able to participate in English

Exclusion criteria:

- head and neck, upper gastrointestinal, or testicular cancer

The sample size specified was a minimum of twenty and maximum of thirty participants. This reflected a commitment to methodological integrity to ensure the inclusion of sufficient participants aligning with the sampling frame, and the boundaries of time available for participant recruitment and data collection. A purposive strategy was used to select a group of eligible participants. A sampling frame was designed and applied to guide recruitment of a participant sample with a variation of demographic and clinical characteristics to diversify the views and backgrounds represented in the sample (Silverman, 2010; Patton, 2002). The sampling frame specified variation of primary cancer diagnoses to reflect disease-related experiences and the diagnosis-specific nature of advanced cancer care. It also stated different durations since diagnosis of primary and metastatic disease to explore medicine management experiences over the trajectory of advanced cancer. Participants with a range of cancer treatment history were sought, including those receiving active treatment, under surveillance or ineligible for further treatment, to reflect the scope of cancer care. The sampling frame also stipulated a range of participant ages, though a skew towards older adults was expected due to the increased likelihood of advanced cancer with age. An equal distribution of sex was sought. The study sample was anticipated to represent a range of socio-economic circumstances due to the recruitment site being a regional referral centre for a large geographic area.

Participant recruitment took place in a large UK Teaching Hospital, between September and November 2016. Written materials promoting the study and inviting participation were displayed in public waiting areas at Oncology Outpatient Clinics and the on-site Oncology Information Centre. In-person recruitment was also conducted at support meetings at the hospital Information Centre, and at Outpatient Clinics for specified diagnostic groups. Recruitment continued for three months during which time data collection was undertaken.

4.2.2 Materials

Written materials used to promote the study were recruitment posters and leaflets, which summarised the study purpose, eligibility criteria and procedures. These were designed following patient and public involvement (PPI) activities conducted during the preparation of the study protocol and ethics application. A Participant Information Sheet (PIS) (appendix 2) and Consent Form (appendix 3) were developed according to guidance provided by the School of Healthcare Research Ethics Committee (SHREC). PPI advisors provided direct feedback on the document content. A basic proforma was used to collect demographic data. A topic guide (appendix 4) was developed to organise research interview format and content. The interview was semi-structured, including core open questions to explore key aspects of people's experiences, and follow-up or prompt questions to clarify meaning and encourage elaboration. The topic-guide was informed directly by the findings of the literature review, presented in Chapter Two. The interview questions specifically sought to address gaps in understanding about people's everyday use of a whole collection of medicines at home. This included exploring their practical approaches to medicines use, the storage and supply arrangements, specific techniques for remembering and managing new medicines, the impact and integration of medicines use on daily life, and the support they received with medicines.

4.2.3 Data collection

Audio-recorded interviews were conducted with all participants at their home within four weeks of their recruitment. The topic guide was used to organise the interview. Participants were invited to make their medicines available. Medicines were used as a visual stimulus for discussion about medicines management and to support participants' recollection of information about specific medicines or exemplify medicines-related activity. Digital photographs were taken of medicines and their storage or administration location, in response either to demonstrate specific practice, or to capture physical examples of ideas introduced verbally in the interview. Photographs conveyed evidence that was otherwise difficult to preserve, providing an aide-memoire to catalogue interview events and data for analysis and later dissemination. Fieldnotes were taken throughout the interviews to record researcher observations, additional medicines-related data, and to cross-reference data sources. Demographic data recorded participants' age, living and employment circumstances, medical history, time since diagnosis of cancer and metastatic cancer. This information helped to monitor participant diversity within the sample throughout recruitment and was used in subsequent analysis (Silverman, 2010; Mason, 1996; Patton, 1990).

4.2.4 Data management and analysis

Interview audio-recordings were transcribed verbatim by the researcher (n=13) and PhD supervisors (n=7). To maintain the authenticity of participants' accounts transcripts retained colloquialisms. Transcription was mostly undertaken during the data collection phase of the study,

which allowed critical reflection of the researcher role during interviews and informed the approach in future interviews. Transcription also facilitated immersion in the data to support ongoing analytical thinking. Interviews transcribed by research supervisors were discussed with the researcher to convey transcriber impressions and enhance familiarisation. Following transcription, field notes were used to systematically attribute any photographs taken during each interview to the relevant section of transcript with which they were associated. NVivo 11 was used to store, retrieve, and manage all study data which included interview transcripts, photographs, fieldnotes and analytical memos. The software was used to cross-reference between evidence sources. For example, to link fieldnotes about non-verbal signals to a section of transcript, or to attach photographs to specific explanation of practical activity within a transcript.

Interview data were analysed inductively using the framework approach (Ritchie and Lewis, 2003). This systematic method supported the iterative, and transparent generation of themes to build a coherent account of the data (Spencer et al., 2003; Gale et al., 2013; Furber 2010; Smith et al, 2011). The following stages were undertaken:

Familiarisation: To become familiar with interview data, interview transcripts were re-read, and audio-recordings re-listened to. This intensive engagement with individual participant's data helped getting to the essence of ideas and depth of understanding of different ideas which provided some foundations for early analysis. Initial impressions about the data were recorded as annotations in transcript margins or as memos in NVivo11 alongside transcripts and photographs. This immersion also helped learn the location of information within the vast amount of raw material. Ease of navigation around different excerpts of interview helped later when trying to connect ideas.

Developing a coding index: Initial codes were used to label interview transcript data to flag ideas arising from the annotations and memos made during the familiarisation stage. Words, sentences, or entire paragraphs were highlighted in NVivo11 and assigned a code. A coding note summarising the rationale for the selection of specific interview data was made. The list of these initial codes produced a Coding Index. The Coding Index was sorted and arranged according to linked ideas, which facilitated the development of initial themed categories. For example, ideas relating to the practical organisation of medicines were grouped together as codes within an overarching themed category 'How and where medicines are stored'; information about obtaining prescriptions from pharmacies was arranged into a themed category labelled 'supply'. This process and these labels were influenced both by a-priori concepts derived from the interview topic-guide and novel ideas introduced by participants. The result of this stage was an initial detailed framework, which organised all the key ideas identified in an understandable set of themed categories.

Indexing: The analytical framework was stored in NVivo11 and applied systematically to the data. Where single passages of text encompassed multiple themes, all were separately recorded. This facilitated the iterative development of themed categories. Modifications to the initial thematic

framework were tracked to support analytical transparency, which also assisted later discursive writing about interpreted data. The thematic framework was refined multiple times, to try and capture the meaning of individual concepts and capture a broader, reasoned account of all the data.

Charting: The Nvivo11 Framework Matrix function served to visualise all indexed data within the framework. The matrix is a chart, summarising every code in the coding index, and populating it with coded data. Segments of indexed data were summarised in each corresponding chart cell. All data stored within the matrix was then summarised as descriptive statements. This enabled data to be visualised in an undistorted, meaningful way. Field notes and memos from early analytical stages about the meaning of codes, categories, and themes, helped to consolidate key meaning in each charted idea.

Mapping and interpretation: During the final stage of analysis, data were synthesised to move beyond describing individual cases and towards developing themes which can provide explanations for what is happening within the data. The interpretive stage is recognised to demand an intuitive and imaginative stance (Ritchie and Spencer, 1994). These data were considered as a whole, some themed categories were merged or renamed to better reflect the evidence to which they were connected, or in keeping with the narrative generated in the overall analysis. The result was a collection of main themes, with integral explanatory subthemes. Making sense of the data in this way, facilitated richer understanding of the participants' meanings.

Photography data was interpreted according to the themes generated through textual analysis. Cross-referencing undertaken during research interviews and transcription, was used to retrieve and group photographs depicting given themes. All photographs were then systematically critiqued against the analytical framework. This provided a mechanism to identify additional examples of key thematic ideas which had not previously been labelled during research interviews.

4.2.5 Ethics and Governance

Ethical approval for this study was granted by Leeds East NHS Research Ethics Committee (REC) (REC reference: 16/YH0221). Health Research Authority (HRA) and local Research and Innovation (R&I) permissions were subsequently obtained (HRA reference: 16/YH0221; R&I reference: MO16/186). Several key ethical issues were considered. Recruitment sought to cause minimal disruption to the clinical environment and patient care. No direct approach to potential participants was made. At the outpatient clinic, the coordinating HCP identified eligible attending outpatients and informed them about the study. Those interested were then introduced to the researcher. All potential participants and staff supporting recruitment were provided with written information about the study. PPI advisors were involved in the development of materials to ensure they were informative, appropriate and accessible. The PIS detailed study aims and procedures and clearly communicated the extent and expectation of commitment in taking part in the study. All

potential participants were given the opportunity to speak directly or remotely with the researcher and ask questions. In both settings, in-person discussions between potential participants and the researcher were conducted in a discreet location. No incentives to taking part were offered. Interested potential participants were contacted within one week of recruitment. A Consent Form, stating permission for the collection, storage and future use of anonymised data, the protocol for breaching confidentiality in the event of concerns of harm, and withdrawal was used to obtain written informed consent from all participants. The consent form was read by participants, and then read aloud by the researcher. All participants signed and dated the form and were offered a copy.

The safety of those participating in the study was paramount. During research interviews, participants' own questions about their medicines were answered within the scope of the researcher's clinical knowledge. Participants were always advised to also contact their care provider. To ensure minimal disruption to medicines use itself, at the end of their interview participants were supported to return all medicines to their original safe-keeping place. To minimise the potential for distress, participants were not asked to make any additional contribution of time following their interview. It was likely that the health of participants could deteriorate, or they may die in the weeks following participation. Returning interview transcripts or research findings to participants for their comment, for example, was ruled out on this basis. Though member-checking is a valued technique for enhancing the trustworthiness of results by ensuring congruences between participants' responses and their representation (Lincoln & Guba, 1985; Tobin and Begley, 2004; Nowell et al., 2017), it was judged inappropriate in these circumstances. As discussed in Chapter Three, alternative conditions for promoting quality were introduced elsewhere in the study research methods. Within eight weeks of data collection a letter of thanks was sent to all participants, containing copies of research photographs, the consent form and contact details for the researcher.

All data were anonymised. Participants were invited to self-select a pseudonym (Dearnley, 2005), which was used to label all data. Potentially identifying information was redacted from transcripts. Participants themselves, any potentially identifying artefacts, and obscured personal details, such as name labels on medicines were excluded from photographs. After each interview, participants reviewed all photographs taken and confirmed they were satisfactorily anonymised. All digital data were recorded on encrypted devices and transferred to a password protected server. Original files were destroyed. All documentary data, including demographic information forms, and consent forms were digitally uploaded and onto a password protected server. All physical documents were discarded as confidential waste. Participant personal information and contact details were stored separately from other study data to maximise discretion.

4.2.6 Reflexivity

Reflexivity was used throughout the study to ensure a focus on the central research aims, to support improvement of methodological techniques, and to acknowledge the influence of researcher conduct in the effort to maintain credibility. During data collection, procedural elements were modified following reflexive engagement with early recordings and field notes (Rubin and Rubin, 2005; McNair et al. 2008). For example, following the first three interviews, it was clear that the audio-recording should start as soon as the consent form had been signed, because participants began to describe the nature of their diagnosis, duration of disease or its treatment as they started filling in the demographic information form. Capturing this data in transcripts provided beneficial context and prevented time-consuming cross refencing with field notes and proformas. The use of annotation increased over the course of the data collection phase. For example, to register something to come back to later in interview and prevent disruption of the flow of the interview. The interview questions were also revised following early transcription and tentative coding, which identified key ideas of interest and patterns. For example, following initial interviews, questions about obtaining prescriptions were made more prominent, due to the indication that this was a critical area of concern for medicines users. Increasingly, the interviews were led by participants and continued according to their responses and cues, aiding the depth of insight offered.

The involvement of medicines and integration of photography in interviews was also developed over the data collection phase. Upon listening back over audio-recordings of early interviews, an urgency to start taking photographs was apparent, and sometimes found to interrupt the cadence of the interview. In later interviews the approach to photography was more natural and assured. In some, all photography took place at the end. In later interviews participants were encouraged to highlight what they felt was important to be photographed.

There would be insufficient time to also analyse data during or immediately after recruitment and data collection phases, due to a planned suspension of doctoral study. Instead, early immersion in the data was facilitated by undertaking interview transcription simultaneous to data collection. This enabled the cautious identification of key ideas, pattern, and areas of interest in the data, which influence subsequent interview questions and provided foundations for later analysis proper. For example, the experiences of the first few participants were dominated by the workload associated with maintaining repeat prescriptions. Later participants were then routinely questioned about their perspective. Similarly, one of the first participants explained with candour the competing effects of different medicines on their bowels. This introduced a new area of inquiry relating to medicines side-effects, not previously planned. The break between data collection and formal analysis had the advantage of preventing early excessive coding of which Thorne (2016) is so guarded. Instead, the tentative labelling of ideas during transcription and openness to new ones created a flexible foundation on which eventual analysis was grounded. Such a lengthy period of thinking over these initial ideas served to keep analytical concepts in suspension (Thorne, et al., 2004).

4.3 Results

4.3.1 Participants

Twenty-four people living with advanced cancer agreed to take part in this study. Twenty-three people were recruited at their routine Outpatient Oncology Clinic appointment and one during attendance at the Oncology Information Centre. After recruitment one person withdrew and three others became too unwell to participate. Twenty people participated in the study, as summarised in Table 5. Most of the sample were of retirement age (75%) and most lived with a partner or spouse (75%). All participants were diagnosed with advanced cancer. The most common diagnoses were lower gastrointestinal (lower GI) and prostate cancer, accounting for 50% of the sample overall. Most participants had lived with cancer for 2-5 years (40%) and some had been living with cancer for over 5 years (20%). The majority (80%) had advanced disease at their initial diagnosis; the remainder had metastatic recurrence of previously cured cancer or progression of a known primary. Most common sites of metastases were the bones, lungs, liver, lymphatic system and digestive organs. Most people had at least two different metastatic sites (55%). All participants disclosed at least one additional medical condition.

Participants were engaged in NHS healthcare for advanced cancer. All participants had a Consultant Oncologist (CO) and a named site-specific Clinical Nurse Specialist (CNS). All were registered with a General Practitioner (GP). Three study participants had clinical input from community Specialist Palliative Care (SPC) services. Some were involved with other medical specialists for non-cancer conditions. Participants had received a range of medical, clinical, and surgical treatments for cancer.

Sex	n (%)	Primary cancer	n (%)
Female	9 (45)	Colorectal	4 (20)
Male	11 (55)	Bile duct	1 (5)
Age		Prostate	5 (25)
40-49	3 (15)	Breast	3 (15)
50-59	2 (10)	Renal	4 (20)
60-69	7 (35)	Lung	3 (15)
70-79	7 (35)	Metastatic cancer	
80+	1 (5)	Thyroid	1 (5)
Home		Bowel	1 (5)
Cohabiting	15 (75)	Stomach	1 (5)
Alone	5 (25)	Liver	7 (35)
Work		Bones	8 (40)
Full-time	1 (5)	Pancreas	2 (10)
Part-time	1 (5)	Lymph glands	6 (30)
Sick leave	2 (10)	Lung	6 (30)
Medically retired	2 (10)	Number of metastatic sites	
Retired	14 (70)	1	9 (45)
Comorbidities		2 or more	11 (55)
COPD	2 (10)	Time since primary diagnosis	
Hypothyroidism	2 (10)	Less than 1 year	6 (30)
Hypertension	10 (50)	1 to 2 years	3 (15)
Osteoarthritis	2 (10)	2 to 5 years	7 (35)
Arrythmia	1 (5)	5 years or more	4 (20)
Hiatus hernia	4 (20)	Time since metastatic cancer diagnosis	
Stroke	2 (10)	Less than 1 year	8 (40)
Cancer diagnosis history		1 to 2 years	3 (15)
Primary at diagnosis	4 (20)	2 to 5 years	8 (40)
Metastatic at diagnosis	16 (80)	5 years or more	1 (5)

Table 5. Research Study One participant characteristics

4.3.2 Themes

Five themes summarising the experiences of using medicines at home during advanced cancer were identified. Ideas were interconnected and occurred throughout individual participants' accounts. These themes are summarised in Table 6 and then described alongside original data sources.

Theme	Subtheme
Having cancer that is never going to go away	Getting your head around it
	Life in peril
	Fluctuating health and wellbeing
	Trying to be normal
Getting along with the medicines	Accepting medicines
	Evaluating medicines
	The right kind of information
	Discriminating between multiple symptoms and side-effects
Navigating the system	Knowing medicines
	Keeping on top of them
	Regimen oversight
Habituation in the home	Ritual and routine
	Conscious placement
	Dealing with outliers
Adapting and adjusting	Developing expertise
	Making sacrifices, feeling better
	Things fall apart
	Creating freedom

Table 6. Themes and subthemes from Research Study One interview data

Theme 1. Having cancer that is never going to go away

Participants' experiences of managing medicines were inextricably connected with the fundamental everyday reality of living with incurable metastatic cancer. This included the difficulty coming to terms with such a devastating diagnosis, feeling uncertain about the future, having constantly fluctuating heath, and trying to maintain as normal a life as possible. Participants described the utter shock of learning they had got cancer that was not going to go away. Their unclear prognosis brought a sense of lost agency and instability. Living with advanced cancer meant enduring an

unpredictable profile of physical symptoms and decline, caused by treatment-related effects, acute exacerbations of disease and overall functional decline. In their attempt to regain some stability, participants adapted their mindset and practical endeavours; undertaking available treatments, trying to stay positive and being engaged with day-to-day activities. However, living with advanced cancer created an exhausting environment and small things could easily become overwhelming.

"I just couldn't believe it" - Getting your head around it

Participants tried to comprehend how and why advanced cancer had happened to them. Though diagnostic routes varied, participants were united in feelings of distress, disbelief and injustice upon learning that they had cancer that was never going to go away. Incredulity was, for many, exacerbated by factors they felt should have been mitigating, such as having a healthy lifestyle or the absence of a family history of cancer. Some participants felt anguished by a sense of accountability in not noticing the physical warning signs of cancer sooner. Others, with suspicions about cancer described still feeling totally shattered upon its diagnosis. The return of previously cured cancer was particularly difficult to accept and incited a sense of humiliation and unfairness.

"it wo' a big, massive shock from start. Come back off, like I say, come back from Fuerteventura in May, end of May, and Di says to me 'you're going t' doctor' because as she says – I wo getting' night sweats, and then went for blood tests and then it was just a massive snowball from there you see.... when we went for t' results, she said 'you know it's spread to your lung so there's not….' What did she say now? She said, 'There's not a lot, but there's too much to operate, to remove,' she says, 'but there's not a lot'. ...But when I asked, 'well how long it's been there?', It could've been there six months, it could've been there 9 month. So then think back, and think well my symptoms like before the Christmas so to speak, what wor I like? Well I wor' alright. There were nowt wrong wi' me. 'Cos like, I'd have never of know. So then you think to yourself, 'how, how can you catch it quick? If you don't know?!"
Tom, advanced kidney cancer

" I found lumps in me neck, it'll be three Christmas days this year and I went to the... I kept ringing the doctors and ringing the doctors and all that can't get an appointment crap, so I must've gone down to the doctors back end of January, February time; she had a feel of my neck. She said, 'can I have a feel under your arms', I went 'yeah'. And it's strange, 'cos as soon as I put me hands on em that day, I thought 'shit I've got cancer' and I don't know why, cos I 'ant had that cough that they say on t' telly cough for three week…I wasn't out of breath, I dint feel poorly, I just had these lumps and I thought, 'oh god I better get..', and I just knew. And she - this Locum – she had a feel under me arms and a feel up me neck and she said 'I need you to go get and x-ray' and I said, 'do you think it's summat naughty?' and she said 'yeah, I think it's cancer'."
Christine, advanced lung cancer

The sense of injustice was intensified for some by perceived shortfalls in the healthcare system. Several participants questioned whether delayed intervention due to the failure to escalate symptoms, a protracted referral process, delays to treatment, or inadequate follow-up had contributed to their fate.

> *"There's nothing wrong with the GPs, but they only react. The first year, when I was supposed to have a blood test and I thought that they would ring me up and say 'we have to monitor you for your PSA' no one contacted me!.... So, er that went on for a couple of years, it went on for two years, or maybe more, and everything was alright but then it wor me who was having to instigate it every time…. I just kept on taking the bicalutamide, and then one day, I said, 'would you tell me what the PSA is? And: 'its eight. 'What?!' and I said, 'that's not right! It should be four!' and now, I know eight's nothing, but, it'd gone up! 'Oh it must be alright, the Dr's said it alright, OK then'. Well next time it was twenty. A year later, so it was only going slowly. And I says this is wrong' 'oh it's not wrong' 'no its not alright, its going up, it should be four, there's something wrong!' ….but last year before Christmas I thought I wo' dead. I lost four stone in body weight. I couldn't eat I just didn't want to eat. And when I did eat, I was sick. ...shirts were hanging off me and I just (starts crying)…. The thing is, it could've all been stopped! I mean! If it could've all been stopped earlier on. I had to go t' doctors, I forgot why.. I went down to the doctors, oh that was it, it was my yearly er, check-up, you get to your birthday. And nobody wo' doing anything… And I went in and I saw this nurse, lovely woman, chattin' away and I said 'I think I've lost some weight' I knew I had. And I said 'can you weigh me?' and she said, 'Of course I can Henry' and I got on the scales and she went to the computer, an went 'gasp!!!' and said 'what's happening here!' and I said 'well I'm not well' and she said right, 'I want you to sit in the waiting area and I'll get doctor to you straight away'."*
> Henry, advanced prostate cancer

Two participants did not find learning about their diagnosis traumatic. One male participant had been unwell for many years with other chronic conditions and advanced cancer now seemed inconsequential; a female participant explained that her initial presentation caused clinicians to suspect imminently life-threatening disease, so she was relieved by her less aggressive albeit serious diagnosis. Participants' descriptions of their conditions were consistent with their clinical diagnoses; however, they rarely adopted the recognised medical terminology such as advanced, incurable or metastatic cancer. Instead, they referred to their disease as cancer that has "spread", is "not going away", or "can't be solved".

"Fuck me, I could be dead tomorrow!" - Life in peril

Being diagnosed with advanced cancer meant living with relentless uncertainty. Participants explained that knowing that their life was limited in some way, but not knowing to what extent, caused feelings of precariousness and urgency. This was particularly evident amongst participants who had been advised of the poor outcomes associated with their disease staging or histology.

" Who knows, you know? I'm very fortunate that the chemo has you know given me a bit longer 'cos they gave me five months, initially, it was one of the Consultants I saw before then and I asked him and he calculated and he said five months and now I've hit six months and [Oncologist] said I've got more than fifty per cent chance of living for more than a year so I'm hoping it'll be longer than that, obviously, but that's one of the uncertain things that make you very...I'm very positive and my friends all say I'm very positive about it I can talk about it, but the fact that you don't know whether it's gonna be a month or a year is unsettling, and it does frighten you sometimes. But I've got it [cancer]. There's no point in saying 'what if' and all the rest of it, you just have to get on with it and I know everybody'll cope after I've gone."
Isobel, advanced bile duct cancer

"I mean you feel down some days. You know you've got cancer, at some stage you're gonna die with it. Simple as that. It's no good sweeping it under carpet and saying, 'oh I'm ok I'm at moment at ok, but sometimes, then if you get diarrhoea on top of that and then you feel…..oh, I've ended up this time, and this is the first time I've had it, all me mouth, it's split, it splits right there int corner."
Malcolm, advanced prostate cancer

The impending decline due to cancer loomed large for some participants and cancer-related acute illness experiences had escalated end-of-life thinking. Awareness of cancer incurability was juxtaposed with hope that death could be avoided or at least delayed. Hope had often been fostered from initial diagnosis, when participants described they were reassured by their oncology team about available or emergent treatment. Hopefulness was consolidated for those who had outlived previous estimates of life-expectancy following treatment. Novel therapies continued to galvanise hope throughout the care pathway for participants whose diagnostic groups offered clinical trials of new treatments.

"When I went twelve weeks ago, I saw one of the doctors and they told me the result of the scan, that the cancer was learning to get past my tablets. And my tumours were starting to enlarge, and I'd got another one in my small bowel, I think that's where it was. And says the only option you've got left is two more courses of tablet. She said if neither suited to you there isn't a great lot for yer…so I came away a bit down and I thought, well we'll see what happens next time when I go. And the last time I went, when I saw you, I saw the Dr and she said 'well I've got some great news for you - they've released another 6 courses of options that are open to you'. The hospital have released some, and the NICE have released some, so she told me there's 5 lots of tablets, all with good results and there is a drip."
Brian, advanced kidney cancer

Participants' hope was moderated by an understanding that successful treatments would ultimately become ineffective. Some recalled their distress following a poor response to therapy and the subsequent anxiety of waiting for an alternative clinical plan of action. The effort of managing expectations and coping with disappointment alongside existing emotional tensions was intense.

Some participants demonstrated a paradoxical state of being genuinely hopeful about the possible future discovery of a cure for their cancer and simultaneously lucid and contemplative about their inevitable approaching death.

> *"I don't know, I can't answer that, because if they said, 'oh it could go away', you know, it might lift me a bit, it might lift me a bit. But now, you know, I'm just feeling like I'm living with a death sentence, so. So yeah. I've just got to try and enjoy every day, but it's not always that easy!"*
> Karen, advanced breast cancer

"Some days are better than others" - Fluctuating health and wellbeing

Many participants' lives were dominated by relentless fluctuations in their physical health. On top of the long-lasting consequences of cancer and its previous treatment, unstable disease or inconsistent symptoms and intermittent treatments now caused regular changes to wellbeing. Participants explained that some days were better than others.

> *" You seem to get good, if you over do it, that's what you tend to do. If I feel a bit better, I tend to go do something, yeah you know you flop. I had one bad, really bad day, I stopped in bed for a lot of the day I just felt rough, you know, no energy, nausea, not interested in anything. But it wore off the next day."*
> Jack, advanced colorectal cancer

Some participants suggested that these day-to-day changes could cause misunderstandings with other people, who might see a good day and assume that things are well and then be surprised when the next day things have deteriorated. Participants described their techniques for coping with the physical toll of cancer and modifying their activity in order to manage ongoing deterioration and prevent symptom exacerbation. The need to adjust was nonetheless restrictive and disappointing. They tried to stay in tune with their bodies to pre-empt these symptoms and side-effects and judge how best to respond.

> *" Times of day, rather than entire days. But again, it's a learning process and just as you have to accept help and learn that you will be better, quicker if you do accept help, erm, you know, I try to learn to live with the tiredness, so instead of saying oh! I'm tired again, I say OK I'm tired, what am I going to do, and the answer is I can't really do anything physically, so I do what is pleasant and comfortable. I go to bed, but I have a, I have support, back rest, that was put in by occupational therapy, so I can sit up comfortably, because when I'm tired comfortable chairs in my sitting room, but I am more comfortable with my legs out like that, so I go to bed, sometimes I get into my nightie, but sometimes just get in in the day clothes and I'm very fond of the radio and I read and I think I have succeeded in turning the tired times from a time of despondency… I am despondent when it comes again but then I say, you have a way of dealing with this, don't sit in a chair waiting for the energy to come back, but do something that is pleasant during the period of tiredness. And it does come back, it always come back. I've developed a strategy to deal with it. I think*

in the medium and long term, the unpredictability of it, of the tiredness, is a bit of a problem. For instance, this weekend, my brother and sister-in-law are coming up, I haven't seen them for a bit, and you know, they can hear my voice sounds better and so on. And my sister-in-law says I'll bring some food and we'll cook it and we can have a nice supper round the table, and I think 'uhhhh, the evening!' …. I get into my bed often at 7 o'clock and I want, I want them to go back happy, I don't want them to be sitting here eating when I've already eaten and gone off. So there are problems in the unpredictability when other people come into your life. If I'm on my own, it doesn't matter, so I can deal with it on my own. But thinking in terms of a social life, or even going downtown, and again getting stranded in a part of town where suddenly, you feel fatigue comes in…so that a slight, a slight anxiety."

Margaret, advanced colorectal cancer

Participants also talked about the challenge of managing unpredictable and strong emotions, which could cause them to feel suddenly very panicked or low in mood. Participants explained their engagement in a complex system of continuing healthcare and described enduring and managing the consequences of numerous, often invasive or life-changing, therapies over the years. Participants with advanced breast cancer had previously required multiple procedures of resection and reconstruction. One now lived with disabling lymphoedema and another with extensive painful scar tissue. Three of the four participants living with advanced renal cancer had undergone a radical nephrectomy as part of their initial curative treatment. All cited their lengthy recovery from surgery and the significant impact on their lifestyle and wellbeing of now only having one kidney. Two participants with upper gastrointestinal primary disease had required emergency surgery due to disease-induced bowel obstruction and now had a stoma, which they had needed to learn to manage. The participants living with advanced prostate cancer described the range of debilitating, humiliating consequences of historical radiotherapy on their pelvic function. Though undergoing treatment could improve prognosis or symptom burden, it could cause short term poor health. Upon reflecting about the previous and late effects of their cancer treatment, participants doubted whether these costs were worth it. Some felt personally responsible for choosing certain treatment pathways and potentially wasting healthier or better-quality years of their lives, to now end up living with incurable cancer anyway. This impacted on their impressions toward having future treatment.

"That's just who I am" - Trying to be normal

All participants expressed the desire to maintain as normal a life as possible. This was realised by choosing to work, exercise and socialise. Responsibility for dependents also provided ongoing purpose and enhanced feelings of determination. Being normal meant sustaining a connection with the past healthy self, which participants did not necessarily expect to return to, but used as a marker for their altered identity throughout the disease.

" Well, I've worked all t' way through lot of it. I've never - There were just one time where er I can't remember which one it wo, one of treatments that I had and it made me really tired, but I wo working like 8 hours a day and like Friday Saturday I just wanted to sleep, I was just sooo tired. I dint feel poorly I was just sleepy, I just wanted to sleep. And I went down to me doctors, and I just says, is there any chance I can have a sick note – and they sort of went, she wo looking up on t' thing and she went – why a week? And I went what do you mean why a week? And she went; I'll give you a sick note – and she give me a month! And I went back and I went you've got it wrong, I only wanted a week! And she went, come back when that runs out. And I went back and she give me another month! And she said don't you understand, Chris? Your body needs time to….but I wo like I don't even feel poorly! What you keeping me off work for? I want to go back to work! And I went back and saw another doctor and he gave me 5 week! And I though oh my god! And when I went down I said that's it! I've had enough of this not working! I need to go back to work."

Christine, advanced lung cancer

The idea of getting on with it and maintaining a normal life was closely associated with having a positive mental outlook. Whether participants felt capable of this or not, they agreed that attitude was influential when negotiating this time of their life. Several participants, however, acknowledged the difficultly sustaining a sanguine mind-set in light of their circumstances and some expressed feeling a reluctant obligation to stay positive. Participants also acknowledged the significance of input from other people in their life to provide support network.

" If they're in their mind set of 'oh I've got cancer, oh I'm gonna die'… get on with it then…cos you are gonna…..but you've gotta be of a positive mind-set. But I think you've gotta be that anyway, regardless, you can't develop a positive mind-set just because you've got cancer. I think you're either that person, or you're not that person. You can't teach somebody that. You've either got it or you 'ant."

Tom, advanced kidney cancer

"We've had each other. I can talk to her [neighbour also living with cancer] about anything and she can talk to me. If I need to talk about anything, I can talk to her. You've got to have someone to talk to! I don't give a monkey's who it is. Like I say. I'm a strong person, but every now and again I have a meltdown like anybody else, and I need that person to talk to. And you know, and she's there and I'm the same for her. If she needs someone. I'm there for her. But you've got to have that friend "

Eileen, advanced kidney cancer

Many participants talked with candour about the profound emotional impact of living with advanced cancer. Unrelenting uncertainty and the prospect of their untimely death, coupled with all the physical stress of cancer and its treatments was draining. This was compounded by the emotional investment required during engagement in cancer therapy and the challenges of everyday life. Seemingly mundane or straight-forward tasks and minor hurdles such as appointment delays,

queues, or administrative errors, could feel insurmountable and participants frequently articulated feeling totally overwhelmed.

Theme 2. Getting along with the medicine

A central part of being a medicines user involved letting medicines into everyday life and getting along with them. This included accepting the use of medicines in the first place, questioning their value, assimilating useful information about their medicines, and managing the impacts of their use. Needing to use medicines was a threat to participants' identity, challenging their sense of healthiness or ability to cope. Though participants consistently would prefer fewer medicines, they reconciled the need to accept medicines for the sake of their wellbeing. Individual medicines were evaluated against complicated and nuanced criteria. Participants wondered if medicines were helping, wondered if their condition was bad enough to need them and weighed these things up against adverse impacts. Excessive information about medicines often felt burdensome when added to the other medical information already received. Concurrent use of medicines made it difficult to determine the root cause of symptoms. As many medicines accumulated for different indications, participants found keeping track of individual medicine's effects increasingly complicated.

"It's just another bloody tablet!" - Accepting medicines

For all participants, their illness with cancer had not been the first time they had encountered prescribed medicines, and most were already using at least one regular repeating medicine. The implication of illness posed by commencing a cancer-related medicine had challenged some participants' sense of identity. Some participants expressed unease with the general principle of using medicines, which was grounded in their association of medicines with poor health. These participants felt disconnected from this new version of themselves that did not reflect who they really were, defining themselves as 'not a medicines-taker', which directly contradicted their medical history. Others were ambivalent and not drawn into thinking about the wider connotations, instead focussing on medicines' function, citing their confidence that medicines were only prescribed when essential and were in fact a means to better health. Some participants were conflicted and exhibited both viewpoints simultaneously. Despite these differences, medicines use was largely considered just a normal part of everyday life. All participants expressed a preference to take as few medicines as possible and were pleased by the reduction or elimination of a dose. This was except for cancer treatments, which most participants were determined to continue at the maximum permitted amount. Despite their different feelings about being a medicines user, participants were consistently committed to their use. Participants described setting aside their concerns and referred to their stoic motivation, expressing the common attitude to just 'get on with cancer'.

Participants demonstrated their vast extent of different medicines, which reflected their engagement in complex specialist services. Participants had many medicines from multiple sources, which could change depending on the nature of the treatment and circumstances of their health.

They explained that medicines accumulated easily and though they would prefer fewer, they viewed it as ordinary. Many made the same light-hearted reference to "rattling" when they walked. Participants explained that needing one medicine usually meant needing another and then another because of side-effects. This pattern occurred throughout their healthcare and seemed inevitable and unavoidable to participants. In relation to their cancer treatment, participants explained that many additional medicines are dispensed pre-emptively in anticipation of SACT toxicities. Though grateful to be protected from possible adverse effects the quantity of these medicines caused fear. Several participants expressed concern about the cost of all their medicines to the NHS. These participants explained privately obtaining their own generic versions of some over-the-counter medicines to prevent a costly prescription being issued.

Figure 6. Lillian's washbag

"I'm not even sure if I need it?" Evaluating medicines

Participants described various criteria against which they judged the importance of individual medicines. This considered their current condition, past experiences of care, and expectations for the future. Concerns about using medicines were influenced by a variety of factors. Some participants were very worried because they had experienced a problem previously with a particular medicine, such as an intolerable side-effect or not noticing any benefit. Sometimes participants were wary about using a medicine because of the side-effects they had heard about anecdotally from other people living with cancer or relatives. For this reason, the medicines that individual participants were worried about differed. For some participants, physically taking medicines was extremely difficult and stressful. This was in some cases related to negative experiences from childhood or of acute illness. Some tablets themselves were more difficult to take than others; some

medicines were prepared as very large tablets or dispensed in small denominations which meant many were required to achieve the prescribed dose. Others were unpleasant in taste or had to be consumed with large amounts of water or certain diet, which for some people could be a challenge. Participants explained that cancer treatments could affect their sense of taste and smell, which made some medicines unpalatable. Disrupted or reduced appetite and nausea associated with advanced disease could complicate demands on oral intake. Others reported being able to swallow tablets without any problems. The administration of *pro re nata* (PRN) medicines, which are directed for use as required, brought other considerations. Several participants who had received PRN analgesia and anti-emetics explained assessing whether their symptoms or condition was 'bad enough' to warrant using them. Some said they were unsure about how severe certain symptoms might become in the future, so they did not want to use them yet, and exhaust their options. Instead, they could ignore or put up with symptoms and save PRN medicines for when they 'really' need them. Other participants explained that their compromised organ function caused by the late effects of treatment made them wary to medicate unnecessarily.

> *" But the only thing they seemed to offer are opioids and, I really don't… until I need to take them, I really don't want to take them... I think because they make me feel really lightheaded, and because they make you constipated, I don't have enough pain to warrant them....I think if the paracetamol didn't work and I was in agony….but the side-effects, the side-effects. Because they always make me feel a bit spaced out. And constipation. So it's like, at times when I was having nausea, and…Do I feel dizzy and cope with feeling dizzy? Do I cope with feeling a bit sick? Do I have just a bit of pain that just paracetamol can cope with? – It's like a balancing act."*
> Holly, advanced breast cancer

Some participants reconciled their concerns about medicines by appreciating their clinical necessity. Knowing why medicines were needed offset their worries. This often related to an explanation provided by an esteemed HCP. Some participants had changed their attitude towards analgesia having received specific education about pain management advice and this had benefitted their daily life. One participant with metastatic breast cancer stated that she was now taking regular calcium supplements despite their disgusting chalky taste, because the oncologist had explained the seriousness of hypocalcaemia due to the bisphosphonate treatment she was receiving.

Noticing a benefit was another protective factor, which gave participants immediate confidence in a medicine. This was particularly relevant when the outcome directly promoted maintenance of desired lifestyle. Proton-Pump Inhibitors (PPIs) like lansoprazole were reported as such because they markedly eased gastric symptoms and contributed to increased or varied dietary consumption.

" I have a bit of an ulcer, so obviously, some of these tablets are going to upset my stomach, so obviously, I take two…. what do you call them?.... [goes back to cupboard gets Omeprazole] ... And that stops me getting lots of acid. I keep those separate, because if I go for a drink. Right, and I drink beer, I take two of them because they kill the acid from the drink, right. I don't take em regularly no…But …very effective…and I don't drink a lot. Anyway.: No, I don't drink a lot. If I have five pints, I'm over the top (laughs) you know that's enough for me. And I only go out once a week. And that's all I'll have. I'm not out Saturday Sunday Monday Tuesday, Wednesday Thursday…I only go out on a Friday and that's to see me friends. You know, pensioners! (laughing). I'm gonna get a bingo hall going…"
Michael, advanced lung cancer

"they've added that [Omeprazole] I went to the clinic, and they added that one in. and that has made a big, big, big difference. It seems to be on a night when I'm laid in bed that I get this, so if I do need a blast during the day, I've got me Gaviscon... But you learn to know what you can eat: like rhubarb, like lemon cheesecake, like red wine, like stuff you know that you try and avoid…people say go on! Have another red wine! Say I don't want it!... but I never drink much, don't want it. And then the other night, was right as rain so I thought 'I'll fill me boots!' (Laughs)."
Brian, advanced kidney cancer

Despite being able to articulate the need for the medicine, the absence of noticeable effect compounded questions about whether medicines were necessary.

"I wanna come off the heart one and the thyroid one... Because…I don't know whether they're doing me any good or not, no-one's mentioned to me that they're working alright. I mean, before I started teking them, I had no symptoms that I knew of...I don't know whether they're working or not. I mean, I do get out of breath a bit, when I'm walking, you know if I'm taking her out, but I don't have to stop and get my breath back, I just feel a bit out of breath. If I went for the walk, up to the waterfall, now the first bit that I have to walk up, I used to walk up it, now, I'd maybe have to stop, three times, just for a couple of minutes, just to get, not so much me breath back but, a bit of tiredness in me leg, this side, so I'd maybe have to stop for a couple of minutes and then carry on, do a bit more, but, before, well, before the first lot of chemo I was alright, I could walk, I used to walk everywhere, I didn't have a car, I used to walk everywhere, all round town, I can't even do that now, you know, since, with scarring me lungs and the irregular heart thing, with the chemo"
Leonard, advanced kidney cancer

Side-effects were a key factor in participants' evaluation of medicines. Corticosteroids, like dexamethasone or prednisolone, which are commonly prescribed in oncology for their anti-inflammatory, anti-emetic, analgesic, or immunosuppressive effects were criticised for introducing unpredictability in mood and energy levels and severely disrupting sleep, which exacerbated existing symptoms of fatigue and frailty.

"I cou'nt sleep. ...she said it can go two ways, it'll either, make you feel high, or it'll make you paranoid, or it can do this to you or it can do that you and they used to give me the prescription and I'd say – you've give me loopy pills, 'ant yer?' and they'd go yeah. And it were like two the day before, the day of the treatment and the day after. Well that were it, I just… 24 hours is a long time! I used to, well I dint sleep! Erm I used to go to work – well great cos I'm a cleaner whoosh whossh! oh god I wo like whoosh everywhere! I'll go do that, I'll do that, and I'll do windows! and id come home and id walk I here and I'd think: what can do? I thought I know! And id clean all me door, all me skirting boards. I don't know what they are called, but I hope I never have to tek em again!"

Christine, advanced cancer

A calcium supplement used as a supportive treatment for the participants with metastatic bone disease was repeatedly cited as unpalatable and several dreaded taking it.

"I take Calcium tablets, which I actually hate them. I really hate taking them. I feel bloated when I take them. I don't know whether it's the water that I've got to drink afterwards, or just the calcium. And they were that bad, because it's all chalky in your mouth, isn't it? I asked if I could have some soluble ones, which they gave me. And I took them for a couple of months, and then I decided to go back to the others because, I don't know, because I seemed to have to drink even more water wi' them. Even though… it seems like it should be so insignificant in the greater scheme of things, but it's the one thing I really hate taking. I've got to sort of force myself on a morning, to just like 'uuugh, right come on get them chewed up quickly. Now right they're done. Right, that's it! Forget about them now'. If I forget about them, and I do 'em at night-time, occasionally, but not often, I've just not taken them. Because I can't face it. And it's silly that really isn't it? Because it's just a little bit of chalk."

Karen, advanced breast cancer

Many participants said that side-effects were reassuring as they infer that the treatment is 'doing something' or light-heartedly referred to SACT as 'poison'. This confidence in SACT was linked to participants hope in therapy, but most had experienced this to change over time as cancer progressed and their health deteriorated. Participants demonstrated a hierarchical attitude towards their different medicines. The side-effects of SACT were frequently dismissed by participants as an inevitable consequence of life-prolonging treatment. The side-effects of supportive medicines intended to treat SACT side-effects or cancer symptoms were received very differently from those induced by cancer treatment. Participants had unresolved concerns about tolerating them and were less convinced of their importance as these medicines were not seen as essential to survival. For most, cancer treatment was perceived as superior, and any negative outcomes associated with therapy were accepted in exchange for possible longevity. Supportive treatments indicated to mitigate treatment-related adversities were, however, not afforded the same acceptance and participants questioned the value of tolerating them.

Many participants had experienced high blood pressure as a direct side-effect of SACT and subsequently required anti-hypertensive medication. In all cases participants were entirely accepting of this consequence, having been advised of the possibility of this adverse effect. Similarly, a participant now receiving a six-month course of anticoagulation therapy for SACT-induced pulmonary emboli was eager to continue with the oral chemotherapy. Most participants were determined to continue at the maximum dose and duration of SACT permitted and expressed anxiety about the prospect of dose-reduction to minimise toxicity. A small number of participants had experienced an extreme ill health event due to SACT and had renewed their outlook and expressed reluctance towards having further treatment.

"You'd never take anything if you read all this" - The right kind of information

Participants varied in the amount and type of information they sought about their medicines. Some were keen to know what medicines were for, how they worked, what alternatives were available and what outcomes should be expected. Others favoured a limited amount of essential detail only. One participant educated to the highest academic level of all participants expressed ambivalence about knowing what each medicine does, citing her lack of medical expertise and complete trust in medics. Several participants explained that they received a lot of education from different HCPs about all sorts of things throughout their treatment, which made them feel swamped. Participants were divided about the value of patient information leaflets (PILs). Those keen to know as much as possible referred to them often, whilst others explained that they could become another source of overload or anxiety. Participants felt deterred by the vast extent of risk information contained in PILs and found this could negatively influence their impression of a medicine and cause them to constantly expect or even imagine side-effects. Many exclaimed that nobody would ever take any medicine if they read all the information in the packet. Most participants had developed a personal approach to acquiring information, where they relied on a trusted source and details that were tailored specifically to them and their condition.

> *"It's a conscious decision [not to read PILs]. I am a worrier, so that when I take my tablets I did start to read the leaflets sometimes at first, which confused you, because by the time you get to the ones that say 'one in one thousand gets this', you know it gets a bit silly don't it, so I trust [my wife] to keep an eye on me for the symptoms. She would react to me and she would tell me 'Simon, you're slurring your words', or you know, whatever it might be. Because once again, you're not prone to get any of these necessarily, or it could be something else that's given it you, another tablet. And this is um, when you start something new, you've got enough side effects from the big sheet, like on the chemo drug, we get enough stuff anyway in advance saying what might happen, from the cancer team, but you don't want to get into depth with the 1 in 1000 problems and that from taking the tablets."*
>
> Simon, advanced prostate cancer

"You don't know what's causing what" - Discriminating between symptoms and side-effects

Participants repeatedly explained how hard it was to know whether physical changes were a symptom of cancer or a side-effect of a medicine and, if so, which medicine. This impeded the identification of medicines-related issues. Participants who were on lots of medicines, or those who described high symptom burden, found this particularly difficult. Participants explained that the combined impact of the different effects of different medicines on the bowels were difficult to monitor and manage. This was especially hard when medicines changed frequently from week to week; for example when having cancer treatment, or during a particular bad episode of pain. This was a significant source of concern to many. Some participants attempted to manage the issue by trying to titrate medicines according to their bowel function, which was particularly complicated when many medicines were used regularly. Bowel effects were particularly distressing for participants whose digestive health was related to their cancer diagnosis; either due to the initial symptoms, or the late effects of previous treatment. Several participants, who also had the most medicines in their overall regime, described this as a time and energy consuming balancing-act.

> *"It's like the Clopidogrel gives me constipation, which in a way is good because of the chemo. So, I come to me third week, it makes me regular, I'm alright. Then I start binding up again."*
> Eileen, advanced kidney cancer

Theme 3. Navigating the system

Managing regular medicines imposed logistical and administrative obligations. These included negotiating the system for accessing medicines, understanding pharmaceutical nomenclature and guidance and maintaining a supply. Participants described an onus of responsibility to get to know their medicines. They consistently demonstrated sound understanding about the individual purposes of their medicines and described the techniques for acquiring knowledge about them. However, understanding them to effectively use them was dependent on their own undertaking of finding and using their own reference system. Difficulty pronouncing medicine names and inadequate medicine labelling were barriers to recognising and communicating about medicines. Participants found alternative means of knowing their various medicines, such as recognising the medicine's physical appearance, taste, packaging or indication. Having enough medicine was a major area of concern. Participants demonstrated their personal approaches to managing their supply, which entailed stock-taking, organising replenishment, coordinating multiple repeats or stockpiling. Whilst participants valued establishing good relationships with HCPs during discussions around specific medicines, they described limited opportunity to reflect with clinicians on their whole cohort of medicines.

"The lickle white one" - Knowing medicines

Participants consistently could not pronounce the names of their medicines. They apologised and explained this was awkward and unhelpful but completely usual for them. They instead exploited other knowledge in order to communicate about their medicines, referring to the prescribing source, symptom being treated, or body part affected. Visual recognition of medicines and their packaging facilitated participants' fluency with their medicines. Many medicines were signified by the colour, size, shape of the medicine itself. Participants described getting to know their medicines by coming to recognise the colour or design of packaging. This enabled them to use medicines in the way they had been instructed. This approach could be restricted by a lack of standardisation of packaging between different pharmaceutical manufacturers of the same medicines. In addition, when dispensed in non-standard denominations medicines are inserted into unbranded sleeves supplied by the pharmacy. Though labelled, the packaging is generic and cannot be used to identify or communicate about medicines.

Participants were frequently able to describe the pharmacological mode of action of their medicines, in particular SACT. Uncertainty about why a particular medicine was indicated was notable amongst medicines which are routinely prescribed for multiple indications relating to cancer disease, its symptoms, and the side-effects of therapy. One recurrent example was the use of corticosteroids, which are used in oncology to treat pain, oedema, appetite, fatigue, suppress immunity and sometimes as an adjunct to SACT to mitigate side-effects. Participants were often unsure why it was prescribed, which alongside the difficulty pronouncing it had made communication challenging. Here both participants refer to the same steroid, dexamethasone.

> *"But, the pack they give yer, is, take three, take three tablets on a mornin', three tablets on a night and the lickle white one. That goes on for four days. Then yer miss three days, and yer just tek a lickle white one each day, from then, then yer start again."*
> Malcolm, advanced prostate cancer

> *"I did tek the sickness tablets, I had to tek it for the first couple of days, and I wo fine, they give me some other kind of tablets, I think it wor a steroid. Them I dint cope with. dint like those. Nutty tablets."*
> Christine, advanced lung cancer

'It can feel like a fulltime job' - Keeping on top of them

Maintaining an adequate supply of medicines was a primary concern for all participants. Participants mainly talked about medicines supply in the context of their repeating ongoing prescriptions. They described the importance of understanding how the medicines supply chain worked and developing intricate ways to monitor and obtain medicines. This task was complicated by the lack of synchronicity of their prescriptions and the locally diverse supply arrangements. Attending a pharmacy could be physically difficult and added to their burden. Participants

explained the many different means to getting prescribed medicines. Cancer-related medicines were routinely prescribed at each outpatient or treatment appointment. Other medicines could be started there and then continued by the GP. Medicines could also come directly from the GP, or other non-medical prescribers such as nurses or pharmacists.

Participants demonstrated extensive methods for monitoring adequate medicines stocks to make sure they did not run out. These included inventories, lists and reminders on packaging. Maintaining the supply of medicines was complicated by the lack of synchronicity between repeat prescriptions. Many participants experienced medicines being initiated at different times and then being due for repeat on different days throughout the 28-day cycle. They could rationalise why this happened, due to the ongoing nature of prescribing, multitude of prescribing sources and individual prescribing habits. However, participants expressed frustration that this unhelpful practice was so hard to address. Many were resigned to complex home records to accurately monitor stocks and multiple pharmacy contacts every month.

> *"Basically, they're about every month. Every three weeks to four weeks, but mine are...I'll get some Monday, but come on Wednesday I might want another one, because you can't get them before time. It's complicated... [reads from paper prescription] 'Next issue due, Thursday 25th August, next issue due, Monday 14th November!'. See what I mean?! You've got tablets at different times in the month, or whatever, and therefore they can't say, 'well we'll put yours to 14th.' Some'll match up. But some won't. So its just a matter of, some will …. I've told 'em once to do it all. Which she did do, t'doctor. I said 'can you void 'em all off and put 'em back in again, so I can pick 'em up at same time?'.*
> Malcolm, advanced prostate cancer

Most participants considered the logistical and bureaucratic aspects of obtaining their medicines to be stressful and add to the sense over being overwhelmed. These accounts also identified the very likely event that medicines are handed to participants by someone who is not clinical, does not know them and does not know why they have been prescribed, without any consultation. Getting hold of medicines required a tailored strategy depending on the prescribing source as different care providers applied different processes for prescribing medicines. Cancer-related medicines were dispensed by hospital pharmacists or by nurses in the treating unit. Several participants opted for a home delivery service of these medicines to avoid a long wait at the hospital after their appointment. Experiences of accessing repeating prescriptions in the community were less consistent due to different local infrastructure. Some participants made an in-person or online request to their GP or pharmacy, which could then be collected. Others had to hand-deliver a prescription to the GP, which was then to be collected and passed to their pharmacy. Due to the workload involved in obtaining repeating medicines, participants preferred longer gaps between their repeat prescriptions. However, they explained that some GPs imposed a two-month limit on advance supplies. Some participants had moved to a different GP-surgery on the basis of this

policy. Participants also explained that there was an imperative window of time within which the repeat prescription request could be made. Premature requests would be rejected, which was restrictive and irritating. Some participants described the notion of hostility around obtaining repeat or extra medicines, particularly uncommon preparations, or controlled medicines.

Participants' experiences of interacting with their community pharmacy varied. Several participants described feeling very supported by an individual pharmacist or pharmacy technician who had helpfully sourced non-stock medicines or provided personalised education. However, participants were generally not in touch with a specific individual directly. Several participants found dealing with the local pharmacy particularly difficult and stressful due to the administration and procedure. Attending in person could be problematic because of unpredictable cancer symptoms, which made it difficult to plan too far ahead and schedule trips out. Participants provided examples of the breakdown in communication between the prescriber and pharmacy, which had led to an error with their medicines. These incidents concerning GP-Pharmacy communication were really upsetting and left participants feeling like they had wasted their limited time and energy.

> *"I was in tears yesterday because it was about a week and a half ago I had to go into hospital to get these injections and they said I would need to get them every two weeks so erm so providing you took this letter in to your GP, which I duly did and the girl was very nice she said if there's any problem otherwise you'll be able to get them. I said, 'will I get them on repeat prescription?', 'oh yes' that's what the hospital had said. Anyway, she said phone up at the end of next week just for your own peace of mind, which I duly did. They knew nothing about it, whatsoever. So erm so, what was the next step? Well, on Sunday I went through my bag with the injections and here at the bottom of the bag was the prescription. I'd taken the letter in, but I didn't realise there was a prescription as well. So I took that in but, again, they still couldn't give me the repeat prescription and they were only giving me ten days'-worth and I had to give the GP a few days' notice every time I needed it. Well, this is ridiculous. Ridiculous! So, anyway, I went to the chemist afterwards and she said we'll see what we can sort out. I said will it be a problem and, again, I was a bit wobbly because you can't cope sometimes you know when you've got so much on your plate and she took me into the consultation room and 'we've sorted it all out' and, yes, well, I've to go down on Thursday to get my first lot as well as all my other stuff"*

Isobel, advanced bile duct cancer

> *"It's always the CDs [controlled drugs], you know they won't let you have one more, 'why do you need another tablet?', 'Well I dropped it on the floor', well you know, things can happen... literally you feel like a criminal if you dare ask for Pregab [Pregabilin] or a patch a day before you need it. You know, it's nice to know you have some drugs at home. Oxynorm that's it. That I would have some in the car, I would have some in my office, a bit like we complained about [my wife's] inhaler. If you are a working man you need to have one in the car cos you could have an attack in the car, one by your bed. You don't just need one inhaler, um and that's the same with the Oxynorm....My Oxynorm for breakthrough pain, I'd have a few*

in my locker, under lock and key. I've told work and I've had permission, you know just to protect myself all the time. But like I say you'd need a couple of supplies sometimes, you know, cos you get break through pain in the car 'where's me tablet, oh it's at home'. Yeah, so sometimes you need more supplies than people think. You might leave a sleeve at your great Aunty Edna's in Birmingham or something by accident."
Simon, advanced prostate cancer

The anxiety associated with running out of medicines compelled some participants to stockpile medicines in their home for the future. This included hanging onto any surplus of medicines they were currently using and not returning medicines that had been discontinued.

"I don't know if my GP even knows I've got cancer" - Regimen Supervision

Interactions with healthcare professionals about medicines varied. Participants often had close relationships with HCPs in their oncology team, particularly CNSs and Research Nurses, with whom they had face-to-face contact. This was organised according to their disease status and treatment type. Participants in receipt of SACT attended hospital at frequent scheduled intervals for monitoring, staging investigations, and outpatient appointments to review their next cycle of treatment. Those in follow-up had outpatient clinic appointments. Participants consistently described an intensive focus of consultation around the initiation and monitoring of SACT. Other medicines were less reliably discussed. Participants valued having conversations with healthcare professionals who knew them well. This encompassed understanding their past medical history, lifestyle and considering their preferences as context for their medicines use. Encounters about medicines involving unfamiliar clinicians were a source of anxiety and frustration. Having to retell the painful story of their health circumstances to people who did not know their background and repeat practical information about their specific medicines requirements was painful and annoying.

Several participants described a close working relationship with an individual Oncologist, which they felt facilitated personalised prescribing. This was most consistently reported by those belonging to small oncological specialties. A group of participants, who all attend the same Renal outpatient clinic, commented on being known by their first name. All participants stated feeling actively involved in cancer treatment decisions. However, they reported little time to discuss their use of their wider cohort of medicines at outpatient oncology appointments, as consultations were short and necessitated focus on disease progress and treatment response.

Few established relationships with healthcare professionals in primary care were reported. Many participants described limited involvement with their GP and visited infrequently, which they attributed to the inconvenience of making and attending appointments, the complexity and inconsistency of their clinical symptoms, and a perceived lack of urgency. Several people expressed doubt whether the GP even knew they had cancer. For some participants, their relationship with the GP was compromised because they considered the GP's role in the diagnosis of cancer was

unsatisfactory. Participants did not talk regularly with the GP about their everyday medicines. GP-mediated repeat prescribing was routinely conducted remotely, and participants received their regular medicines usually without face-to-face consultation. Following their initiation, maintaining a dialogue with individual prescribers about medicines could be difficult because Oncologists and GPs who issued prescriptions were not directly contactable.

Participants recollected few opportunities to discuss their medicines as a whole group. Two participants could recall a telephone review of all their medicines from the GP and two others could recall bringing their medicines into hospital at a previous inpatient admission, during which time the ward team had looked after them all. Most were unclear about who was professionally responsible for them overall. Few participants perceived their GP as the manager for their medicine cohort of medicines due to both the limited chance of them having regular contact and their lack of specialist oncology knowledge. Although participants acknowledged that lots of their medicines were not prescribed by their Oncologist, many perceived their care as centralised at the is cancer centre. This meant direct access to a named CNS or research nurse who was making decisions about future treatment. The CNS was a key provider of support, irrespective of medicines being cancer-related. If issues occurred locally, in the absence of routine community follow-up, some participants explained contacting their oncology team, as they felt they knew them best. Several participants highly valued their good relationship with the CNSs or chemotherapy outpatient nurses, for providing information and guidance around medicines use. Participants enrolled in a clinical trial considered their Research Nurse the main point of contact. Nurses were accessible and had real-world knowledge about medicines and they were aware of some of the obstacles.

> *"A daily injection of that, which was meant to be, they say three days of it or the small amount of it. And they did say you should contact the GP who would then supply everything, and the GP, er, hadn't received, it hadn't been worded…the information that came to the GP hadn't been appropriately worded and she couldn't take the responsibility of ordering this particular drug to be administered to me. And it was hell's own work to try and get anything…they don't, understandably, the ward doesn't want to know you; you're not a, you're not an inpatient any longer, you're an outpatient, so they don't want to give you any information etcetera, the GP sent an email to the consultant secretary explaining the situation – that didn't help – and It was only resolved by my speaking to my CNS who dealt with it and she, and then the doctor said 'in any case the pharmacy cant supply it, it's in short supply at the moment and they're not sure when they'll get it'. So, I mean always I recognise now I should have contacted her always first! She is my main contact and she refers me to Dr A [GI oncologist] if she thinks that's appropriate and he sees me from time to time, and it's a wonderfully helpful contact, I mean she does emails, she does telephone, but then I contacted Jen [CNS] and then I gave her details to the district nurses, who wanted to help me, but they couldn't get the vaccinations – they were cross with the GP, the GP was cross with the hospital - anyway, how it was resolved, it was resolved by Jen [CNS], working some magic. She came round in her own car!"*
> Margaret, advanced colorectal cancer

As an exception, three participants had been receiving ongoing medicines management education and supervision since their referral to a Specialist Community Palliative Care service. All three of these participants reported input related both to guidance around medicines administration, particularly the appropriate use of analgesia and medicines reconciliation. Most notably, these participants reported feeling that they had a definite point of contact for medicines, that their care was being coordinated and that medicines were consistently reviewed and refined as a cohort.

Participants questioned how effective the dialogue was between settings of care, as medicines-related interventions were routinely not communicated. Participants described scenarios when the actions of an individual prescriber were not shared with other professionals and that they felt personally responsible for passing on information. One participant explained that his long-term medicines for hypertension were recently stopped during a hospital admission for an acute chemotherapy-related illness. Now recovered, he was unsure whether to start taking this again and did not know who to talk to about it. Participants expressed their frustration about the limited use of technology for their medicines care and within the healthcare system in general. Many agreed that the introduction of online and remote resources in other utilities management was helpful, and they thought that the NHS might benefit from adopting digital communication strategies to address some of the existing problems.

> *"there's something wrong! I mean I can't understand….we have computers! I mean even I have a blimin' computer meself! I've a Mac. I've an iPad! I'm on a phone. What I don't understand is, why don't the doctors have something, for people of my age, which flashes up and says 'oh so and so..' it's only got to come up on t' screen, and send me a letter? Why doesn't something like that happen? I can understand in the days of old when it wo' all shuffle papers and they only dealt with yer when yer went. Well, this is natural, you expect that. But today, with technology. Everybody, everybody who has some illness, or even older people - and I'm lucky; I've got a family, I've got me wife, lovely. "*
> Henry, advanced prostate cancer

Theme 4. Habituation in the home

Using regular medicines at home required a reliance on habits. Despite variation in their diagnoses, symptoms, and medicines type, participants shared common approaches, which involved using fixed timings during the day and places in the home to make sure they used medicines. Establishing a recurring procedure, embedded into lifestyle, gave a stable structure for medicines to be used and caused minimal disruption. Deliberate placement of medicines in a location relevant to their ritual of medicines use was key. Dispensing medicines ahead of their use was one way to create a visual cue and associate those medicines with an activity in the daily routine. Some medicines were less easy to integrate into the daily routine and were therefore harder to use. This was because of their alternative preparation, irregular use, or specific administration directions that did not align with established habits.

"It's just become part of my day now" - Ritual and routine

Methods were based upon regular repeating processes, which were simple and easy to reproduce. Participants emphasised the importance of their method being simple and embedded into normal life. Several participants explained that taking medicines as part of a breakfast, for example, allowed them to keep medicine-taking routines as simple as possible. Many participants described doing the same thing every day. This was a reliable structure for medicines taking which they felt in control of and had confidence in their ability to take their medicines appropriately. Participants explained that medicines use typically required them to follow set times and actions, throughout the day and so they had developed time-stable daily system, which had become habitual.

> *"So, the way I do it is, uh, we usually wake up about seven o'clock and one of us will get up and make a cup of tea to drink in bed ... bring the tea to bed and put four tablets in this dish and that comes up. 'Cos I always have a glass of water by the bedside. And I take those, so say that's usually about quarter past seven. Um and then really we get up by eight o'clock, so then we'll be having breakfast about quarter past, half past eight and that's OK because it's over an hour from having taken that one. And basically, what I do, ..I sit here and I have it there and I take them after I've had breakfast. We usually have porridge, something like that, you see, so having done that I then take them all out and then take one, I usually that that first, that second, third, fourth... it's just a habit, you know."*

Timothy, advanced prostate cancer

> *"It's just part and parcel of, it's just the same as putting the toast on, after a while, you know, after a while you just get used to it... part of me breakfast is that now, yeah. It just becomes habit forming, yeah uh, and you just, I never think about it."*

Tony, advanced prostate cancer

Some participants explained how they did not make major adjustments to their day to accommodate medicines. Instead, they would do normal things and then make medicines work around that. This meant sometimes not taking medicines at certain times. Attributing medicines-use to a specific activity facilitated remembering. Many participants referenced the habit of using medicines at mealtimes, or with hot drinks. This consolidated the idea that medicines have a 'home'. Keeping medicines in the kitchen for example, supported the link with dining, which aided both memory and the direction to consume medicines with food. This was complicated for participants who, because of their disease or its treatment, had difficulty desiring or eating meals, or lacked a specific mealtime routine. The absence of daily structure for medicine-use compromised remembering. This was more notable in people living alone who did not share a mutual routine. Likewise, participants with demands on their time due to their working pattern or childcare explained having more difficulty establishing a structure.

"I just have them all on here" - Conscious Placement

All participants used a central storage location for their entire supply of medicines. Some participants dispensed directly from this source. The majority of participants also had a smaller collection of medicines in a convenient location elsewhere in the home for daily dispensing. Meticulous organisation of the dispensing collection was observed. Medicines were collected in a range of containers including recycled tubs, cartons, and boxes. Medicines were commonly separated according to prescriber, with documentation stored alongside respective medicines. Three participants used privately obtained compliance aids to help them store, organise and dispense their medicines. These participants found their devices useful in accommodating multiple medicines and doses throughout the day. They felt they had taken control of their system which had previously been complicated or time-consuming. Other participants had avoided compliance aids, arguing that they created additional work or were no use for large tablets, or unstable or toxic medicines that cannot be unsealed and handled prior to administration. Their whole cohort of medicines could not be put together in a single device.

Figure 7. Jack 'I can't believe it's not butter'

"I keep everything in here… together in a box and they're in the top shelf of the cupboard in the kitchen."
Jack, advanced colorectal cancer

All participants had a designated place for their medicines. Medicines supplies were commonly located in drawers, cupboards and on work surfaces throughout the home, in a room linked to their daily routine for medicine taking. For example, those who took morning medicines in bed with the first cup of tea kept medicines in or on their bedside table. Daytime medicines were often kept on

the coffee table. Participants demonstrated a range of storage scenarios indicative of their organisational preferences. Some participants included methodical medicines storage as part of their overall inclination for order. Those less concerned with visible 'tidiness' still assigned a dependable place for their medicines management system, which though apparently chaotic was useful for them. Participants used intentional visual cues, which could then prompt remembering. Actions such as leaving compliance aids on the living room coffee table all day, or placing medicines next to the kettle, proved reliable to many participants.

Figure 8. Rosalind's coffee table

Some participants put their medicines out in advance of their administration in preparation for the following occasion, by placing them directly onto a surface or into a receptacle, or within a compliance aid. Visual cues also helped people recall if medicines had been used. Several participants shared the experience of taking medicines but then subsequently questioning if that had happened. Again, this had been addressed by introducing a visual aide-memoire to signify if medicines had been used, either putting the used box in a different place, or orientating the packaging in a certain way.

Figure 9. Henry's jewellery box

"Now it did break down at one point.... I was over there, I'd taken those, and I had that one out on the surface there and something had cropped up, cos I usually have the radio on, and we had been talking and I suddenly said, 'have I taken those or not?' you see because I'd taken it out but I couldn't remember whether I'd taken them or not. So I rang up [CNS] and said 'I don't know whether I've taken them or not' and she says 'oh well don't take any more cos that if you do, if you were doubling up you could'. So now I'm more careful but well, you know….I only take it out when I'm ready to take it. So I take it out, take the top off, get the tablets out, and put the top back on, yeah, so I know where I'm up to."
Timothy, advanced prostate cancer

"It's a little bit a pain in the backside" Dealing with outliers

Regimen complexity was perceived to relate to the inconvenience of specific administrative directions and difficulty integrating medicines into lifestyle, rather than the number of different medicines prescribed. Participants explained the challenge of managing medicines due outside of the established routine, or not associated with specific activity. Remembering pre-meal medicines was difficult and some participants acknowledged the likelihood of unintentional non-adherence.

" it's like my sickness tablet, I forget to take that. I don't feel sick. I'm supposed to take it before food…so that I'm not sick… And it's like, sometimes I'll have me tea and I'll be alright and I'll go to bed and I'll think 'oooh God, I feel sick, oh God, I forgot to take me tablet. It becomes….what it is, it's a little bit a pain in the backside, having to remember to take a tablet half an hour before you eat. Because normal thing is: if you're hungry, you eat. End of. It's not: I'm hungry 'oh, I've gotta take a tablet, before I eat!"
Tom advanced prostate cancer

"that's quite important, because we had to have regular mealtimes, so that I could get this pill in, half an hour before… and that was again problematic, because say, 'oh today I think I'll have supper at seven, but you know the carer has got everything sorted for 6. So you know, But. I was lucky to have a carer at all of course! But there are problems with that synchronisation… it's easily done [forgetting] because say you're having a good morning and you're not thinking about – well particularly me if you're trying not to think about lunch, the last thing I want to think about is food! But anyway, that all got sorted out… I got better at it, I got better at it, and yes, practice made perfect. And I knew my carer was going to go and I had to manage to deal with this! And I wanted to get as well, as fit as I can be and that is my aim, to be as it as I can be whatever that is…and nobody, nobody knows that. So the determination drove me on."
Margaret, advanced colorectal cancer

Some participants evaded this issue, by ignoring the direction to take medicine before eating. Many participants described taking their gastro-protective medicine, which is directed for use on an empty stomach prior to medicines and meals, with breakfast and all other morning medicines. Though they knew this was not directed, they rationalised that it was much simpler this way and because the medicine had continued to work when administered in this way, it was fine to continue this method of ensuring it was remembered. Medicines between meals were similarly difficult to remember. A common example was steroids due mid-afternoon. This could not be brought forward due to the proximity with other earlier doses and could not be delayed due to the likelihood of inducing insomnia, leaving only a small window of opportunity to use this medicine. Remembering to take medicines was also connected to noticing a tangible physical effect. Medicines which brought instant symptom relief were much easier to remember to use than those where there is no immediate perception of benefit.

Transdermal patches were hard to remember because they do not follow the same dosing schedule as oral medicines. They are typically repeated every 3 days, or 7 days, so the day can change from week to week. They are also temperamental, falling off in heat or in the shower, imposing an immediate patch change and thus altering future replacement dates. The renewal schedule which differed from other medicines made it difficult to incorporate patches.

"I change it Saturday mornings and Tuesday evenings. Now I've remembered now –' it's Tuesday' - but come this evening, I'll totally forget… I just realise suddenly and think oh I didn't do that so… …I mean I went a week, where I'd just totally forgotten about it, and then one day that I thought oh I ant put me patch on! It were when I'd had a bath. And by time id got done it'd forgotten, and it just went out me head and about a week, I went without one and I knew about it!"
Eileen advanced kidney cancer

Simon used one of his wife's haberdashery buttons to indicate the time-point that the patch is due to be replaced. The button can be easily moved, and fits into his existing system.

Theme 5. Adapting and adjusting

Establishing and maintaining responsibility for medicines use required an overarching responsive and resourceful approach. This dynamic self-management involved learning the skills of practical medicines management, making compromises in everyday life, reacting to changes and disruptions, and creating stabilising methods which help people to forget about their medicines as much as possible. Becoming regular medicines users had involved and still required acquisition of administrative skills and practical techniques. This could be haphazard due to the different processes in different settings and the different impacts of individual medicines, with limited specific supervision. Making necessary modifications to their lifestyle and mindset had also supported their accommodating medicines. Knowing their system was likely to be disrupted by changes in medicines or breakdowns to the process was key. There was also a connection between the effectiveness of personal strategies and general health and wellbeing. The presence of medicines in the home was a regular reminder of cancer, having to replenish and remember medicines, having to evaluate their use, all contribute to a mental load of medicines use. Creating and sustaining a seamless system for self-management allowed some escape from this.

"It was a case of trial and error" - Developing expertise

Participants described how their medicines management practices had been developed over time, and they had developed a habit. They had not received specific tuition or practical guidance to support medicines use at home. Several recalled being daunted by coming home with new medicines without clear education about materially using them or combining them into their existing regimen. Though they had interacted with HCPs about whether to try a medicine, or why a medicine might be beneficial, conversations did not explore how to use them. Learning how to deal with them at home was a process of trial and error. Many explained forgetting to take medicines or running out of them, before figuring out techniques to manage.

> *"With my tamoxifen, I used to put a reminder on my phone until I got into the habit of taking that."*
> Holly, advanced breast cancer

Several participants explained the lack of support for medicines practical use. They referred to the process of learning a way of using medicines. Some, who described themselves as naturally methodical or organised, found that developing a system came easily. For others, the approach was learned via experimentation and refinement. Some participants could not pinpoint having intentionally developed their routine and instead described doing what needed to be done, by 'going through the motions'. Amongst the participants who cohabited with other adults, receiving support from others in the household had helped initially. This included gentle reminders and collaboration when someone else in the household also used medicines.

Participants demonstrated some specific proactive approaches which practically facilitated their medicines management system. Several participants opted to personally annotate their medicines packaging with information that they felt was relevant for the use of that medicine. This was detail that was lacking, or an alternative description of information already present, such as specific administration directions. Participants said this could minimise confusion.

> *"The names don't mean a lot to me, but - 'Ring the ward if diarrhoea' - you see, I've found that absolutely marvellous really...I mean you look at the tablets and I mean you got ..Loper..Loperamer…Loperamide..and that [metoclopramide] ends in an 'amide' don't it? and they're for different things. So I found that, that was good writing on those boxes."*
> Jack, advanced colorectal cancer

Others described their long search for the right personal compliance aid to meet their specific needs. Participants had developed their own administrative processes, in view of the known difficulty of transferring medicines information to healthcare professionals. Some participants stored key information electronically on their mobile phone. This accessible list helped during encounters with other healthcare professionals and served as an everyday reminder. Many took further steps to seek the best medicines experience for themselves. Some participants attempted to reduce medicines consumption by simulating their effect by alternative means such as a dietary change, for example eating lots of vegetables to avoid administering laxatives; or introducing oily fish and red meat after years of vegetarianism, instead of taking vitamin and mineral supplements; and drinking commercially available energy drinks instead of prescribed nutritional supplements.

> *" I just saw this [Redbull] on the shelf, I picked it up and read it and I thought 'well it can't do any harm!' it was one pound twenty-five and I thought well '£1.25, its nothing is it?' have a try. So I'm trying. I thought I was better after I'd had it, but I wouldn't swear…I wouldn't say to anybody,' ohh you want to take that'…so I've only had one. And yesterday I bought 5 and I'm gonna take one when I go out today."*
> Henry, advanced prostate cancer

> *"because I got constipated after the anti-sickness pills and then it turns the other way em it but just recently I've been making a lot of vegetable soup and I've not had to have the Movicol I'd rather take it naturally because I've got so many other things I mean I've got my high blood pressure stuff and my Omeprazole for my erm hiatus hernia and Gaviscon and stuff so the least stuff I can take the better [yeh] so I've been making a lot of homemade vegetable soup, which I love anyway."*
> Isobel, advanced bile duct cancer

Others sought additional complementary sources of medicines, purchasing herbal or homeopathic preparations privately. Some participants felt frustrated by the lack of clinical guidance for this, and perceived healthcare professionals to not acknowledge or appreciate their desire to help themselves.

Figure 10. Christine's herbal supplements

Some participants established their own innovative solutions to manage medicines effectively. These personalised touches all supported memory and participants had confidence in their approaches, easy to understand and operate. Many participants demonstrated a proactive attitude towards the integration of medicines into their lives, describing problem solving and exhibiting practical innovations. Participants explained devising specific techniques to overcome obstacles related to medicines familiarisation and administration.

> *"Routine and be tolerant. Nobody's gonna hurt yer, and everybody I have met have been absolutely wonderful and helpful and so there's nothing to be afraid of. As people say – just keep taking the tablets! That's all you can do, and but a brave face…put a bright face on it! I wont say brave face. Put a bright face on it. It's far better than being down all the time about it. It's your attitude, how you feel and how you cope with it. They're there to help you rather than not help you… So yeah, just keep taking the tablets."*
> Brian, advanced kidney cancer

"That's the price to you have to pay…" - Making sacrifices, feeling better

Participants explained that they had made lifestyle changes to accommodate medicines administration, acceptance and use. These ranged from seemingly minor amendments such as dietary alterations to avoid contraindication, to significant changes, such as the curtailment of activities.

> *"I'd never go anywhere until I'd taken them. I'd always be in to take the Capecitabine. I wouldn't plan to do anything until after that.…I mean have you seen em'??? I aren't sittin' in public with all these …(pause). I'm not sure if I have taken them out with me once or twice. Or if it's just my paracetamol and*

anti-sickness that I take out ...because they're so big and disgusting….and they'll say 'oh, try putting them in orange juice'….I wouldn't recommend that to anybody…bloody awful. Because they're just so big I find I have to have a gallon of water to get 'em down."

Holly, advanced breast cancer

The side-effects of medicines themselves could impose lifestyle changes. These restrictions exemplified the modifications people make in their lives when they have cancer that is not going away. On the other hand, medicines provide relief from side-effects or symptoms, and allowed them to enjoy lifestyle this that they had previous withdraw from.

"Of course. it can all go out of the window!" - Things fall apart

Participants explained that despite feeling like they had a reliable approach for medicines use, things could easily fall apart when their routine was put under strain. Though prescribing changes were commonplace, participants described how awkward it could be to implement changes to the dose or type of their medicines, especially if the overall system has been entrenched for a long time. The system could be disrupted when they personally felt under stress at home. This included unplanned or unsettling events, such as a bereavement or hospital admission.

"I didn't not take the tablet, but I didn't take them like on a regular time. I lost, well, I'm not saying I lost the will to take them, but what I'm saying is, I maybes...See when I get up on a morning, I take some of 'em before I have me breakfast and I take the rest after... but there was few days over a period of two or three weeks [after wife's death] where I'd get up, I'd take me tablets before me breakfast, and I'd think 'oh'. I did find it hard to adjust. Now I just get up on a morning, get me tablets, get me breakfast, stick the telly on. But the first few months, it just seemed as though I didn't have the time, it took a while."

George, advanced colorectal cancer

Misunderstandings and delays could also threaten the routine. For example, participants referred to developing understanding about the organisation surrounding medicines supply, and strategies to manage reordering which pre-empted disruptive incidents. Many participants had example of things going wrong with pharmacy and these encounters influenced their subsequent approach.

" yeah, yeah mmm and I mean it is so easy. I order online, because we had problems over that: not last time but the time before, it infuriated me, it really did. I'd ordered them all, 6 different sets of tablets and said please send electronically to [Chemist] which is what they're supposed to do. They sent 5 electronically and printed one out on a paper and left it in [another town]. So when I went to pick my prescription up from the chemist, I said, 'I'm short here' And of course they were like 'oh sorry lets have a look t your prescription, da de da de da, this is the script that's come through from the doctor. These are what the doctor's put on. Ring doctors up. Of course the receptionist says ' Oh the doctors printed one item out so you've got to pick it up, up here!' and the other five are….'Ridiculous!'. So I wrote to Practice manager and

complained about that. They were having problems at the practice…I've done it meself, you sort of apologise and blame it on whatever, don't you? But I did get it sort it out. And the chemist now are also extremely good on here, so I always, when I do, when I order my prescription – was I last week or the week before? I think it was, I just put on the note, 'please send all items' – and I did it in capitals! – (laughing) PLEASE SEND ALL ITEMS ELECTRONICALLY TO [CHEMIST]' and as soon as they'd made it up they delivered it! Its brilliant, its brilliant, when it works like that its brilliant."
Lillian, advanced lung cancer

"I can forget all about it" - Creating freedom

One key motivation for maintaining a viable system for using medicines, was the opportunity it gave to stop worrying about medicines altogether. Several participants agreed that having a reliable routine and methods for medicines use, were ultimately a means to forgetting all about them for the rest of the time. This was perceived to create a sense of freedom, whereby participants could go about their daily lives, getting on with normal things, and medicine use was integrated into their activities. Many participants demonstrated eagerness to support themselves with their medicines, which was often was expressed as a determination for control and certainty. Participants enthused about the thought, time and energy they had invested in sorting out their medicines and exemplified measures to use, store and obtain medicines effectively.

"you don't have to take them first thing in the morning but for me that seems to work fine cos then I forget about them, for the rest of the day... it's easier just to make sure I've done it if I do it that way than if I had to remember to do them later in the day or remember to take some of them at lunchtime or some in the evening, you know that would be more complicated and therefore more likely to go astray than if I do it all first thing in the morning. And the fact is, if it was later I might have gone out and come back, be late back, and you know, all sorts of things, might be out for the day, you know, whereas I'm always going to be here for when I wake up or when I having my breakfast.
Timothy advanced prostate cancer

Participants with multiple medicines, outlying medicines, or a less predictable routine found this harder to achieve. Remembering to use or obtain medicines felt burdensome and a constant reminder of cancer.

"I do an inventory of what I've got. And then I know, they won't give me these now because I've still got twelve days etcetera. So you ring, you make an appointment to speak to the duty doctor, who eventually rings back, but he keeps you in all day because you're waiting for this, and then it's done, fair enough. But it's a perpetual reminder of your health, and I've spent far too long thinking about my own health and myself, I don't want to, and I do it as little as possible! There are more interesting things in life! But, it brings me back to me, my medication, my condition"
Margaret, advanced colorectal cancer

4.4 Discussion

4.4.1 Summary of findings

The findings of this study provide new understanding about how people living with advanced cancer manage their medicines at home. The evidence illustrates the complex and multifaceted self-management endeavour entailed. Five themes summarise the detail and nuance of this experience and demonstrate how medicines use is intricately embedded in the unique physical and emotional burdens endured by having cancer that is not going to go away. In response to the vulnerability imposed by advanced cancer, people adjust their lifestyle and expectations, adapt to physical changes, and maintain a commitment to living as normally as possible. Using medicines is a key feature of this adjustment and was shown to relate to three core areas of responsibility. Negotiating with medicines, describes the work people do to get along with their medicines by accepting, acquiescing, and confronting uncomfortable feelings about them, to maintain a viable ongoing relationship. People were found to undertake complicated evaluations about medicines, which are influenced by their association with disease, side-effects, and their impact on the rhythm of normal life. Navigating the system of medicines, explains the required development of functional knowledge of medicines, meticulous awareness of supplies and use of precious energy to replenish stocks. Habituation captures the ritualisation of activity in the home, necessitated by sticking to a stabilising, practicable daily schedule for medicines-administration. Developing and reinforcing these areas of responsibility demands a proactive effort. Operationalising medicines management is accomplished by gaining knowledge, pre-empting, or addressing potential administrative or practical disruptions, and using personally relevant, robust techniques. This learning curve is not necessarily restricted to the initiation of a new medicine, but an ongoing response to the ever-changing circumstances of life with cancer and medicines, which allows normal life to flow and function, and medicines, in some way, to be forgotten about.

The themes of evidence provide a conceptual summary of what using medicines whilst living with incurable metastatic cancer is. A diagrammatic representation of these concepts is shown in Figure 11. This depicts the central immutable reality of advanced cancer which governs daily life. It then shows the relentless, unnegotiable responsibilities of medicines management, and their dynamic interplay, self-management activity. This involves pre-empting and dealing with various disruptions caused by cancer, the medicines, or the system within which these things are situated.
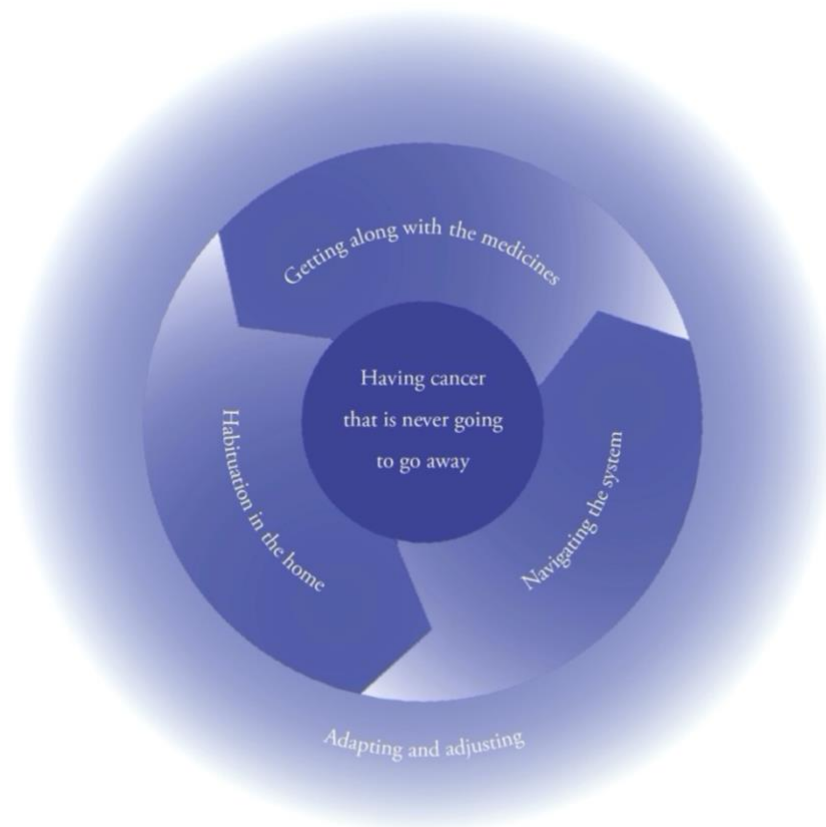
Figure 11. Conceptual description of living with advanced cancer and using medicines at home

The review of research literature presented in Chapter Two, provided a summary of existing evidence, using the outcomes for understanding people's experiences with medicines suggested by the first principle of the Medicines Optimisation Framework (RPS, 2013). These outcomes concentrate on people's engagement with their medicines in everyday life, their beliefs and preferences about medicines and making shared choices, effective medicines-taking and sharing medicines experiences and impacts. Returning to the synthesis helps to connect and compare the new findings in this study with the evidence base. There is overlap between the findings of this study and evidence identified in both the literature review and the broader research field. In addressing some gaps in understanding about people's experiences, this study also adds rich new understanding about management of a whole regimen of medicines, in the context of indefinite cancer. These new insights relate to people's understanding of medicines, their practical approach, the physical impact of medicines, access to and renewal of a repeating supply, and the interaction between medicines use and the core aim to maintain a normal life.

Participants in this study were highly engaged in the responsibility of medicines self-management. Like some previous studies, this research found people to well know the reason medicines have been prescribed (Klein et al., 2013 Yeager et al., 2012; Wickersham et al., 2014). People were simultaneously found to experience significant difficulty pronouncing or recalling long,

unpronounceable, unintuitive pharmaceutical names and abbreviations (Schumacher et al., 2002; Sand, et al., 2009b; Campling, et al., 2017; Klein, et al., 2013; Yeager et al., 2012). Likewise, medicines labelling was found to be inadequate. As other authors have observed, people living with advanced cancer experience medicines packaging to consolidate the barriers to knowing medicines (Stoner et al., 2010; Campling et al., 2017; Schumacher et al., 2002). Like both Camping et al., (2017) and Schumacher et al., (2002) demonstrated in people's use of analgesics, this study highlighted that people overcome the challenge of recognising their whole cohort of medicines by relying on their indication and the appearance of their packaging and using annotation systems to support their familiarity. In exploring the practice of medicines regimen use, this study added richer context, set in the home, to the importance of understanding what specific medicines are for, amongst a whole collection. These findings highlight how people get to know their medicines intricately, adopting personally helpful ways to relate to them. This involves moving beyond medicines nomenclature towards a physical familiarity, which rather than signalling an ignorance about medicines indication or administration, instead unlocks their ability to manage them. Developing this functional knowledge about medicines is crucial in being able to plan, talk about, and use medicines and thus engage with the core areas of medicines use responsibility. It is potentially extremely challenging and frustrating when this currency by which people know their medicines, such as the packet, colour, or denomination is changed. The first principle of the medicines optimisation good practice guidance (RPS, 2013) separates the outcomes of knowing what medicines are for and taking medicines as agreed. Yet these findings indicate they are inherently connected. The habitual use of medicines in the home is not simply an intellectual enactment of the prescribing rationale but is underpinned by this physical fluency with medicines.

These research findings also demonstrated the extent of peripheral and preparatory work that is entailed for medicines 'taking'. Managing medicines use during advanced cancer is a type of work that people do to manage their wellbeing. Studies specifically about pain medicines management highlighted the necessary responsibility and competency for a series of practices including obtaining prescriptions, understanding, organising, storing, scheduling, remembering, and taking medicines (Schumacher et al., 2002; Campling et al., 2017). This current research adds insight to the key areas of responsibility to enable medicines use and highlights how it applies to a whole cohort of medicines not just analgesics. This work adds detailed description of this medicines work and describes its intricate association with the perilous, tumultuous everyday world of living with advanced cancer.

As discussed in Chapter One, the concept of medicine use as 'work' has been described previously in the context of chronic illness. Corbin and Strauss (1985) identified 'medicines-taking' as the regimen work that varies with illness trajectory and everyday life and alongside other labours of chronic illness. In specific populations this medicines work has been outlined in detail (McCoy, 2009, Cheraghi-Sohi et al., 2015; Huyard et al., 2019). Most recently, in relation to unintentional

non-adherence, Huyard et al., (2019) characterised the routinised processes involved in medicines use and described their being challenged and disrupted in affecting the ultimate outcome of medicines use. One key similarity of this work was the observation that time-stability was not necessarily linked to clock-time but fixed alongside a sequence of actions and a relevant physical placement that turn it into a routine. These authors also observed the phenomena of people not needing to remember, not feeling they will 'forget', due to automatic following of the routine that works (Huyard et al., 2019). Cheraghi-Sohi et al, (2015) extended the conceptualisation of medicines as a type of chronic illness work by focusing on the broader social context, networks, and influences and identified this personalised, contextual multifaceted entwinement of medicines work in life. The authors concluded that work processes and necessary personal infrastructure included: medicine-articulation, the planning and coordination and taking; surveillance, keeping track of supplies and progress within the daily regimen; monitoring, for the occurrence of potential errors in dispensed medication; emotional, gaining reassurance and support from social network members; and informational, which primarily occurred when medicines where changed or new ones started.

One aspect of the work of medicines use identified by this current study regards the systematic strategies of routine, ritual, and repetition, which enable people's to use medicines. This is formed through use of consistent locations, cues and according to individuals' daily routines. These results reflect observations amongst people using pain medicines (Schumacher et al., 2014b; Campling et al., 2017). Schumacher and colleagues described the "ongoing problem-solving" of medicines management and the 'unending work" of using analgesia (2002; 2014a and b). Rather than the chaos suggested by Stoner et al., (2010), this research highlighted people's highly ordered arrangements and use of personally viable systems which embed medicines use into their exiting routine. These habits provided security and control amidst the underpinning destabilising background of advanced cancer. In exploring medicines use in the natural home environment, rather than a clinical setting the research has also illuminated the complex and messy reality of everyday life which medicines inhabit. What might look like disorder or a haphazard approach was here often a deeply relevant strategy which enabled using medicines with maintenance of independence. Elsewhere in non-cancer chronic illness research the crucial importance of routine-based strategies as means to independence and control in medicines use are described (Bytheway, 2001; Wolf et al., 2011; 2016) as a key concordance factor. The focus of concordance on prescribing should therefore acknowledge the importance of people's life routines. Wolf et al., (2011) found that addressing inefficient consolidation of regimens by implementing standardized instructions could potentially help people routinise and take their medicines. May et al., (2009b) talk about how medicines need to be minimally disruptive. This research also added how there are disruptions to the system, incurred by the disease volatility, errors or obstacles in the medicines supply chain, for example. This echoes the findings of other research findings which explains medicines use routines being challenged and disrupted (Bytheway, 2001; Huyard et al., 2019). The

absence of specific coaching or education around the practical techniques for medicines use was reported universally. All people in this study established their own methods, following their attempts to use medicines at home. Only Schumacher and colleagues (2002; 2014a; 2014b) in relation to managing analgesia have pointed out the significance of this. A new finding in the context of living with metastatic incurable cancer in this study was that many participants demonstrated simple solutions to overcome some of the tension and effort. These were vital in implementing their medicine use; and in enabling escape from constant thinking about medicines.

Like other research, this study identified the challenges people experience related to coping with many complex and simultaneous symptoms. Having so many medicines means that being physically vigilant is very challenging. Other studies, too, showed people with cancer are aware of what symptoms mean and what medicine is causing or treating what (Klein et al., 2013; Sand et al., 2009; Schumacher et al., 2002; Schumacher 2014b; Campling et al., 2017; Yeager et al., 2012). This is particularly impactful for people living with advanced cancer who are living with uncertainty and are highly tuned into what is happening in their body. One novel finding amongst this group of participants was the effect of a whole combination of medicines on bowel-care. Maintaining regular healthy bowel function was now a major consideration in medicines users' everyday life. The individual effects of types of medicines have previously been explored (Bell et al., 2009; Farmer et al., 2018 CRUK, 2021; Gibson and Keefe, 2006; Andreyev et al., 2014). However, examining the use of a whole collection of medicines highlighted the difficulty of self-monitoring the various effects when using many medicines together. The evidence about the combined digestive impacts of medicines is new in this advanced cancer context. The resulting preoccupation and effort to mitigate the impact of concurrent medicines on the bowels is a key facet of the experience of using medicines.

The findings also highlight the work required for people to obtain their medicines. Other studies have observed discontinuity and disintegration of the medicines supply process, caused by poor communication, resulting in dispensing delays and mistakes (Stoner et al., 2010; Campling et al., 2017; Schumacher et al., 2002). The Medicines Optimisation first guiding principle outcomes do not acknowledge this vital aspect of people's medicines management experience. Using medicines as agreed involves having them in the first place, which this evidence shows has huge logistical implications for people living with advanced cancer. The insight generated in the research provides important emphasis on the significance of these issues for people living with incurable metastatic cancer, who will take many medicines for the rest of their lives. The lack of synchronisation of multiple prescriptions is a source of great inconvenience and stress. Monitoring multiple prescriptions throughout the 28-day cycle of repeating medicines, forces people to record detailed inventories and negotiate contradictory local arrangements. In this specific context this contributes to becoming emotionally overwhelmed and drains precious energy. Continually tracking medicines also necessitates constant thinking about medicines and restricts any sort of escape. The research

also provides new evidence related to people's perspective about why their medicines might mount up. The enormous quantity of medicines that people acquire in their home was here found to be central to their medicines management experience. The number of different prescriptions can easily escalate, and people feel this is out of their control. The pattern of consequential prescribing associated with symptoms and side-effects was perceived by participants in this study as an inevitable consequence of cancer.

The Medicines Optimisation first principle outcomes refer to people's choices about medicines (RPS, 2013). Like observations of wider medicines literature, the findings of this study indicate a complicated picture regarding choices about medicines use. They confirm previous research that people living with advanced cancer do not want to take a lot of medicines, (Zeppetella, 1999; Schumacher et al., 2002; Yeager et al., 2012; Klein et al., 2013; Wickersham et al., 2014; Milic et al., 2016; Campling et al., 2017). Other studies also previously identified this complicated picture fraught with internal conflict (Schumacher et al., 2002; Sand et al., 2009b; Yeager et al., 2012; Klein, et al., 2013; Wickersham, et al., 2014; Schumacher et al., 2014a; 2014b, Campling et al., 2017). Amongst people living with advanced cancer, deliberate omission was reported to avoid side-effects of poorly tolerated medicines and as an indicator of asserting control and agency and rational self-management action (Zeppetella, et al., 1999; Sand et al., 2009b; Yeager et al., 2012). In this study, people made a complex assessment involving numerous factors including side-effects they have experienced themselves or heard about from others, whether medicines are helping, if their symptoms are bad enough, the taste of medicines, and the ease with which they integrate into the daily schedule. These assessments are sometime connected to maintaining activities and routines that are symbolic of normal life. Some medicines indeed promote normality, by increasing energy levels, or eliminating unwanted symptoms such as pain or incontinence. However, others pose a clear threat to sustaining function, by interrupting sleep or disturbing appetite or interfering with bowel health. By investigating medicines use as a whole regimen, this study also exposed clear discrepancies in the relationships people make with different medicines. Supportive medicines, intended to help people to feel better, were often evaluated negatively, due to the criteria discussed. Conversely, cancer treatments with severe side-effect and risks escape these judgements and are highly regarded and used unquestioningly.

Reflective about their inevitable decline, people living with advanced cancer were here shown to focus on maintaining connection with 'themselves'. A striving for normalcy is known to underpin people's experience of advanced cancer, who governed by uncertainty, adjust by developing coping strategies which encompass positivity, engagement in life-endorsing activity, and hopefulness (Ryan et al., 2005; Coyle, 2006; Lin, 2008; Bertaro et al., 2008; Nissim et al., 2009; Dale and Johnston, 2011; Sjövall et al., 2011; Harley et al., 2012, Garcia-Rueda et al., 2016; Arantzamendi et al., 2020). Taking charge, is specifically recognised as a key outcome for people who are dealing with incurable cancer. In medicines management, this attempt to retain agency and practical independence is also

apparently applicable. Outside of cancer care in chronic illness, this has been observed as the motivation for the systematic approach to medicines (Bytheway, 2001). The approach to the work of medicine use in advanced cancer it would seem, is deeply connected to this important maintaining of self. Consequently, an appreciation of the medicine use by people living with advanced cancer, can only be fully understood by confronting this context of living whilst facing death (Coyle, 2006). Webster et al., (2009) discussed how medicines are social objects within the social phenomenon of medicines use and highlighted the importance of people's perspectives on medicines and how they should be situated within their personal health narratives. This research, found that medicines use is embedded in the social conditions of advanced cancer illness, its healthcare and everyday life, as Webster, et al., (2009) previously reported in other chronic illness.

4.3.2 Strengths and limitations

A major strength of this study is the involvement of people living independently with incurable metastatic cancer. Previous research about medicines has excluded this population and considered specific stages of the disease trajectory which are easier to delineate such as the start of a new cancer treatment or the end-of-life. Where studies have included people living with metastatic incurable disease, samples have been broad and inclusive of other diagnostic stages, therefore making it difficult to ascertain specific issues characteristic for this population. This study has attended to the essential complexity of long-term cancer, where medicines use occurs. The research sample included a group of participants with various primary cancer diagnoses, different disease extent and a range of duration of illness. Useful insight into some experiences with medicines are afforded by these personal accounts. However, the sample is not sufficiently large or varied to make generalisations. A limitation of sampling was the exclusion of certain cancers and tumour types, which means that some specific experiences are not included. For example, everyone involved in this study could swallow oral medicine. Including people living with upper gastrointestinal or head and neck cancer may generate rich data regarding the complexities associated with using medicines in different preparations or via different routes.

The study also excluded people who used pre-filled compliance aids supplied by a pharmacy. This prevented the opportunity to compare experiences of people self-dispensing their medicines with others who are using compliance aids. The current study has generated some insights into the management work associated with independently-maintained compliance aids. Inclusion of participants with pharmacy supplied compliance aids may have added richness to this discussion and the results are limited by this exclusion.

The unpredictability of the recruitment process limited sample variation. Other than primary diagnosis, no information about individuals attending clinic outpatients appointments was available in advance. The reliance on busy HCPs to facilitate recruitment created challenges. Some clinic coordinators liaised directly with the researcher prior to the clinic, to assist with this evaluation.

The variation in individual HCPs approaches made it easier to recruit people from some diagnostic groups than others. Thorough and consistent communication was maintained with recruitment hosts to try and mitigate the impact of this on the sample composition. Recruitment became more focussed over time as the sampling frame was populated and gaps in sample variation arose. Targeted sampling was facilitated by communicating required sample parameters to supporting HCPs and attending specific oncology outpatient clinics. Recruitment was restricted to a specific time frame. Towards the end of the recruitment phase, activity focused on key clinics to improve inclusion of underrepresented diagnoses. This focus on diagnostic variation however, distracted from an imperative to achieve demographic differences. Therefore, cultural diversity was neglected resulting in an ethnically homogenous study sample.

Another limitation is the potential bias introduced by the sample of participants interviewed. Those who participated were committed to medicines use, engaged with them and were eager to talk about them. It is likely that inclusion of other participants with different attitudes would have impacted on the findings of this study. Further, the study did not include the perspectives of carers. It is evident from the interviews conducted that other members of the household often participate in supporting medicines use, even when people 'take' their medicines independently. Where carers were present in these interviews their contributions could not be included due to the absence of ethical approval. The research findings would have been enhanced by including the experiences of carers.

Undertaking a single interview meant that this study could not capture variation in individuals' experiences over time. A longitudinal approach was considered inappropriate for this study because of issues of time, sensitivity, and relevance. The research was not so concerned with the process of change and sought instead to capture a snapshot of what people are doing. Instead, variation in experiential evidence was achieved across the sample of participating individuals.

Another key strength of this research is its focus on the use of a whole cohort of medicines, rather than a specific medicine-type only. Unlike previous high-quality research in this field, the research has considered the practical and emotional consequences of having many different medicines in the home and being responsible for all of them at the same time. This has brought new insight into some of the complexities entailed by multiple medicines use. A limiting factor is the exclusion of formal medical documentary evidence. Consequently, participants' specific clinical background and prescriptions were not known. This was a deliberate strategy to maintain focus on what people do with their medicines, rather than why medicines are supplied or what type of medicines are used. There was also a considered intention to not collect specific data about the medicines in people's homes. Medicines counting or categorisation was deemed irrelevant to this discrete exploration about how people manage their responsibility for medicines. Previous research evidence had already recorded medicines extent and multitude (Zeppetella, 1999; Sand et al., 2009b; Milic et al., 2016; Kotlinska-Lemieszek et al., 2014; Guthrie et al., 2015; Given et al, 2017). It had also demonstrated people's knowledge about medicines indication (Klein et al., 2013 Yeager et al., 2012;

Wickersham et al., 2014). This research was concerned with approaches and attitudes, regardless of the medicines themselves. Though the type of data collected in the study was limited to individual subjective accounts, a major strength was the involvement of medicines in the research interview. The naturalistic research methods of interviewing participants face-to-face in their homes and physically interacting with medicines, elicited data about medicines management in the context of their everyday life. This approach provided authentic insight into how people engage with medicines, including their storage, placement, and recognition. The methods facilitated discussions about use of individual medicines and the whole regime. Involving relevant items in interviews has been described to prompt participants' recollection of memories and feelings towards specific life events (Mitchell, 2011). In this study, interviews came to life when medicines were physically present. Discussion remained focused on domiciliary issues, rather than steering towards a clinical framework of meaning about medicines indication, action and impact. Participants recounted specific anecdotes about their medicines and indicated emotion towards them. The findings suggested that what might look like chaos or confusion are successful attempts at dealing with the challenge. This unique, rich understanding can inform essential support for people living with advanced cancer. One limitation of the photography method was the risk that with advance knowledge of the use of photographs, participants may alter, organise, or curate their medicines to present the medicines or themselves differently from the natural conditions. The findings observed and photographed did not suggest this; however, this is impossible to control when giving advance warning of photography use. Not doing so, presents obvious ethical and moral conflict.

4.4.3 Summary and next steps

This is the first known UK study to explore how people living with advanced cancer independently manage their whole regimen of medicines at home. Nine women and eleven men receiving NHS healthcare for advanced breast, kidney, lung, colorectal, bile duct and prostate cancer prescribed medicines to use independently participated. All were interviewed face-to-face at home and shared their first-hand experiences of living with advanced cancer and managing medicines. All made their medicines physically available. Data were captured by audio-recording, photography, and annotation. Inductive analysis of people's accounts illuminated the complicated interplay between key areas of responsibility for using medicines, with the underlying instability of life with advanced cancer, and the effort of steering through disruptions from the system within which medicines are governed. Five themes summarised this experience as Having cancer that is not going away; Getting along with medicines; Navigating the system; Habituation in the home; Adapting and being tolerant. These themes portray a multi-dimensional undertaking, and the unique, dynamic workload of medicines use, which extends far beyond remembering to take a tablet or accepting a particular side-effect. In receiving prescribed medicines, people assume responsibility for learning how to get hold of, recognise, and integrate medicines into their existing medicines regime and their lives. In enacting their responsibility, people strive for freedom from the burden of medicines, and develop simple approaches that allow them to live as normally as possible.

This exploration of people's experiences has exposed a critical interaction between the unique circumstances of living with advanced cancer and the intense self-management expectation imposed by medicines use at home. Whilst this study gives a deeply personal, and powerful description of what is happening in people's lives, the evidence also makes patent that their experiences are inextricably connected to the broader system within which medicines are provided and supplied. People's medicines encounters, and what they do with their medicines at home, is about them and their lives, but it is also a response to what is being asked of them. Therefore, these accounts and the insight they offer are most valuable if they are considered in terms of the organisation that sets the fundamental conditions of medicine use. To understand this experience, then, demands that it is appreciated in the context of NHS healthcare. Consequently, an imperative next step in this research was to access the perspectives of healthcare providers, who have relevant clinical contact and knowledge about this process and associated protocols. This was an opportunity to allow the accounts of people living with advanced cancer, to be considered by those HCPs most relevant to their care and enquire about their understanding of what is happening for people. In addition to illuminating the systemic processes or practices or conditions that impact people's experiences, this next step would also permit exploration of means to make improvements. HCPs are best placed to be able to think about how some of these issues might be addressed, given their applied understanding of how things work at the point of care. For the new knowledge to be useful to other people living with advanced cancer, it was essential to generate evidence about opportunities within the system itself, to support people's experiences.

Chapter 5. Research Study Two

What do healthcare professionals understand about the experiences people living with advanced cancer have using medicines and how they could be better supported?

5.1 Introduction

This second empirical study aimed to explore what healthcare professionals (HCPs) understand about the experiences people living with advanced cancer have with domiciliary medicines, and how they think people can be better supported. The research was designed to explore the specific gaps in knowledge by examining the findings of the research about how people manage their medicines, in the context of National Health Service (NHS) care for advanced cancer. The study sought to illuminate the insights of nursing, medical and pharmacy clinicians involved in the medicines use process of people living with advanced cancer, to further develop the conceptual description of the experience and identify potential opportunities to improve support.

5.2 Methods

5.2.1 Participants and setting

The study sample were HCPs currently working on behalf of the NHS in both primary and secondary care, responsible for the care of people diagnosed with advanced / metastatic cancer. Clinician inclusion in the sample reflected the routine encounters of ambulatory people living with advanced cancer in routine healthcare. These were informed by the HCP roles identified by participants in Research Study One and during Patient and Public Involvement (PPI). In primary care, General Practitioners (GPs), Pharmacists and Nurses based in GP surgeries were specified. Practice Pharmacists were included due to their direct involvement in clinical care and routine lead role in medicine reviews. Pharmacists working in community commercial pharmacies were not eligible, due to their perceived separation from NHS cancer services. Other community HCPs were excluded from the study because of the assumed lack of requirement for professional or lay domiciliary healthcare support for the population defined in this research. In secondary care, Oncologists, Clinical Pharmacists, Clinical Nurse Specialists and Research Nurses, were eligible. These roles were identified as important in the site-specific cancer care pathway. Clinicians with expertise in the care of cancer of solid-tumour origin were specifically sought to contribute insight relevant to the previously explored experiences. Haematology specialist clinicians were excluded due to the difference in clinical pathway for treatment of blood and lymphatic disease.

Inclusion criteria required participants to be able to provide informed consent and be able to participate in English.

In summary, the following eligibility criteria were applied:

Inclusion criteria:

- Registered medical doctor, nurse or pharmacist employed on behalf of NHS
- Routinely involved in care of people living with advanced cancer
- Able to provide informed consent
- Able to participate in English

Exclusion criteria:
- Haematology HCPs
- Community pharmacists

An overall maximum sample size of thirty participants was specified. A minimum of two participants from each clinical discipline was stipulated, from both primary and secondary care. These limits were considered sufficiently comprehensive to generate valuable data whilst being practically manageable. A purposive sampling strategy was used to select eligible participants. A sampling frame was designed and applied to ensure representation of HCPs from different disciplines and settings. Participant recruitment took place in a large UK Teaching Hospital Trust and a regional Clinical Commissioning Group (CCG) between September and December 2018. The recruitment strategy was tailored to site-specific organisation and in response to participant uptake. Promotional recruitment materials were disseminated to eligible cohorts of HCPs by local gatekeepers. In primary care, the regional NHS CCG Research and Innovation (R&I) department contacted all 'Research Ready' GP practice managers, who shared information with surgery clinicians. In the Teaching Hospital Trust, the Lead Nurse for research, circulated information amongst discipline-specific clinical leads, who distributed information to eligible staff cohorts. Study information was also shared in-person with primary care HCPs attending educational events hosted by the CCG. Snowball sampling was used to extend the reach of recruitment. Recruitment continued for four months.

5.2.2 Materials

The questions in the topic guide were informed directly by the findings from Research Study One and were structured around the five core themes. For example, HCPs were asked about their interpretation of people's experiences of the administrative labour of obtaining medicines entrenched in their use, to understand more clearly the procedural and technical reasons why people have the experiences reported. A connected question explored participants ideas about how in their own practice that could be made easier. The topic guide had a flexible structure to allow responsive discussion. The interview schedule also included a photo-elicitation component. This used photography data collected during the first study as a means of prompting participants

responses in the current study. Photographs were selected which specifically exemplified themes relevant to the interview questions. Photographs from the first study were systematically screened in relation to study questions. Individual photographs were identified and labelled, and cross-refenced with the topic guide, to ensure timely introduction of each photograph during the interview. For example, questions relating to HCP understanding about practical approaches of medicines use, introduced examples of medicines management techniques. Likewise, when discussing how people store their medicines, photographs depicting various methods were introduced. All photographs were collated digitally and could be retrieved in reference to a specific question, or in response to a participant comment. A slideshow of all photographs was also prepared.

5.2.3 Data collection

Audio-recorded interviews were conducted with all participants either in-person or over the telephone within four weeks of their recruitment. Interviews were semi-structured around the topic-guide. Digital photographs of people's medicines management experiences at home were also shown to participants to stimulate additional reflections and ideas, either on a laptop computer during in-person interviews or via an emailed digital slideshow for telephone interviews. At the end of each interview a slideshow of all digital photographs was shown, to ensure that all participants observed the same evidence regardless of interview content or structure. Audio-recording continued during this time to capture participant comments. Fieldnotes were taken to report non-verbal data and cross-reference photo-elicitation responses with individual photographs.

5.2.4 Data management and analysis

All interview audio-recordings were transcribed verbatim by the researcher. NVivo11 was used to store all transcripts, fieldnotes and analytical memos, photographs, and to make linkages between evidence sources. For example, when interview responses related to photo-elicitation evidence, this was recorded in the transcript by referring to fieldnotes made during interviews. The section of transcript was linked in NVivo with a specific photograph and related fieldnotes.

Interviews were analysed using the principles of the framework approach (Ritchie and Lewis, 2003) previously described in Chapter Four. Analysis using this method could accommodate a-priori themes introduced from the interview topic guide, and allow new concepts to be inductively generated from analysis of data. The analysis specifically focussed on finding patterns and variation amongst data, in relation to HCPs understanding about people's experiences with medicines in the context of their healthcare and what opportunities may exist to support them better. This would strengthen the coherence of the account generated about people's experiences with medicines during advanced cancer. The following stages were undertaken:

Familiarisation: Transcripts were read and re-read, and segments of interview audio-recordings were revisited. Initial ideas were annotated in transcript margins and memos were created to explain and expand on the thinking behind ideas. Initial impressions were recorded in NVivo11. This deep immersion in the data helped to increase familiarity with the content of transcripts and the location of evidence in them. This made subsequent analysis and cross comparison more manageable.

Developing a coding index: All transcripts were coded with initial ideas arising from annotations and memos made during both data collection and familiarisation. These initial lists of codes together produced a coding index. The coding index listed concepts generated from participants accounts and responses. These were both derived directly from the analytical framework in Research Study One, which was used to structure this current study interview topic guide, and novel ideas introduced by participants. The coding index was then arranged according to linked ideas. This process of sorting facilitated the development of initial themed categories. For example, one initial category was called 'having information' to refer to codes capturing participants' data regarding access to medicines records and accounts. A code within this initial category was called 'being a detective', which labelled data relating to participants' energy and effort obtaining clues about what medicines people use.

Indexing: All data were then systematically coded according to the analytical framework. The themed categories were developed iteratively throughout this process, to accommodate new ideas or different articulations of existing ideas.

Charting: Summarised descriptions of all data stored within the framework matrix were charted to support the final interpretation stage. The framework matrix function in NVivo11 was used to visualise all indexed data within the framework. All data within the matrix was then summarised as descriptive statements within the table.

Mapping and interpretation: Finally, data were brought together through the synthesis of thematic concepts. Themed categories were reorganised and renamed to capture this additional layer of interpretation, which considered the broader and richer meaning of the data set as a whole, and in relation to the previous meaning already generated by Research Study One.

5.2.5 Ethics and Governance

Ethical approval to conduct this study was granted by the University of Leeds School of Healthcare Research Ethics Committee (SHREC) (SHREC reference: HREC17-033). Subsequent HRA and local research and innovation (R&I) department permissions were obtained from all participating sites prior to starting research activity (HRA reference: 19/HRA/0141; R&I reference: CO18/109078). Several key ethical issues were considered. Potential participants were not directly approached by the researcher. Recruitment was facilitated by local gatekeepers, who disseminated

written information about the study. In primary care a R&I representative facilitated dissemination of study materials to eligible attendees at education events. For snowball sampling, existing participants were asked to invite eligible colleagues. The PIS detailed study aims and procedures and clearly communicated the extent and expectation of commitment in taking part in the study. All potential participants were given the opportunity to contact the researcher directly and ask questions. No incentives for taking part were offered. Interviews were scheduled to minimise disruption to participants' clinical responsibilities. The Consent Form stated permission for the collection, storage and future use of anonymised data, the protocol for breaching confidentiality in the event of concerns of harm, and withdrawal. This was used to obtain written informed consent from all participants. All participants signed and dated the form and were offered a copy, and telephone interviewees returned a digital copy. As described in Chapter Four, section 4.1.5, the use of photography data from Research Study One was addressed in its NHS Research Ethics Committee approval, permission for their use was documented at consenting and photographs were also screened by participants.

All data generated in this current study were anonymised. Participants were assigned a code denoting their profession. Participants with a unique role or job title agreed a generic equivalent based on their clinical discipline, to minimise the likelihood of identification. The code was used to label all data. Potentially identifying information disclosed during interviews was redacted from transcripts. All digital data were recorded on encrypted devices and files were transferred to a password protected server and original files were destroyed. Consent forms were digitally uploaded and onto a password protected server and physical documents were destroyed confidentially.

5.2.6 Reflexivity

Reflexivity was a valuable device for evaluating and improving the photo-elicitation method. This was a new technique for both the researcher and all research participants. Undertaking transcription during the same time as data collection facilitated critical reflection about the role of the researcher and informed the approach in future interviews. It became apparent after the first few interviews that participants were unsure about the nature of the photo-elicitation technique. The process for the approach was explained in more detail to subsequent participants. Also, even with more information, some participants were not forthcoming with commentary upon viewing photographs or responded only tentatively. As the data collection phase progressed, individual participant reaction during this part of the interviews was more promptly evaluated to allow the technique to be adapted to avoid participants' unease or sense of pressure to comment. The digital presentation of photographs as a slideshow enabled participants to view photographs in their own time, and without researcher involvement. This afforded participants a sense of privacy and time to control the pace of their engagement with each photograph. Subsequent conversations gave participants the opportunity to relay their reactions and enriched the interview data generated.

5.3 Results

5.3.1 Participants

Twenty-six healthcare professionals agreed to take part in this study. Eight participants responded to the initial recruitment materials and ten were identified through snowball sampling. A further eight HCPs from primary care were recruited via a CCG education event. Six people who agreed to take part were unavailable to be interviewed during the data collection phase. Twenty people participated in this study. Eighteen face-to-face interviews took place at participants' clinical workplace and two telephone interviews were conducted.

Participants working in primary care were based at various locations and represented seven different clinical sites. Most were General Practitioners (20%). One practice nurse and two pharmacists based in different GP surgeries participated. Six of the 13 participants working in secondary care were clinical nurse specialists. This group comprised four oncology and two palliative care specialists and made up the largest role proportionally in the sample (30%). Three oncologists participated. These were specialist consultant doctors from three different diagnostic specialities. Three clinical pharmacists were involved who worked in different oncology settings. Participant characteristics are summarised in table 7.

HCP participants n = 20 (Percentage of overall sample)			
Primary Care n=7 (35%)		Secondary Care n=13 (65%)	
General Practitioner (GP)	4 (20%)	Oncologist	3 (15%)
GP-based Pharmacist	2 (10%)	Clinical Nurse Specialist (CNS)	6 (30%)
Practice Nurse	1 (5%)	Research Nurse	1 (5%)
		Clinical pharmacist	3 (15%)

Table 7. Research Study Two participant characteristics

5.3.2 Themes

Three overarching themes summarised HCPs perspectives about the experiences people living with advanced cancer have with medicines at home and the opportunities to support them. These are summarised in Table 8 and are then discussed alongside original data sources.

Themes	Subthemes
Insight and information	It all happens behind closed doors
	Having the chance to talk
	Talking the same language
	Talking it over
	Access to contemporaneous information
Oversight and ownership	Taking responsibility
	Collaborating
Expertise and resources	Having the right knowledge, skills and tools
	A support predicament

Table 8. Themes and subthemes from Research Study Two interview data

Theme 1. Insight and information

HCPs explained that their own limited insight into basic information about medicines may account for some of the experiences people have with their medicines at home. This ignorance was due to the absence of transparency about what medicines people are using, where they have come from, who prescribed them and why, and exacerbated by the manner and nature of direct interactions with people about medicines use. The evidence relating to this theme focussed on HCPs contact with people at home, the chance to talk about medicines in the clinical setting, and access to relevant information either directly from people, or via healthcare documentation. HCPs were unlikely to encounter people's whole collection of medicines in the context of their routine cancer care. Opportunities to interact was based on scheduled contacts within the care pathway, such as treatment and follow-up appointments. There was limited time during clinical consultations to talk about medicines use. During conversations with people about medicines, HCPs felt reliant on what people chose to tell them, rather than necessarily being objectively abreast of all relevant information. They consequently made assumptions about people's experiences. Communication itself could be challenging due to the barriers of talking to people about medicines. HCPs had access to documentary resources about people's medicines; however, the existing system for sharing information about medicines was inadequate. The lack of a central electronic record prohibited insight across settings of care. As a result clinical time could be devoted to locating or re-documenting information. Opportunities to better support medicines use for people living with advanced cancer revolved around improving communication. This was thought to be possible via more streamlined systems for sharing information with other HCPs, improving the language and nature of the dialogue between HCPs and people using medicines, and creating more space in clinical practice for people to talk about domiciliary medicines use.

It all happens behind closed doors

Participants appreciated the likely toll of multiple medicines use. Reflecting how people manage their medicines at home, participants across disciplines agreed that people living with advanced cancer commonly encounter many medicines throughout their care. They observed people being overwhelmed with disease symptoms and treatment side-effects, whilst contending with existential fragility. However, many expressed difficulty relating to the physical everyday reality of managing medicines in the home, due to the few opportunities to encounter people in the natural environment of medicines use.

In the community, some Pharmacists and GPs felt confident in their understanding of the practical aspects of medicines use generally, from their contact with the wider population. However, their insight into medicine use at home was not specific to people living with advanced cancer. People living independently with advanced cancer were unlikely to receive home visits from their GP.

One exception was a Practice Pharmacist whose role incorporated domiciliary service. This specialist provision gave close insight into issues, and afforded a broader perspective on medicine use, beyond medicines 'taking'. However, domiciliary contact was determined by specific criteria, which was usually people with impaired cognition or known to be non-adherent. It did not necessarily include an advanced cancer population.

Hospital-based HCPs would never meet people at home, and it was unusual for routine outpatient interactions to involve the physical presence of medicines. Medicines brought into hospital during inpatient admission were stored away, not used by inpatients, and then redistributed prior to discharge. This prohibited HCPs from observing people's independent medicines use.

The photographs presented to participants during interviews assisted in exploring some of the medicines management issues despite their limited access to people at home. Reaction to the different evidence varied. Several observed how just seeing what people have and how they go about things very helpful. Most participants found it unremarkable for example that people had so many medicines, yet the images of kitchen cupboards and drawers stuffed full of them were important. The photographs also provided new visibility of aspects of medicines use. This method prompted participants to consider the value of physically seeing medicines, as a means of understanding people's perspectives of using them. Participants identified that improving insight into what is happening with people at home was a key opportunity to better appreciate the experience of medicines management. However, suggestions for achieving this were limited. Developing community roles to include home visits was an obvious solution, yet overwhelming workload and restricted time and resources might make this unlikely. The domiciliary pharmacy service could possibly be extended to access this population but again this would require additional financial and human resources.

Figure 12. Eileen's drawer

Having the chance to talk

HCPs identified that their own lack of insight into people's experiences with medicines during advanced cancer reflects their limited opportunity or time to talk to people about their medicines use due to the inflexible clinical pathway. Participants agreed that the system of having clinical contacts dictated by established timepoints did not necessarily serve people at the time of their need for support with medicines. Participants from different disciplines observed that because treatments for cancer were increasingly given at outpatient clinics, or self- administered, some people living with advanced cancer rarely attended hospital, further limiting the opportunity for contact. The result was a reactive approach. Appointments themselves would not necessarily provide the chance to reflect on or scrutinise medicines use. There was variation in the perceived scope to discuss medicines in the context of their own clinical practice.

Participants in some oncology settings, such as the chemotherapy day-unit, felt they had better opportunity to accommodate medicines-related conversations. Alternatively, one Oncologist explained that their outpatient appointments prioritised essential discussions about disease progress and response to treatment. Hospital Pharmacists felt restricted in their chance to talk to people living with advanced cancer about their medicines. They were primarily involved with outpatients receiving ambulatory treatment, yet following the first-cycle systemic anti-cancer therapy (SACT) counselling they were unlikely to see people regularly. Another opportunity was during hospital admission, but this was more likely to involve specific medicine adjustments in the clinical context of the admission. Specialist Palliative Care (SPC) clinicians also described inpatient admissions as being a key time within their role to talk to people about their medicines. They explained that their input was reserved for people with complex or poorly controlled symptoms, and they were unlikely

to attend to ambulatory outpatients in clinic. Whilst they agreed that these people may benefit from expert input or require additional support, they do not presently meet their qualifying criteria.

In primary care, participants did not have routine contact with people living independently with advanced cancer. They had direct contact only if people attended the GP for a specific reason or had other continuing healthcare needs, which required nursing or allied HCP support at home. GPs stated that their medicine-related input focussed on the renewal of repeat prescriptions and medicines reviews. GPs acknowledged that even if people do have a scheduled appointment, it is acutely timebound and would rarely involve a conversation about medicines management. GPs were likely to become more involved as people living with advanced cancer stopped having active cancer treatment and instead received Best Supportive Care. These people would be discussed at Gold Standard Framework (GSF) meetings, with the wider community team. Contact would be determined on an individual basis. GPs regretted that time and resource pressures in primary care restricted them from proactively engaging with people living with advanced cancer in the meantime. Medicines reviews were an obvious opportunity for GPs and Practice Pharmacists to assess and address medicines use. They facilitated effective prescribing and de-prescribing decisions and discussions about the impact of medicines use. However, participants agreed that the conventional schedule for reviews was restrictive and lacked scope for exploration about practical and emotional contexts of medicines use. Involvement from Pharmacists was otherwise determined on a case referral basis, and they were unlikely to see people living with advanced cancer specifically due to their diagnosis, rather because of comorbidities which entailed use of medicines requiring specific supervision or audit.

> *"I think what's difficult for the patients is understanding what my role is, not particularly the CCG, because they won't see them, but my role is versus what the Community Pharmacist role is - that's really confusing for the patients - So I had a patient say to me 'well a community pharmacist did all this with me the other day' and I said, 'well they don't send us that information!'. So there's a real disconnect, between that and primary care, which could be so much better."*
> Practice pharmacist 1

Improving access to HCPs specifically for the purpose of talking about medicines was identified as a major opportunity to improve the support for people living with advanced cancer who use medicines. It was suggested by some participants that clinical roles within the care pathway could be developed to allow better insight into people's medicines management. Participants who dispensed medicines directly to people described being afforded the opportunity to physically display medicines and counsel them about each one and give them the opportunity to ask clinically specific questions. However, this practice was either role-specific or self-directed, rather than being embedded in standard care. Participants with a background in primary care agreed that medicines reviews were a good opportunity to provide support. They suggested a tailored, intermittent approach using a modified medicines review process at specific stages of cancer treatment might be

helpful to this population. Reviews might also be improved by considering and evaluating people's practical implementation of medicines regimens. Participants were unclear who was best placed to deliver reinforcement education around medicines use and support the ongoing supervision and review of medicines in the community.

Talking the same language

The difficulty people living with advanced cancer have in enunciating and remembering pharmaceutical language was consistently acknowledged by HCPs. Participants recalled their own experiences of people attempting to making themselves understood, either trying to use the correct terminology, or referencing other characteristics, such as medicines indication or appearance.

> "I've seen it over the years, and you see it when the patient comes to clinic and says this metoclopramide is rubbish for my diarrhoea, because its come in a similar box to loperamide and then I've taken the wrong ones for the wrong side-effects. So you do see nurses write on 'sickness' or 'diarrhoea' -"
> Clinical pharmacist 1

> "'The little white one', 'the box is pink!' We don't know which brand we've given you. Even I don't know. I don't see the boxes ever. Sometimes I'm ringing the pharmacy technicians saying, 'which one is white and anti-sickness?', 'cos we don't dispense them as pharmacists.
> Clinical pharmacist 2

HCPs highlighted how the absence of clinical standardisation between medicine manufacturers and the fragmented nature of the supply chain, limited HCPs' ability to understand people's alternative methods for familiarisation. People's dependence on medicines' physical form was not useful language for prescribers as they would not necessarily know what medicines looked like. In the context of their own clinical role, this was a barrier to communicating with people about their medicines. Prescribers expressed awkwardness at their ignorance about practical aspects of medicines, such as dose denomination, which they were aware people really valued information about. This discrepancy between packaging was also an opportunity for error. Figure 13 is an image of Leonard's medicines in the kitchen drawer where they are stored and highlights this issue. The photograph shows the same medicine, lansoprazole, supplied in two different types of packaging. Discussing this with HCPs also drew their attention to this aspect of integration. HCPs seemed aware that people routinely had to annotate their medicines packaging to support their use.

Figure 13. Leonard's lansoprazole

Talking it over

Participants acknowledged the importance of talking to people about medicines use, and some had lots of direct contact which facilitated their clinical insight into many of the issues affecting people who use medicines. The suggestion that medicine support for people living with advanced cancer is inadequate was considered by some participants to be related to the nature and extent of information people decide to disclose to HCPs about their medicines use. In their own practice, HCPs had the sense that people were reluctant to tell them about problems with their medicines. One explanation was that people felt unable to discuss negative experiences because it could reveal that they were not using medicines as intended. For example, poor tolerability, which HCPs said may result in intentional non-adherence, was under-reported. This was considered common in specialist oncology, particularly in the use of Calcium supplements, which are large and chalky, and steroids, which have a high side-effect profile. Participants also anticipated that people living with advanced cancer downplayed the adverse effects of systemic anti-cancer therapy (SACT) in their determination to pursue treatment. HCPs recounted examples of people concealing serious adverse effects of cancer-medicines and expressed concern about them taking major health risks by under-reporting toxicities. They also recognised that people were not forthcoming with combined tolerability issues.

> *"I don't see many patients still on treatment. But I suppose the only thing I could say, is that people often tell me, they carried on with treatment even though it was really hard work, and so, I think there's something in that about people do that because they feel they should, for reasons to do with not wanting to let their family down, not wanting to give up, not wanting to let the doctors down. You want to do what's right. So there's something around that people tend to complete the courses and they'll go back and have*

reduced dose chemo, but actually patients might not – so people will refuse to take their laxatives because they're frightened of having loose stools and having and accident as they get more fatigued – so there's something around people feeling they have more control over that because its just a drug for symptoms, rather than, it's a life-saving chemotherapy."
Palliative care CNS 1

It was unsurprising to most of the HCPs participating in this study that the results of Research Study One highlighted that bowel management was a major pre-occupation for people living with advanced cancer. Simultaneous use of multiple medicines was likely to cause physiological changes, which varied from medicine to medicine. However only some HCP participants felt they got to know about this in their clinical practice. Others, who had less frequent everyday contact with people living with advanced cancer, thought people felt unable to bring this issue to discussions. Some made a point of asking about it.

"I think laxatives is a big issue – huge issue! So people not understanding how they work, bowel care generally, people don't – and it's not their fault! It's about at the point of dispensing, what information is given? Or the point of prescribing – whether its over-the-counter or prescribed - understanding how that works, what they can expect from that drug. And I think it doesn't matter what drug it is. It's what can they expect the outcome to be?, how can they use it? Tolerability's a big thing, so they might, in lots of different settings – we do it as well – it is can this patient actually physically tolerate this medicine? The taste, the consistency, the size, lots of things. So they don't take it because they physically can't! It makes them gag, or vomit or, you know…"
Oncology CNS 3

Several nurses described their own observation of people who have taken so many different medicines for such a long time becoming disengaged or ambivalent over time. They called this tablet fatigue, something that they had become aware of, but was not necessarily openly discussed. Participants who had routine contact with people living with advanced cancer at the end-of-life discussed the hindsight with which people describe tolerating past medicines. People had expressed feeling like they should continue demanding treatments, despite them being terribly hard, but continued out of a sense of personal responsibility.

"I think people get tablet fatigue. For me, I think they just get sick of taking all these medicines and then they see what they can try and cut out, and then they make their own decisions about what they'll move out of what they should have and what's prescribed, and they will chop and change depending on what they're doing, because they feel they know their bodies now, more. And then sometimes what happens is, they become, they have problems then, because they're not taking them as prescribed. I think you get to know their personalities and you know you can talk to them about 'I'm sensing, that you're not that keen on

taking the medicines, is what's coming through to me – am I right? Or?' and usually they'll say 'I'm not

taking them because of this' or 'I'm not taking them because of that'."

Oncology CNS 2

"If you have to take morphine because you've got cancer, that equals bad to most people emotionally – and

it's much more than just a side-effect. Side-effects are rubbish though, sometime. And we just give you more

medicines to manage the side-effects, so then the tablet burden increases"

Palliative care CNS 1

The individual nature of living with advanced cancer was perceived to be crucial in supporting medicines management. There was no one-size-fits all approach and individuals needed distinct types and levels of input. Participants explained it was important to consider this personal context for medicines use to plan and evaluate appropriate care. HCPs observed that people in their care who were living with advanced cancer have specific individual educational needs. They explained they directed people to trusted sources, which included manufacturers information such as Patient Information Leaflets (PILs) and NHS guidance via the National Institute for Health and Care Excellence (NICE). However, participants acknowledged people can feel overloaded with information, particularly during long-term care and so ideally resources should be succinct.

Improving medicines communication between HCPs and people living with advanced cancer was considered an essential means to improve support. HCPs were very clear in their responsibility to support people to know why their medicines have been prescribed and understand them. Unfortunately, the communication issues identified were prohibitive. Standardisation of medicines supply was an obvious solution but was impossible due to the privatisation of pharmaceuticals and the organisation of commercial pharmacy services. One GP suggested that having a visual reference, showing what the medicine supplied by pharmacy will look like would be helpful. A hospital-based CNS described requesting that people physically bring medicines from home into the outpatient clinic to assist with conversations.

"Maybe if there was better information on System One or EMIS – we use System One. When you

prescribe a drug, maybe if you could click on, to see what different brands look like, and maybe practical

information about how to take it. So very basic, visual. The information needs to be very simple and quick

to absorb. Particularly when you're in the middle of prescribing something, because we already have pop-

ups....There's a program on everyone's computers that when you're trying to prescribe something it'll pop-up

and say 'don't prescribe that, prescribe this, it's cheaper'. But often you have to overrule it, because you

happen to know that this person needs a particular thing. So there's already things going on that are

making out time more pressured. So it'd have to be an optional thing that you could click on, just to say

…because you're not going to be able to say to them exactly what it looks like. You don't know what

brand you're gonna give them in Pharmacy...I've no idea what brand! Apart from a few things - there's one

or two things that we have to prescribe by the brand and then everything else we have to prescribe generically. And not only that, we're being forced into specific generics. Branded generic they're called. Because of the way the NHS is buying drugs. I really don't like it because we're having to prescribe these specific brands of generic drugs that next week might be more expensive and they want us to switch them again, so it feels like a slippery slope. They've spent years telling us not to prescribe branded drugs. And now they're making us prescribe cheap branded drugs. There's pressure on every single thing you do as a GP, there's a weight on your shoulders about everything you're doing."

GP 3

Several HCPs also suggested that exploiting the knowledge of pharmacists was a potential means to improving interactions with people about their medicines. This sharing of expertise could enhance the personalisation of information for people living with advanced cancer and benefit clinicians' own professional knowledge about medicines. Oncology specialists suggested that greater involvement of Clinical Pharmacists in cancer outpatient services might improve personalised information provision, as they have more of the practical and technical understanding around medicines and may be able to give support beyond the scope of the medical consultation.

"Sometimes it like as basic is I know the doses – Full dose Pezopanib is 800mg daily, I know that - You say to me 'does that come as 2 400's, 4 200's, or one 800?': One, I don't know; Two, in a sense, I'm not that bothered.... well – I should be bothered – but I have to prioritise what I have to commit to. And the other thing is, if I say 'well its one 800', there's a high change I'll go to pharmacy and pharmacy will say 'we haven't got any 800's in, I'll have to give you 2 400's', and you create the uncertainty and someone'll say 'maybe he doesn't know what he's on about!'. Maybe that's a bit of an excuse but its reality. Sometimes it depends what pharmacy've got. Some tablets I know. Like Abiraterone comes as 4 250's but, so its those little detail that I don't necessarily go into. So obviously I'll focus on the side effects, I'll say 'you can stop it at any time, you're in charge', 'we can try it and if you don't like it'…that's my fairly standard patter as you can imagine because I do it day in day out… I do quite a lot of treatments. So they go 'can I have it on a full stomach?', well like that – again - it's quite difficult. So I try and avoid that... But that [having a pharmacist next door in clinic] would be so good! In our clinic, we're very fortunate, we're very well supported by our Nurse Specialists, so the standard procedure is that I'll do the: 'are we doing this? OK here's the consent,' do some brief discussion around the practicalities, but I will leave that, because of time etc. so they will the spend time with the nurse Specialists, who I'm sure does a lot more of that, the actual nitty gritty of that. They then go to pharmacy of course. But, I'd love that, I think that's be great if you had a pharmacist. Because all the time there's stuff like…because part of it is what other tablets are you taking? What other medical issues have you got? What are the interactions? You know it would be so much more joined up."

Oncologist 2

"....So, I don't know if there should be a role for having Pharmacist in that clinic, so when they go and see the doctor, they can say 'these are all the meds I have, what's this for, do I need to be on all this'. I think I heard at BOPA [British Oncology Pharmacy Association] were setting up a pharmacist clinic and I think the pharmacist was there while clinics were there, and patients could come and chat to them. Because we kind of have that in haematology. The pharmacist is upstairs and you're checking the chemo, you just don't particularly have the time to… which is when we're giving them all the piles [of medicines] actually. But I don't know if that's something that would be a good way of tackling it. if they know they have somebody that when they come to clinic with the doctor, and the doctor prescribes something. Because sometimes I think they feel a bit intimidated by consultants. So, to have someone who's sort of in there for that."
Clinical Pharmacist 2

Another opportunity to improve communication identified by nursing participants was via better resources to assess people's medicines experiences. This could enable deeper exploration of people's medicines use and facilitate access to personally relevant, nuanced insight into their medicines management. Developing existing tools such as the Holistic Needs Assessment was noted as a potential means via which nurses could improve this evaluation. Such a tool was seen as a potential avenue, for example, for exploring the combined impacts of multiple medicines of bowel care, which may not necessarily be addressed in a routine oncology or GP consultation.

Access to contemporaneous information

The experiences people living with advanced cancer have with medicines, were related to the absence of relevant accurate documentary information for HCPs. The lack of a single, shared, contemporaneous interface was frequently observed. The inconsistent model of record-keeping limited HCPs insight into medicines use and the wider context of their healthcare. In the community, an electronic primary care record was the trusted source of information about medicines. This list could theoretically be shared between healthcare providers; however, regional variations in information technology (IT) infrastructure meant that access was not universal across all settings. Participants in secondary care described how outpatients' medicines were recorded during clinical consultations according to the local departmental practice, either as standalone documents or as annotations in medical records. External access to electronic information again depended upon IT system compatibility and permissions. Handwritten documentation was available only to HCPs with physical access to medical records.

Participants agreed that knowing what medicines people are using is vital to deliver safe and optimal care. However, access to accurate information about people's medicines was challenging and variable. HCPs explained spending much precious time trying to find reports, results, letters, or past notes. It was common to work with an incomplete history, or to depend upon people living with advanced cancer themselves to provide clarity. HCPs knew that this population were likely to have frequent changes to doses and types of medicines, but not being able to confidently see these

alterations invited confusion. Participants recalled people in their care having difficulty understanding 'what's what' when confronted with multiple medicines, but being unable to help them, due to not having access to sufficient information.

"Data quality is not good. Each practice, Let's say, build a practice in their own way, say you're moving out of your practice, or a locum comes, and doesn't know how to put in your record, so information is misplaced, your Medication not coded in a way that is clear for others. Its non-existent... If you are going to be making medicines safer, or prescribing safer...One department I hospital doesn't know what's happening in other departments even! Remember sometimes patients go to one hospital for something, and another hospital for another thing. And then you are the bridge trying to find out well this is what medication - because you go to a chest clinic here, and they say 'cut down on this medication' and then the other one say 'oh from a cardio point of view, you should increase it'. We have to have a better understanding."
GP 4

" So now, we can now see in hospital on [the electronic record], we can see what's on the current prescribed list from the GP. But I don't know how quickly that's updated, so there might be a time lapse, which is quite important, so like for our group of patients, they might of tried 3 different anti-emetics at home, they're then admitted with nausea and vomiting, there's a danger that we then go through those 3 cycles again, rather than think, 'they've been used, discarded and not worked.' Because you haven't got it and I think also now, much as I think paper-less working is great in a lots of ways and for us its revolutionary. But there is a danger of unpicking through it all cos its massive now, so you get consultation after consultation. So trying to unpick what's worked, or had side-effects, is really difficult. It is quite hard to unpick."
Palliative care CNS 3

Lists of medicines provided a snapshot of someone's medicines history and were only valid if updated in real time. Prescribers felt the format of the medicines-list contributed to poor understanding. It provided essential prescribing and dispensing information; however, it did not include contextual detail about previous experiences, preferences or expectations. This was an inadequate source of information in facilitating interactions about medicines. The extent of any information trail was at the discretion of individual record keepers and would be embedded in medical records and subject to the discrepancies previously described. For example, several CNSs believed that tolerance of medicines taste, smell, size, and side-effects, were crucial factors in the judgement people made about medicines, yet they had no way to confidently communicate that to prescribers or highlight which medicines had already been tried. Participants described feeling like detectives, trying to track down clues about where and why medicines were initiated, how long they had been used for and whether they were still needed. Many relied upon people to fill in the gaps and were grateful when they brought medicines to appointments. However, they acknowledged

that this still might not provide the full picture. A major opportunity to improve medicines support was in revolutionising the archaic system of recordkeeping. It was essential for all HCPs have access to the information they need to provide safe care. This would mean standardisation of the interface for all HCPs involved in an individual's medicines care, in order that information is accurate and up to date.

Theme 2. Oversight and ownership

Another theme associated with HCPs understanding about the experiences people living with cancer have with their medicines related to the overall accountability for medicines. Participants identified how ambiguity in responsibility for individual medicines and the coordination of the whole collection, and shared working between HCPs working across multiple settings, may impact on how people are required to manage their medicines. HCPs identified that caring for people living with advanced cancer takes place across a vast and complex network of services. Participants identified that unclear leadership for the whole medicines cohort of people living with advanced cancer affected their own practice and ability to offer support. Participants perceived this to perpetuate a reliance upon NHS hospital oncology departments. Specifically in relation to their own practice, participants articulated the notion of not wanting to interfere with other clinicians work and so avoiding involvement with medicines. Trying to collaborate with other HCPs about medicines was seen as crucial, but this could be particularly difficult due to communication barriers. Professional challenges arose specifically within advanced cancer, due to complex questions around the goals of treatment. Poor links with community pharmacy could also exacerbate some of these issues. Obvious opportunities to solve these problems related to better identification of the clinician responsible for medicines. This person would provide much needed focus of medicines communications and serve as a conduit for collaboration between others. Another key aspect of improving oversight, concerned articulating complex clinical decisions to the wider team. Participants identified that advanced care planning and effective communication of those related conversations and evaluations was essential in the care of this population and would help in their own judgements about the appropriate use of medicines.

Taking responsibility and claiming ownership

Participants reflected on the increasingly complex healthcare needs of people living with advanced cancer associated with aging and co-morbid conditions. People living with advanced cancer were commonly receiving care from a range of HCPs for multiple conditions. One consequence was ambiguity about the overall responsibility for the whole medicines cohort. The evolution of cancer care had contributed to this lack of coordination. People now remained in the cancer care system, under surveillance and receiving different consecutive or concurrent treatments for many months and years, often until the end of their lives. The shift towards the ambulatory provision for cancer was not perceived to have been accompanied by a transformation of community services. Participants from both primary and secondary care felt that the intensive outlay of support during

cancer diagnosis and acute treatment encouraged people to rely on specialist oncology services throughout their subsequent care. Patients were observed to develop strong therapeutic relationships with HCPs in their oncology team, which unintentionally discouraged them from engaging with other services. When patients then had long-term needs in the event of advanced cancer, rather than seeking support locally, they contacted acute oncology services, or waited for advice at their next oncology outpatient appointment. This detachment from primary care could be disadvantageous during less intensive phases of cancer care such as long-term follow-up. Specifically in the context of the care they provided, HCPs in oncology felt that the high-volume of continued patient contact was unsustainable for their service and prevented patients benefitting from other specialists' immediate support. CNSs felt that they received a disproportionate number of telephone queries related to medicines, because outpatients either did not want to or did not know who to contact locally. Whilst able to provide general advice, they often required significant administrative input to resolve and was unscheduled so encroached on clinical duties.

Oncologists in this study explained that they were not responsible for medicines unrelated to cancer care. GPs reflected that although they were assumed to have overall oversight of the medicines collection, they often had little knowledge of what was happening day to day with people living with advanced cancer. They neither saw them regularly, nor communicated directly with other specialist HCPs, in an oncology multi-disciplinary team, for example. With certain medicines they expected to take responsibility, but they expressed wariness at getting involved with speciality medicines, or intermittent medicines given their lack of specialist current knowledge or insight into the person's care.

> *"A really good example, is somebody who had really high blood pressure, is on all the drugs for blood pressure, they lose 4 stone because they've got cancer, and then they're really fatigued and light-headed because they're still on BP modifying drugs. But the ownership of that - once a patient's under oncology, the GP will assume the oncologist will look at it, the oncologist will be thinking, 'well the cardiologist's looking at the heart-failure drugs' – a good doctor, might actually write to the GP and say, 'can you look at this this and this, their blood pressure was low' – but I think there's a sense of nobody has ownership of the prescribing. And I think there's a lack of knowledge as well, people don't want to stop drugs. The oncologists are not going to manage long term diabetes and heart failure. So there's a lack of ownership and the patient doesn't own that – other than just stopping stuff because they decide to stop it. there's not insight into that maybe."*
> Palliative care CNS 2

The experience of multiple unsynchronised repeat prescriptions, identified in Research Study One, was considered related to this issue. The photograph of Margaret's intricate inventory of managing medicines unsynchronised supply prompted a lot of people to reflect on the reality of dealing with the complexity of the supply system for medicines. Poor alignment of different prescriptions was

considered normal, and HCPs said it was complicated to address, due to the difficulty manipulating prescriptions initiated elsewhere or the impracticality of cancelling and re-prescribing an entire medicines list that they perhaps did not ordinarily have cause to consider. Primary care participants also identified the difficulty of effectively reviewing repeating prescriptions in general practice. GPs stated that they had little time to see people, let alone oversee impromptu medicines reviews. There is simply not the space and time to review these prescribing cascades individually, especially when people are not involved in the discussion; such is often the case when GPs trigger repeat issues of medicine. One GP explained that some financial incentives for GPs are linked to prescribing targets, which might encourage prescribing of certain types of medicines. Other participants explained that stocks of medicines in the home could also easily add up, due to automatic reordering which meant some pharmacies continued to repeatedly supply medicines regardless of whether people needed them.

Medicines accumulation in the home was also perceived to be connected to a lack of ownership. Participants with specific expertise in medicines optimisation strategy or prescribing expressed their stance that those issuing repeating prescriptions had a responsibility to minimise build-up.

> *"So what I hear a lot, from my patients, is that they have so many medicines to take, and they don't know what's important anymore. And a medicine leads to a side-effect, so you know we put them on codeine or morphine for their pain, they get constipated, they need a laxative, so it's like a vicious circle of… you're adding another tablet in, another tablet in and you're kind of guide them through that and educate them about why. And I think its really important that as Healthcare Professionals GPs, Oncologist, us look at exactly what they need to be taking.. do they really ned to be taking a statin? To prevent? Do they really? Is that a priority for them? Or should we get rid of some tablets? So I do tell my patients a lot to bring all their tablets to clinic if they're quite overwhelmed and we'll sit with the oncologist and we can just get rid of some of the ones that they just don't need anymore....because I just think that they get put on more, and more and more and more tablets. You know, they'll come in acutely, they'll get given that, then we'll give them something else and GP might give them something else, they just don't know what to take. "*
> Site-specific CNS 1

Some participants explained their reluctance to make changes to medicines previously initiated elsewhere in the care pathway. This was in respect for other HCPs as it seemed unprofessional to 'interfere'. In other cases, participants were committed to making prescribing interventions, but could not do so due to poor access to relevant information about people's medicines. Some participants expressed their frustration about the lack of ongoing supervision of medicines by some prescribers. A hospital-based CNS explained how to address the issue of medicines multitude; she often requested they attend outpatient appointments with all their medicines and would ask the Oncologist to review them.

Improved clinical leadership or oversight was judged to be paramount in improving people's medicines experience. Ownership of the whole medicines cohort from a named individual would attribute oversight of everything that is happening to one person. A GP and Practice Pharmacist suggested that a Consultant in Palliative Care or Consultant Geriatrician may be involved and sometimes able to do this. Other participants suggested that a Practice Pharmacist or GP might be in the best place to review the whole cohort and clarify any medicines rationalisation.

> *"I think it is a good model, to have someone who looks holistically at the patient. So that's part of the role that the pharmacists in general practice will do, because we'll try and look at everything that's going on and do that kind of review. Now if they've already been seen by one of the doctors at the hospice, then we probably won't do it on top – because again that's more fiddling isn't it? you just want one person doing things. Or we'd liaise with them, or if there was something maybe that they'd missed we may go via them and get them to talk to the patient. And I do think that is a really important role. Now how you manage that in a practice or a population where there isn't a Practice Pharmacist, whose role that is? That's quite difficult, isn't it? so whether you develop some specialist nurses? Who could do that – but it depends if they feel comfortable, because you may have the cancer that they feel comfortable with in a specialist situation. But then they may not feel comfortable with all the heart failure drugs and other stuff that's going on. Which is where the pharmacists maybe come in, because we can take that broader look across. Some people get the same service from the Care of the Elderly physicians, because they'll look holistically across the broad as well, but obviously you have to be elderly to access them!"*
> Practice Pharmacist 1

HCPs identified that this would be a way of introducing some continuity of care and overall keeping track of everything, which might minimise some of the disruptions or difficulties associated with managing many medicines. This might not automatically eradicate the issue of unsynchronised prescriptions, but it would mean the one individual to take the issue forward. Practice pharmacists recognised that their expertise and resource could be useful; but work was needed to investigate how they could fit into the care pathway for this particular population.

> *"it's challenging because as you can imagine, you've got a patient list the size of 11,000 – and you've got lots of patients probably with unsynchronised medicines, which isn't ideal at all. I think we've got a role to prescribe an acute prescription, for a certain amount of tablets, 'til they get them back in sync, and that's something we can do. I think it's something we could do a lot better. I think it's very time constrained"*
> GP 1

> *"It's really difficult to maintain synchrony though. I honestly don't think I've got anyone who is truly synchronised or stays that way. Because as soon as they go to outpatients, and have something added there, or at hospice, or from the DN or the palliative care CNS, then it all immediately goes out of synchrony.*

And also then you've got the pack sizes are different. So you've got 56, or 60 or 100, or – and they just don't…"
GP 3

"Like everything with medicine, you can try to do a bit all the time, so it doesn't get out of control - or you leave it and suddenly say 'oops!' and it's impossible. We tend to do in our own way. And to me, the ideal is for every patient that say I'm on repeat I need everything, I tick the box, and everything comes out. And then hopefully, sometimes I have to ask 'oh you have a salbutamol inhaler, this should not be coming every month' 'oh yes ok, I don't need that'. But my ideal is you ask for medication every 3 months. And then for older people or people who are not good at managing, you can set it two months, one month, 2-weekly in the dossette boxes. We have all different parameters. But for people active and so on, generally its three months. And then we try and make sure that everything catches up. And I guess, unless you put a bit of effort to keep the system running smoothly, you are going to have that the system everything is a bit of a mess, and no, I don't like that!"
GP 4

It was suggested that overall oversight would also prevent some of the medicines accumulation observed in clinical practice, because one person would be keeping track of everything as it was prescribed and would be able to identify unnecessary medicines, duplications or discrepancies.

Another approach to targeting medicines accumulation, would be in having tools to make effective clinical decisions about stopping medicines that were no longer needed. However, participants explained this was hard to achieve in practice, because medicines are continually initiated by different individuals, with few opportunities for future overall review. Time constraints limited their scope to review medicines and explore deprescribing during consultations. Some HCPs were uncertain about stopping medicines due to a lack of confidence particularly in this population of complex people with many unfamiliar medicines. Participants with specific expertise in pharmacy and deprescribing explained that official guidance would provide a clear framework and would assist in sound deprescribing decision making for this population.

"Specialists very rarely look at the other medications, I don't think they see that as being part of their remit, because, you know, they've not started the medicines for hypertension and over-active bladder, and cardio-vascular disease prevention. They don't necessarily know why the patient is on it. They can probably get a good idea from the records, but they don't know the full details of why it was started, so, and they're also time pressured, so they're not going to have time to go through the persons' entire past medical history in non-cancer related things, and make that decision about whether they should …most of the time it's not urgent to do that, so I think it's reasonable to expect it would be done in primary care. But, equally, it's not prioritised at the moment. ... What we could do with, is NICE to look at it, and say, if people fulfil this criteria, it's reasonable to stop this medication, because there's very little data available about how helpful,

or how effective these preventative medicines are... it feels, if you stop somebody's statin, and then they die of a heart attack next week, it might be your fault. But in reality, that statin, might be doing virtually nothing for them....I think there's a massive push at the moment to get everyone on anti-coagulants who've got AF, but I think it's gone a bit too far. Because there's pretty much no reason why somebody shouldn't be on an anti-coagulant apart from bleeding. .. you can go ahead and prescribe. But if you take that away, so if you stop the anti-coagulant for people who've got cancer and are at risk of bleeding, like with solid tumours, you feel like 'oh, what if they have a stroke now? This week?'. You know? So, what will the family think, if I've stopped this anti-coagulant and they have a massive stroke, they're gonna think it was my fault. When actually, the reality is, it's maybe reducing the risk of stroke by about 1 or 2% per year. So there's a bit of an over-emphasis I think about getting people on things, and then absolutely no guidance whatsoever about how to take them off it. So we're kind of a bit left at sea, with all of it."
GP 3

"I think because they get more and more medicines added on, without necessarily a holistic review of all the medicines they've got. So you can see lots of things here that are for long term conditions, but if these people are living with advanced cancer – are all those still sensible things to be taking? Or could we stop some? Given that presumably they've got a limited life expectancy now, should we have not got rid of some of those tablets? I'm very keen on getting rid of tablets if possible. It's probably true, or possibly true, for GPs [uncertainty to deprescribe]. I think some of the Pharmacists might think differently about that, because we've done more training around that, in de-prescribing as well as prescribing."
Practice pharmacist 1

Collaborating

Reflecting on people's experiences with medicines, participants agreed that having limited mechanisms to share information about care and decisions with other HCPs in the broader care team rendered collaboration poor, which they suspected affected the experiences people have with their medicines. HCPs expressed their unease about the assumption from the 'outside world' that everyone involved in healthcare is talking to each other. Many participants felt that because people living with advanced cancer straddle multiple services, their continuing healthcare needs and own expectations were not unilaterally addressed. This made sound care judgements about medicines necessity difficult. Sharing understanding between clinical teams about people's goals of care and ceiling of treatment would help support robust clinical decision-making.

Contextualising this observation in their own clinical practice, participants observed that they witness people continually receive medicines that are possibly not necessary. Prescribers in both primary and secondary care expressed their own uncertainty about when to deprescribe medicines. This was connected to concern about the evaluation of medicines' long-term benefit versus people's limited life-expectancy. Participants also said they often lacked sound understanding about

the prognosis itself, or people's own knowledge of their prognosis, to enter such discussions. Deprescribing decisions seemed even more complicated in this population because of improved outcomes with cancer treatment, which extended life expectancy. Participants with specific end-of-life care experience observed the downstream impact of this avoidance. HCPs said it was common for medicines to just be continually re-prescribed and only when people were at a crossroads in their care would it be addressed. This was a particularly regrettable feature of the Specialist Palliative Care role, as it perpetuated a notion of their coming along and taking everything away, which could cause people to feel abandoned as though everyone was suddenly giving up on them. In fact, they were often doing deprescribing work that could have been done much earlier in the trajectory causing no impact on people's clinical outcomes and far less emotional distress.

"There's an emotional context to stopping long-term medication, because it's another sign, that this is somebody that is going to die."
GP 1

There were also clear discrepancies in the transfer of information between clinical settings. A Research Nurse explained how clinical trials data were not collected in the same place as other notes and so information was not easily exchanged between the treating team and other HCPs. This individual independently added extra communication to people's standard medical records to ensure other professionals had the same insight. However, this was not necessarily a routine practice.

Being disconnected from the dispensing pharmacy was another example given by participants as how poor collaboration in the medicines use process had obvious downstream ramifications for people who use medicines. Some HCPs, who were not necessarily the original prescriber, explained having to facilitate access to medicines when issues occurred at local pharmacies.

"[discussing access to medicine] we've had so many phone calls from patients in the last 5-6 months – so distressed. A lady last week, in [town x]. She is now 5 years post-Wipples, but she's phoning us, she had her surgery here, to say, I can't get my Creon. Yet she's had it for 5 years. And guess that comes down to money now. Everyone's cutting down, so she couldn't get hold of it. so I must have spent about 3 hours, phoning round. The pharmacist there was so unhelpful 'we don't have it' – 'well you've got an obligation to find it for her! This is your – she's come to your pharmacy, she lives in [x]. And you're thinking 'why am I sorting this out?' and it always comes back, 'we haven't got it, we haven't got it' and it always comes back to us. it was really frustrating… But I don't know why that is always our problem to sort out as a CNS. You're always gonna sort it out – but it's that passing of responsibility. That's tricky."
Oncology CNS 1

The absence of a shared platforms for communication with pharmacists restricted the dialogue about individuals. HCPs acknowledged that this disconnect from pharmacy colleagues was strange, considering the adjacency of their roles in medicines management. The few cases of working relationships between individual primary care participants and community pharmacists were based on proximity or prior personal experience of working in the pharmacy setting. Participants noted that it could be difficult to give consistent advice to people and prevent, mitigate, or solve problems, due to the limited relationship with the medicine supplier. Participants perceived the commercial aspect of NHS prescribed medicines as unhelpful. The vast network of independent medicines suppliers meant different supply chains, different stock, and different internal dispensary protocols. Some participants were also sceptical about the underlying ethos of some community pharmacies. They referred to the remuneration process for pharmacies who supply NHS-prescribed medicines and observed that these private companies might not necessarily share or do everything possible to support a wider medicines optimisation agenda.

"so another big issue, is that they can't see what we can see. So, All they've got really is a list of drugs. And you can make inference from that, but you don't know a lot, you don't know everything from that, and because they can't see what we can see, they can't see the electronic care record, I don't think, so they haven't got that clinical information about patients. But they've got the patient, so that's something. But without that background, it's really hard to find everything out that you need to. So I would like at some point to see things mesh better. There's some things to get over… in terms of where their priorities lie in terms of business, and things, and how we make sure that access to records is done in a way that isn't business orientated rather than patient-orientated. So I don't quite know how you resolve that situation"
Practice Pharmacist 1

A clear opportunity identified for supporting medicines use was embracing a more coherent approach to the medicines use. Basic adjustments to improve channels of communication between HCPs were seen as essential. In secondary care HCPs identified that better dialogue at transitions of care, such as admission to or discharge from hospital, could be helpful. One oncologist described their deliberate attempts to maintain continuity by updating the GP with helpful information about recent hospital consultations or admissions. Revisiting the format of discharge summaries and letters was one potential solution to this delayed transmission of vital information.

"I think if someone's an inpatient, it's probably easier, because the discharge summary gets sent to the GP with an updated list. If someone's in outpatient clinic, it's harder unless you make it very clear on the letter. What I tend to do is if there's something I want the GP to do is I highlight it in bold and put 'For action by GP' at the bottom. But I've seen other people's letters when it just mentions somewhere in the text. GPs probably get hundreds. I guess sometimes it's not clear how much that's been discussed with the patient in the clinic as well. So if I was a GP, I don't know if I'd feel I needed to make an appointment for the

patient or at least speak to them on the phone before stopping it. or they may complain... consultants have said if you want another team or the GP to do something, you've got to make it really clear, because people might have dozens of letters and they're just skimming through, or they might just look at the bottom."
Oncologist 1

Another opportunity was in managing people's expectations about how long medicine might be required, from the time of medicines initiation. This might remove some of the perceived hurdles to stopping medicines. Many participants felt deprescribing was fraught with clinical ambiguity. They said that they needed robust criteria upon which to base their decisions about stopping medicines. This would give them confidence to make decisions, even if a different profession had been previously involved and in the absence of thorough documentation about prognosis and advanced care plans. Participants introduced the idea that collaborating on Advanced Care Planning could improve medicines optimisation for this population. Improving communication links with pharmacies was another obvious opportunity to improve the experiences people have using their medicines. Participants thought that providing dispensaries with basic information about the individual medicine user and the indication for their medicine, or their other medicines could be one valuable step towards tailoring the advice or support people receive when collecting medicines. A strategy proposed to facilitate this was by adding free text to the prescription itself, or to the medicines label, which could provide more context for the medicine. Another suggestion of something that could help, made by several hospital-based prescribers, was to find a way of having better insight into the specific brands and denominations of medicines supplied by pharmacies available in the community. This could assist their insight into what medicines people may receive, to improve communication and help them minimise some of the supply issues people have.

Theme 3. Expertise and Resources

The resources HCPs have available for supporting medicines optimisation influenced their involvement with people living with advanced cancer and they agreed likely affected people's experiences at home. Participants explained that having relevant skills and knowledge affected their approaches, and uncertainty about the nature of appropriate advice was apparent. HCPs readiness to engage with people about medicines was influenced by their own pharmacological knowledge. Prescribers and Pharmacists referred to role-specific training which facilitated structured conversations about medicines. Participants in other roles lacked relevant communication prompts and felt uneasy and ill-equipped to address concerns or give specific advice. Several participants were unclear about advocating strategies to support medicine use that had not been scrutinised or validated by a prescribing clinician. Others were pragmatic and stated the importance of being non-judgemental and appreciating people's everyday practical reality and need to use medicines in a way that works for them. Participants' perspectives were grounded in the clinical exposure afforded by their role. Disparities existed both within and between different HCP disciplines.

Having the right knowledge, skills, and tools

The experiences that people have with their medicines were found to relate to HCPs knowledge, skills, and resources. This concerned both practical support with medicines management and rationalising medicines indication. Whilst acknowledging that sound understanding about medicines was essential for safe clinical practice, many described a need to remain focussed on their own clinical remit. Some expressed insecurity about their own professional knowledge, which in the context of their clinical practice caused a reticence to embark on conversations with people. This was particularly relevant now, given the modern context of advanced cancer. As specific diagnoses were more like chronic conditions, HCPs identified the required shift in their knowledge around the associated complexity and challenges in supporting medicines use. Many HCPs were reluctant to get involved with medicines whose indication or mode of action was highly specialised, as they perceived this being beyond their clinical competence. In primary care, for example, HCPs who were experienced prescribers themselves felt unsure about having conversations with people living with advanced cancer about anti-cancer treatment, due to the plethora of novel medicines available and the difficulty maintaining up-to-date knowledge.

Complementary medicines were also difficult for clinicians to discuss. Reflecting on the evidence presented from Research Study One, several participants recounted the popularity of alternative therapies, which often followed trends corresponding to public media coverage. But because of the dearth of robust scientific evidence and related clinical guidelines regarding their safe use, participants could not engage with people easily about them. HCPs in both settings described feeling useless. They were sympathetic to people who wished to receive advice or guidance around the use of alternative medicines but were obligated to discourage their use.

> *"it's really difficult because none of these things are regulated, there's no evidence on efficacy or for their safety. And for a pharmacy perspective were often asked to look at interactions"*
> Clinical pharmacist 1

The experience people have with their medicines was also related to the resources HCPs have available. Participants highlighted the fundamental absence of standardised clinical tools for supporting independent medicines management for people living with advanced cancer. They explained that the medicines prescription which people receive from the pharmacy is in the form of a list, which is small and does not have space to include specific directions for medicines use and does not present an administration schedule. However, it was not clear to some participants if this information could or should be translated into a useful format for people. Reflecting on their own practice, HCPs identified that strategies to help people manage their medicines existed only at a local level. Some individual HCPs constructed their own timetables for people who they were concerned about. Participants from oncology referred to diaries, which are a standardised resource for documenting SACT administration and associated side-effects. These were recognised as a

useful tool both for practically managing medicines and in facilitating accurate medical consultations. However, these documents did not have scope for recording non-cancer medicines, nor were they applicable to those not receiving oral SACT.

Across clinical disciplines, participants were confident that appropriate use of medicines was linked to the knowledge people have about their indication. HCPs consistently perceived that people are more likely to use medicines as directed when they understand the rationale for the prescription and intended benefits. Participants reported being dedicated to helping people learn why medicines were important. They explained that having information about the need, mode of action, and likely effects was essential.

> *"yeah I think it's understanding and education...It's certainly something that I try and do because I think it's quite quick to say 'take this medication at this time of day', but it's the why. And patients want to know the why, of course they do. It's their body and they want to know what the benefit is!'*
>
> GP 1

Some participants assumed that patients with more medicines are more susceptible to administration difficulties. This directly informed who they anticipated would need help. Several HCPs in both primary and secondary care also made generalisations about patients who were 'fine' and referred to having a sense if people 'get it'. One Oncologist described the people in their diagnostic speciality traditionally being 'well-informed' and 'obedient'. However, others acknowledged it was difficult to judge competence and some had experience of people not managing at home, who they had assumed understood everything. Some participants indicated that issues often cropped up later when patients telephoned in crisis.

> *"They've got a lot to obviously cope with at any one time – and trying to fathom out what medicines to take. And I think that's why we get a lot of phone calls… 'I'm not sure, I'm not sure' and it's about educating and empowering them about taking some control... They get sent home with this back, and they'll ring me and say 'oh I feel sick' and you say 'have you taken any anti-sickness?', 'What anti-sickness?',' the anti-sickness that's in your little bag that they gave you in the chemotherapy unit' 'oh! That bag!'*
> Site-specific CNS 1

> *"When they initially get prescribed the patches, I go to pharmacy, pick the patches up, and try and give them to the patents to try and save them having to go along basically, and show them, the patch, so that they know what they look like. A couple of patients have first opened the packet – and there's a silicon bit inside it, but it's attached to the outside of the packet with a silver covering over it. They were trying to peel that off – thinking that that was the medication, putting that on and using the patch to stick it on with. Two people have done that, and one of them was a retired GP. And I'd explained it to him beforehand, because I'd seen it. I spoke to pharmacy to say, 'what can we do about this? can we get in touch with the*

company? to say "can we put something on the box?"'. It's just the clear patch. Now I always pick the patch up, open it, take one out and show them, and say, when you go home, you can put – or if it's a day that I want them to start it, I can put them on myself so that they know. "

Research nurse

Participants explained that the main intervention available for patients requiring support with their medicines was a pre-filled compliance aid. Some HCPs described referring their patients for a compliance aid if they were concerned about medicines burden, adherence, or safety. However, others were cautious and critical of their use. These participants explained that although recommending people receive a compliance aid was a way of doing something, they were needlessly disempowering. These participants reported feeling passionate about giving people choices and opportunities to be in control and argued that in fact more creative tools may be available, which could delay or avoid their use altogether.

"I could talk for 40 minutes on dosette boxes and the problem that we've got with people going 'oh there's a medicines problem!' and people ending up on dosette boxes – which may or may not be appropriate - But I have such strong feelings about the inappropriate use of dosette boxes.... disempowerment, cost, the environmental cost – because they're plastic and they have to be chucked away! From a stability of medicines point-of-view. It stops us having to acknowledge that maybe people don't want to take x number of medicines because we stick-'em in a dosette box and then they take them – so it promotes medicalisation of life. But mainly the biggest beef is the amount of plastic! And that's nothing to do with pharmacy. So one of the referral criteria that I've put in place for [service] is that when you think someone needs a dosette box – and like when the Doctors'll send a referral and say 'I think this lady might need a dosette box, can you just see her?' – and it really bugs me when they've already said 'you're gonna have one'. I find it really hard to not get them. And you'll get patients who say 'I want one'. It's often laziness, and if it's just for convenience that you want a dosette box you should pay for it. So - difficult."

Practice pharmacist 2

A key opportunity to better support people with their medicines was consequently identified by HCPs as the availability of robust, standardised tools or frameworks that they could use to offer practical support for people to use their medicines at home. This might be a simple chart, or some useful advice about using a specific medicine optimally. Enhancing understanding about the practicalities of medicines use would be particularly helpful for nurses who do not necessarily prescribe medicines but are often contacted by people who need support. This was seen as a meaningful way to help people which could promote maintenance of independence.

"Patient empowerment is a big thing, that we should think about rather than solving something… it's really powerful in Palliative Care. People are losing such a lot, losing control of many, many facets of their life – why should we assume that they're gonna lose control of their medicines management? If we put things

the things in place to support them. So I don't think we should make that assumption...one of the things I do, quite frequently here, and I've don't it through my carrier in different places, is write down just on a simple chart, what they take, why they take it, for them – and give it them. I've done that on and off."
Palliative care CNS 3

A support predicament

Participants expressed their professional obligation to uphold medicines management best practice principles. However, they also demonstrated conflicting perceptions of people's medicines management approaches, and their professional responsibilities to provide support. Responding directly to evidence about the experience people living with advanced cancer have with their medicines from Research Study One exposed uncertainty about whether it is best for people to use medicines sub-optimally, or to not use them at all. For example, some participants believed that the practice of dispensing medicines in advance by placing them out in useful locations for later use, is grossly unsafe. Medicines are separated from their original packaging, which leaves margin for confusion, as they are no longer stored alongside relevant information. Removing medicines from their sealed blister pack also means medicines were exposed to the atmosphere, promoting degradation which may affect their efficacy. Leaving medicines out on surfaces was, moreover, seen to present a risk to vulnerable third parties in the home, such as children or pets who may mistakenly come to harm. These participants were reluctant to advocate this approach. Similarly, some participants were worried about people modifying medicines administration instructions to suit their lifestyle or manage side-effects. They could not promote this practice, citing that deviance from clinical direction was unsafe or might render medicines pharmacologically ineffective.

Figure 14. George's kitchen table

Others expressed that they had limited knowledge about the risks of modifying medicine dispensing directions, so just discouraged people from doing so to be on the safe side.

Annotating external medicine packaging with handwritten information also divided opinion. The absence of standardisation and verification in this method caused concern to some Pharmacists, who feared instructions might be incorrectly transcribed.

"but in terms of the label, it's difficult because some medicines are used form multiple indications there's also confidential aspects, so if a patient has chose to write on their own box that's their choice, but if we were putting that information on it would have implications. And labels are small as they are and we have a lot of information to put on them legally, you wouldn't want to make it smaller...It's difficult because you're not able to validate if that information's correct. Everything that happens in pharmacy labels are written by one person and checked by another and it's who writes on it? Who checks it? So it's impossible to prevent patients doing that – the medicines are theirs once they take them out of the hospital, but I don't think it's something we could introduce – it's another risk. It's definitely a grey area."
Clinical Pharmacist 1

Participants talked about the alternative options to help people with familiarity with medicines. The practice of people annotating labels served to confirm HCPs belief that labels did not contain information people need. Some prescriber-participants explained it would be possible to manipulate the information on the printed label by adding free-text to the electronic prescription. However, they did not do this at it was a disclosure of confidential information. In the context of their clinical role, this had also become an issue in terms of supporting the use of alternative medicines. Some HCPs respected people's efforts to help themselves and recognised this concept of doing anything possible. However, others expressed concerns about the lack of clinical evidence demonstrating the benefits of alternatives. In response to photographs of herbal supplements, HCPs were also concerned that this provided an opportunity for unregulated industries to take advantage of vulnerable people.

"Well, what we say is, there is no advice about herbal supplements and we can't advise how to take them. We don't know the effects, we don't know the side-effects. People think they're natural, but you can get horrific side-effects from some of these supplements. Cannabis oil – we had a guy who was sectioned because he was delusional. So its educating them that ...we have really good Cancer pharmacists who will have conversations with people's so a lot of the time we'll seek they're advice. Because it's a bit all over our heads really with all these natural things. And some of it can be really helpful. Ginger really helps our patients with nausea. But we can't go into the things where there isn't the evidence, like blackgold or manuka honey'
Oncology CNS 1

Figure 15. Christine's blackgold and mushroom supplements

Alongside acknowledgment of concerns for people's safety, participants described the importance of supporting people to use medicines in a way that suited them. They were compassionate about the everyday challenges faced by people living with advanced cancer and encouraged individual approaches. These participants stressed that people were doing their best with the resources available, and that medicines use should not compound their distress. They suggested that a pragmatic approach was best if it meant that people could use medicines at all.

Some participants appreciated people's rationale for modifying medicines directions and using them according to their lifestyle preferences or constraints. Likewise, some participants felt that on balance, the benefits of having a system to remember, for example, outweighed concerns about the safety of dispensing medicines in advance of their use. Other participants suggested that a lot of things to do with home medicines use relate to common sense, which clinical frameworks or guidelines cannot necessarily encompass.

This differing stance about personalised medicines management approaches and clinical best practice was articulated by two pharmacist participants. Both had similar length of NHS experience; one as a hospital specialist and the other in the community. The former advised strongly against regimen modification and advance dispensing, citing principles of safety. However, the pharmacist with a background in primary care was relaxed. Whilst acknowledging the ambiguity for HCPs supporting medicines optimisation, this participant identified that blanket disregard of people's approaches towards medicines did not help anyone. People could too easily be deemed unable to use medicines 'appropriately' and have their independence revoked.

"there's a risk to other people, you don't know who could be visiting, children. It's a risk to animals, but also it's a risk to the stability of the drug. If they're packed in a blister pack or they're in a container with a desiccant for example, when they're exposed to the atmosphere they could be absorbing water, it could be changing the formulation....They must stay in their original containers until the time of use. ...And it is a balance between the risks to the medicine, and the risks of not taking it at all. It's a massive balance. We often don't know this goes on. If you know, you can provide advice and support....I guess the question for some meds is if they're not taking it optimally, should they be taking it at all? Would they be having gastric symptoms without the lansoprazole? Its difficult to know. That guidance [pre-meal] is a is about the optimum way to take that medicine to get the best from it, its balance between the GP, the prescriber, as to how to get the best adherence for the patient in combination with the best from the medicine."
Clinical pharmacist 1

"For me, if the medicine's degrading, it'll show up in his bloods, if his Thyroid Function is not being treated properly, maybe we can ask the question. If his cholesterol's not coming down, if his blood pressure's rising, then we can say there's a stability problem. But if he's on 3 different anti-hypertensives and his blood pressure's alright, what are you doing trying to solve that problem. It is not even a problem. He is taking responsibility. So that really bugs me"
Practice Pharmacist 2

Some participants identified an opportunity to support people in their own clinical role by equipping people with skills that allowed them to retain independence and promoted their preferred lifestyle. This commitment to enabling people was grounded in respect for people's agency and autonomy. Participants considered this to be particularly relevant in this population, who valued having some measure of control over their lives. HCPs explained that providing tailored, personalised specific advice and support was essential to developing person-centred approaches with this population.

"I'm a bit of a personal trainer around medicines. I think we underestimate that at our peril - that the inter-personal relationship that I build with people, is as personal. And it come back to how you speak to people and what people want, in terms of, they want meaningful connection don't they? They want someone to understand. So I think that if you can build a rapport with people then that's meaningful. But its bespoke, I would say. I don't go around going 'this is what I do for everybody'."
Practice Pharmacist 2

5.4 Discussion

5.4.1 Summary of findings

The findings of this study enhance understanding about the experiences that people living with advanced cancer have with their domiciliary medicines. In response to the evidence generated by Research Study One, HCPs recognised aspects of advanced cancer healthcare which influence the complex self-management activity entailed by medicines management. HCPs were also able to translate their observations from clinical practice into ways to improve support for people to use medicines at home. The findings offer critical insight into the organisation of care and its supporting infrastructure, HCPs individual roles and responsibilities, and their potential to affect change. The three concepts which captured this added depth of knowledge about the experience of medicines use encompassed clinical insight into people's experiences, clinical oversight of the medicine cohort, and clinical resources to support medicine use.

The provision of safe and optimal medicines care relies on HCPs having access to accurate information about medicines, and the chance to talk to people about their use. Yet HCPs feel that they are often working blind, and do not know what is happening with people and their many medicines. The medicines self-management needs of people living independently with advanced cancer are potentially hidden from the view of people providing their care. Evidence also highlighted that oversight for the whole medicine cohort is key in the delivery of coordinated and efficient support. With no single clinician tying everything together, medicines care persists in silos, which can be poorly coordinated. Individual HCPs are reticent to take charge, due to the difficulty in understanding decisions made previously by other HCPs, the few chances to collaborate with others and the tremendous complexity of the clinical scenarios. The expertise, knowledge, and tools that HCPs have available in everyday practice to provide support to people who use medicines, also impacts on the opportunities to meaningfully impact their medicines optimisation.

This evidence highlights how HCPs are constrained by what they can see, who they can talk to, when they think they should intervene and what they know about supporting medicines use. In this research HCPs interpret that these challenges have downstream consequences for people living with advanced cancer which are realised in their medicines management experiences. This understanding helps to better appreciate aspects of the experiences highlighted in Research Study One. Figure 16 portrays the ideas raised here by practising HCPs integrated into the conceptual description of what is happening for people living with advanced cancer who use medicines at home. The diagram places these three new concepts from this current study alongside the self-management effort that people undertake. It is suggested that addressing some of these areas in the healthcare context might mediate some of the burden incurred in this area.
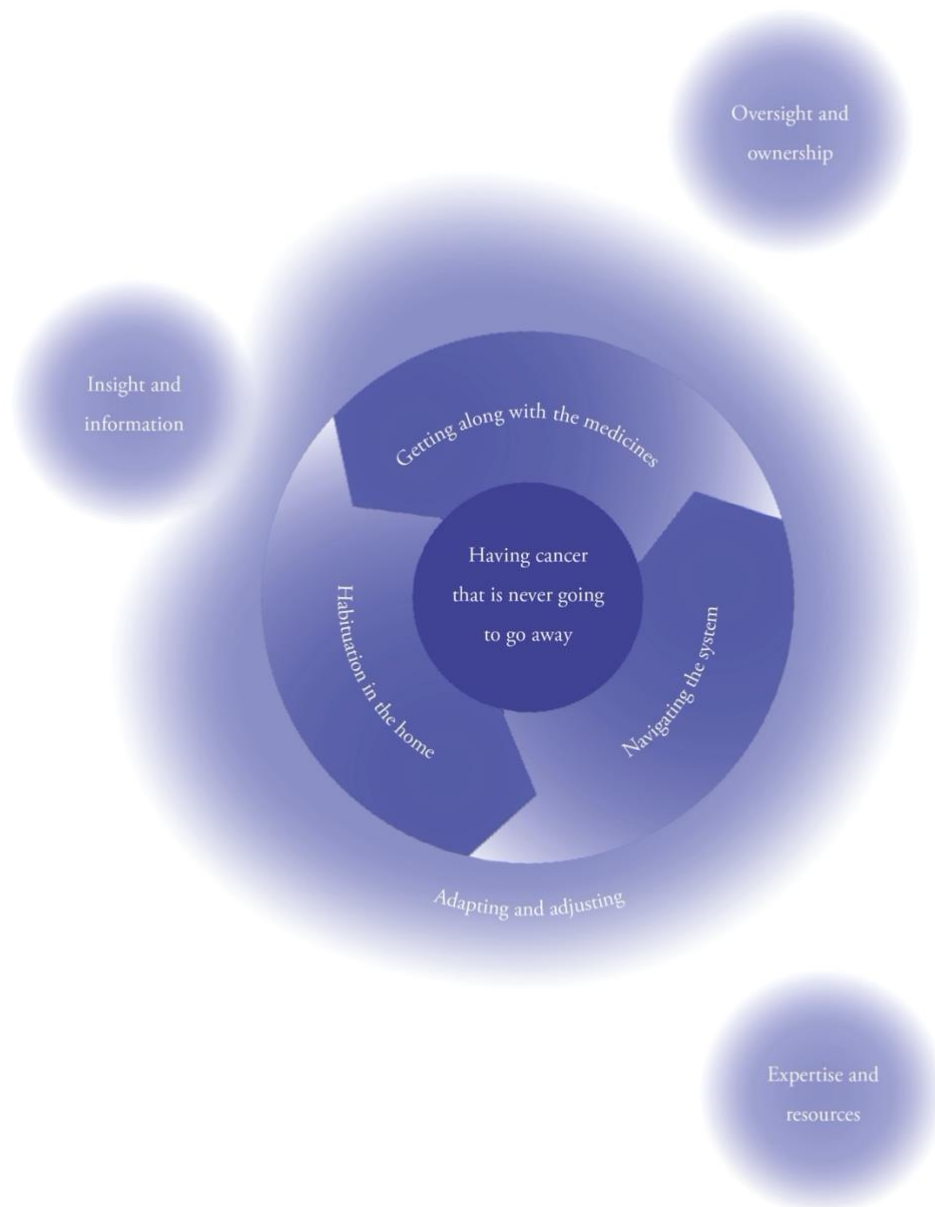
Figure 16. Conceptual description of medicines use in advanced cancer in NHS care context

The approach taken in this study, to use the powerful and emotive accounts of people living with advanced cancer as a means of exploring medicines use experiences with healthcare professionals, was judged a promising means of exposing rich new insights and moving ideas forwards. The research has generated some useful evidence which gives contextual depth and examples of changes in practice. The responses from different HCPs varied and highlighted disparity in HCPs insight into people's experiences, depending on their clinical role and experience, which impacted on the extent that they were able to talk about and enhance understanding about the related issues in clinical practice. Some had knowledge relating to the ideas and provided valuable commentary based on their own clinical experience and critically examined advancements possible in their scope of practice. A select number of participants demonstrated significant investment in the interviews

and offered detailed, compassionate contributions. Notably these individuals were all working in roles with frequent direct contact with people living with advanced cancer such as CNSs or had a role which included formal responsibility for the implementation of medicines optimisation policy, namely Pharmacists. In addition, some participants, who admitted not previously considering these specific issues, showed an openness to gaining new knowledge via this research about people's experiences.

Others, however, did not demonstrate the same enthusiasm for the focus of this work and several interviews felt stilted. Consequently, this data is not always as enlightening or future focussed as the methods aimed to effect. There was a recurrent challenge of steering HCPs towards providing their insight into the specific issues associated with the evidence from Research Study One, rather than issues from their own frame of understanding associated with medicines use. A deeper contemplation of the issues was sometime elicited when photographs were introduced in interviews. Yet, in several situations participants had little to remark. This difficulty in interacting with some participants about the research appears to reflect a fundamental issue that some HCPs are disconnected from people living with advanced cancer and unaware of many of the issues around medicines use and so they find it challenging to reflect and talk about it as it is outside of their frame of reference. This certainly suggests that some HCPs, particularly those who have less routine contact with people living with advanced cancer, or whose input is not specifically related to medicines, would benefit from training and education around the expectations for medicines use in this population. Another observation was that participants were sometimes guarded in their responses. This may be due to a perceived disconnection from some of issues; because they are enacted in the community setting or sit in a phase of cancer care where there is potential ambiguity around clinical decisions and advice. It also may indicate a hesitancy on the part of HCPs around giving advice or information about an area of care that is so complex and clearly presents a challenge in everyday practice.

The study provides important new evidence to expand understanding. In addition to some contextual insight about people's experiences, the divergence in opinions amongst HCPs involved in advanced cancer care highlights how a collective issue like medicines optimisation, which is labelled as 'everyone's responsibility' (RPS, 2013), is interpreted so differently across care settings and professions. Rather than a collaborative, connective ethic, the approach is siloed and uncertain. This fragmentation of the process for medicines use, reflects other broader observations about continuity of care in the advanced phase of illness. Continuity of care has been defined as the coherence and relatedness of care (Haggerty et al., 2003). These types of continuity and their effects are categorised as Informational, Management and Relational, which refer to the transfer of information, interpersonal relationships and care coordination. Dumont et al., (2005) exploring continuity in relation to advanced cancer care recognised the overlap of these principles with the care of people living with advanced cancer. The sheer complexity of advanced cancer has been

previous explained as a reason for discontinuity in medicines management (Cortis et al., 2017). A lack of clarity in roles and responsibilities has been found to lead to frustration and reduced trust from people receiving care in those providing it (Haggerty et al., 2013). The findings here about the fragmentation observed in medicines care during advanced cancer, and the possible ways to improve people's experiences are well aligned with these dimensions.

The apparent disconnection between HCPs and people's use of medicines at home is surprising, given the ubiquity and extent of medicines use in this population. There are problems with the passage of information between professionals, particularly across settings. Informational continuity is defined as the effective transfer of information (Haggerty et al., 2003). Dumont et al., (2005) showed that information gets more complicated as more professionals are involved and impacts on how people and their families experience disease. One of the key barriers to achieving continuity was the communication between secondary care specialists and GPs (Sangster et al., 1987; McWhinney et al 1990; Wood and McWilliam, 1996). In this current research, a central issue of the medicines management experience related to the practice of different HCPs witnessing or intervening with distinct aspects of the process, yet having ineffective information platforms to share information. This prevents cross-setting visibility and collaboration regarding medicines.

Elsewhere in cancer care, this impression of an inefficient flow of information between and across settings is consolidated. It has been demonstrated that effective communication about medicines arises at interfaces of care (Foulon et al., 2019; Petrov et al., 2018; Almanasreh et al., 2016). Medicine errors during hospital admission for example, are a common consequence of an incorrect medication history taking at clerking (Petrov et al., 2018; Mazhar et al., 2018; Mohiuddin, 2019). The methods used to exchange information also contribute to this. The standard process of writing letters is a known source of communication lapses about medicines (Cresswell et al., 2015). In specific relation to medicines, lists of prescriptions and changes were frequently omitted from secondary care discharge letters (Redmond et al., 2019; Dinsdale et al., 2020). A national audit in the UK found that information about medicines generally, and the rationale for medicines changes, were the data most frequently omitted from hospital discharge summaries (Hammad et al., 2014). A more collaborative approach between GPs and Specialists for referral and discharge summary and appointments has been recommended (Dinsdale et al., 2020; Greenfield et al., 2016; Doyle et al., 2015; Backman et al., 2019). Rowlands and Cullen (2013) also highlighted how communication within teams in the same setting can also be limited, drawing attention to some of the flaws of multidisciplinary team working.

Accurate and up-to-date record keeping is also important to support the transfer of useful, correct information. Poor standardisation of records has been shown to disrupt care (Green and Thomas, 2008). The need to urgently improve electronic record sharing is well known. The inadequacy of NHS Information Technology (IT) hardware and infrastructure has been widely agreed to prevent

exchange of accurate, timely medical information (Warren et al., 2019; Darzi, 2018; Haggerty et al, 2003; Coleman et al., 2003). This is particularly relevant given the landscape of increasingly specialised services, like cancer, where care is spread about (Warren et al., 2019). Much better joining up is needed (Darzi 2018). This current study has shown that this IT problem relates specifically to medicines use. Whilst there is some congruence of infrastructure, this is often local or restricted to certain disciplines and settings. These findings support the broader call for better medicines IT infrastructure (Frisse et al, 2010; Mohiuddin, 2019), and indicate a potential to impact positively on the ability to support people living with advanced cancer with their medicines. Very recent research identifying and quantifying these 'operational failures' of poor transfer of information and technology in primary care, found they disrupt care and impact on GP experience of work. Yet the work GPs do to compensate for these barriers unintentionally makes them invisible (Sinnott et al., 2020; Sinnott et al., 2021).

Another significant finding in this work relates to the apparent unclear coordination of responsibility for the whole medicine collection. This resonates with the concept of Management Continuity, which describes the coherent, holistic, and timely scheme of coordinated care (Haggerty et al., 2003). In the context of advanced cancer care, Dumont et al., (2005) acknowledge the inherent complexity of the undulating trajectory of advanced cancer care and the lack of overall long-term leadership for people living with advanced cancer. This phase of care necessitates cooperation between HCPs in primary and secondary settings to facilitate continuity (Sangster et al., 1987; Wood, 1993; Wood and McWilliam, 1996). The current study identified how people's needs with their medicines span both settings and vague ownership can restrict how people are supported to make decisions. The changes in cancer care over time have resulted in a lack of clarity about roles and responsibilities during cancer treatment and beyond between HCPs in Primary and Secondary care. GPs have been reported to feel disconnected when people go through phases of specialist treatment (Christ et al., 2021). Having a named coordinator could help to fill some of these management continuity gaps. In older adults living with cancer, it has been suggested that Geriatrician could be integral to addressing complexity, assessment, continuity, and palliative care (Gosney, 2007). Other GPs dealing with multimorbidity highlight how a Geriatrician has an excellent 'global view' (Smith et al., 2010). The involvement of the GP during treatment has also been recommended to ensure continuity of care (Ogle and Plumb, 1996; Wood, 1993).

In this current work the role of the manager would clearly be relevant in terms of advanced care planning (ACP). In this study ACP was highlighted as an area intricately linked to medicines optimisation. ACP is the process of considering and sharing values, goals, and preferences for future care, and it underpins care during serious and chronic illness (Sudore et al., 2017). ACP has the potential to promote people's autonomy and shared decision making (Boyd et al., 2010). The evidence in this study suggests that ambiguity related to ACP has implications for medicines care and the need to support shared decision making between the people receiving care and primary and

secondary care. There is a proven surge in the discontinuation of medicines for co-morbid conditions towards the end-of-life (Hui et al., 2015), which participants in this study also observed. Decisions about stopping medicine consider people's prognosis, preferences, co-morbidities, and the benefits of medicines over time and aim to suggest medicines which are tailored to suit people's symptom profile, prognosis, and preferences. Improved ACP could potentially have an impact in supporting rationale for and enactment of deprescribing. HCPs in this study were fundamentally apprehensive about causing distress by stopping medicines and felt they lacked clear criteria to support their decision. The other side of this issue relates to the initial prescribing interaction. HCPs identified that there was a key opportunity to discuss potential future medicines discontinuation at the time of medicines being initiated.

Some of the fragmentation of medicines care is also apparently related to differences between people's experiences of medicines use and HCPs appreciation of the nature of the work. The third component of the Haggerty et al (2003) description of continuity in advanced cancer care is Relational. This describes the importance of a meaningful relationship between HCPs and the people for whom they care. This is resonant with these findings because of the observed barriers HCPs identify in creating meaningful relationships with people about their medicines use. The evidence in the first study demonstrated the need to recognise medicines as integral to people's experience of using them at home, so they refer to their medicines by knowing the shape of boxes or the colour of tablets, and so can use them. In this second study, HCPs explained referring to medicines based on their pharmaceutical terms, which people living with cancer cannot always say or commit to memory. Because they do not have physical access to the medicines that people use, they cannot see what medicines people are using. This limited knowledge is compounded by a disconnect from the dispensing process so they are unclear what brand or shape that medicine will be. The way this restricts the ability to safely communicate with people about medicines verbally is highlighted in other evidence (Stevenson et al., 2000; Parrott, 1994). This may lead to misunderstandings and may be a barrier to safety because there are no guarantees that people and HCPs are referring to the same medicine.

The findings refer to relational continuity, in terms of the possible misalignment of the agendas of people living with advanced cancer who are using medicines and those providing care. The evidence in this study showed that HCPs emphasise the importance of people's knowledge about why medicines are needed and felt this influenced their use. This is in contrast to the needs of people who use medicines, who explain multiple factors of medicine management which impact on their use. HCPs concentrate on pharmacological detail and medicines benefit, rather than supporting people with information about how medicines affect normal activities; for example, whether they are easily integrated into their day, how difficult they are to retrieve from pharmacy. This helps to understand HCPs' potential insecurity about advising and supporting people with their personal medicines use strategies. The evidence from Research Study One presented to

participants in this second study highlighted some everyday practices of medicines use in the home; leaving medicines out on the side, placing medicine in a non-specialised receptacle; using medicines at a slightly altered time, such as with rather than before food. These 'workarounds' help make their systems effective and robust to potential disruptions. Some of the HCPs, however, interpreted this as risky, irresponsible even. They explained that rather than representing a diligent visual reminder to support medicines use, such self-management was unsafe practice which they could not advocate. Such approaches to medicines use have been described by some as deviant. Elsewhere, however, they are recognised as a reaction to the work of medicines use, and a means of fitting medicines in with life. For example, alternative use of pre-meal medicine, to instead take it at breakfast along with other medicine, strays from prescribers' direction, yet simultaneously prevents that medicine outlying the routine and enables its use. Pound et al., (2005) talk about people's worries about medicines being marginalised as 'beliefs' rather than acknowledging their accounts about the reality of physical and mental effects of medicines and making rational decisions. HCPs demonstrate compassionate awareness for the toll of multiple long-term medicine use, but simultaneously express powerlessness to support medicines use professionally. There is an apparent disconnect between the impetus to understand what medicines are prescribed and why, rather than how, and to integrate them into people's everyday life at home. This suggests that a gap exists between what the Medicines Optimisation good practice guidance (RPS, 2013) recommends and what HCPs are actually able do in everyday clinical practice to support people with their medicines.

Improving continuity of care is a key feature of the Survivorship initiative (DH, Macmillan Cancer Support, 2013) and guidance on Supportive and Palliative Care (NICE, 2004) also recommends enhancing continuity of care. This also here seems to extend to the specific practice of medicines optimisation and offers part of the solution to supporting people have better experiences. The research generated evidence about potential changes in clinical practice to support medicines optimisation, and to healthcare services more broadly. Suggestions made by HCPs in this study attempt to address issues of fragmentation and poor coordination. The kind of medicines management support HCPs would like to offer was aligned with their core clinical practice values of seeing people as individuals, caring for the whole person, and giving people the knowledge and skills to help themselves. Participants were also concerned that adding more contacts to the existing care pathway might increase the burden. Solutions were centred on relieving strain, to minimise pressure on people and individual HCPs to shoulder the medicine management burden.

One obvious way to address this is to drastically improve the opportunities to gain insight and try and better understand people's experiences. CNSs perceived themselves as extremely well placed in oncology clinics and they are already doing in depth assessments with people. They saw scope to better the type of information collected in the Holistic Needs Assessment (HNA) about medicines, to be more nuanced and capture complex factors. The current tool does have a checklist item concerning medicines; however, it does not explore this further. Recognising individuals' capabilities and restrictions via such a tool would support personalised care and have a clear focus

on quality of life. Another idea generated related to the role of pharmacists in both primary and secondary care. This was considered a means to provide a bridge between prescribers' clinical knowledge and people's practical medicines use. One example was a CCG pharmacist liaising with a GP, or a specialist oncology pharmacist sitting in oncology outpatient clinics. The well-considered placement of pharmacists in given clinical areas could provide that opportunity. Medicines reviews are another potential point in the care trajectory to facilitate dialogue about medicines.

5.4.2 Strengths and limitations

A strength of this study was the inclusion of HCPs from multiple clinical disciplines and areas of speciality. This provided broad and varied insight into the issues observed in different clinical settings and stages in the medicines use process and gives an important sense of the bigger system within which medicines and advanced cancer care operate. The study included a small number of participants. A planned suspension of study immediately after the data analysis phase meant that the study recruitment schedule was inflexible. Recruitment was reliant on organisational gatekeepers. Gatekeepers were contacted throughout recruitment to discuss strategies and target under-represented HCPs. Poor uptake of participants in Primary Care, prompted promotion of the study by CCG representatives at local education events. The characteristics of HCPs were monitored throughout recruitment to ensure variance across the sampling frame (Silverman, 2010). Because of the breadth of the disciplines involved in this aspect of care, even better insight would have been achieved by including other member of the MDT. In addition, the sample of participants are all from same region, which means that study findings are restricted by the local context of the study. Other geographical areas may use different operational policies and infrastructure.

Another apparent limitation within the sample is self-selection bias. The HCPs who volunteered are likely to be the people who have thought about this issue and are interested in the inquiry. Furthermore, the evidence in the study which was most rich and detailed was contributed by individuals with a clear role in support that prioritises people's quality of life outcomes, or professional investment in the goals of medicines optimisation. It is therefore plausible that whilst this self-selecting cohort had some awareness and insight about these concepts, there are many more HCPs working in these fields who are less involved, or informed, and the research does not capture those alternative perspectives.

The absence of community pharmacists from the sample is also potentially limiting. Their exclusion was rationalised during PPI which indicated their limited insight into the needs of this specific population. However, medicines supply and the dispensing stage of the medicines use process is a significant part of the medicines management experience and HCPs in primary and secondary care really have limited insight into this practice. HCPs in this study identified a possible disconnect between NHS services and community pharmacy. Having their input in the research may have

allowed access to opinions about this and may have generated additional ideas about opportunities to improve medicines self-management support. Similarly, no community domiciliary care staff were recruited for the research. This was due to the focus on people's independent medicines use. However, given the limited insight of the study participants into people's medicines management practices at home, it may have been valuable to explore the perspectives of HCPs who have first-hand experience of domiciliary medicines use.

A key strength of this research was the use of photo-elicitation in the data collection method. The incorporation of photographs into interviews served as a stimulus for continued exploration of some experiences familiar to participants and resonated with their own understanding of medicines use for people living with advanced cancer. Photographs were a useful way to communicate challenging concepts. The method was continually developed to ease and promote participants' engagement with the data.

5.4.3 Summary and next steps

This study explored NHS healthcare professionals' perspectives about the experiences that people living with advanced cancer have with their medicines at home. Twenty practising NHS HCPs from nursing, medicine and pharmacy who care for people living with advanced cancer in primary and secondary care participated. All were interviewed and shared their reflections on their own clinical insights about medicines use during advanced cancer and responded to evidence about how people are found to manage their medicines at home. Data were captured by audio-recording and annotation. Framework analysis illuminated key themes of evidence related to the insight, the oversight and the expertise HCPs currently working in clinical practice have for people living with advanced cancer who use medicines at home. These summarise how the structure of NHS services, the infrastructure surrounding care, and the role-specific capabilities within advanced cancer, impact on HCPs understanding of people's experience and provision of medicines optimisation support. The overarching concept of continuity is identified as central to this understanding. This study generated evidence which has deepened contextual knowledge about medicines experiences during advanced cancer. We know from this research that a lot of people's encounters or efforts go unnoticed, or are observed in one setting, but not universally acknowledged across care. We also know that the impetus to support medicines management is often centred on the rationale for medicines and their safe use, rather than necessarily built up around understanding if and how people can use them. This study does identify some areas of clinical practice where protocol or procedure could be adapted to try and address ongoing issues identified related to use of medicines during advanced cancer. These relate to acquiring the relevant information from people, and giving people access to HCPs who have relevant information for their needs. They also indicate the need for a broader shift towards appreciating the work that medicines use entails for people living with advanced cancer.

The findings of Research Study One were broad and detailed and held much potential for the future. The additional insights in this study add to that complexity. HCPs offered their commentary on the areas people living with advanced cancer identified as potentially benefiting from change and connected these to their roles and responsibilities. However, there was also conflict and confusion in this data. The people supplying medicines and supporting their use are not necessarily using the same words, and working on the same information, or towards the same goal as people using them. The next step in this research was to find a means trying to establish the priorities for the way forward in this work. There was a need to share this information with the involved communities and engage with other perspectives before moving on. This was a means to preventing rushing ahead and overlooking important factors; to allow further endorsement of ideas; and consideration of the feasibility of clinical practice related suggestions. The aim of the next stage of work was to set priorities with wider communities, in a manner underpinned by the need to keep people living with advanced cancer at the heart of the work, in keeping with the Medicines Optimisation principle of aiming to understand people's experiences.

Chapter 6. Stakeholder Engagement

What is stakeholder feedback to people's experiences and what are the priorities for supporting medicines optimisation in advanced cancer care?

6.1 Introduction

This final phase of the research aimed to disseminate findings and identify the priority of future work to support medicines use by people living with advanced cancer. The research evidence presented in Chapters Four and Five illuminated that using a whole regimen of medicines at home is a complex self-management activity, and the surrounding healthcare is complex and disjointed. People living with advanced cancer describe a multi-faceted workload; and healthcare professionals involved in advanced cancer care recognise a range of systemic factors affecting people's experience and identify multiple avenues for improving the structure and nature of supportive care. However, the intricacy and breadth of the social, clinical, and professional factors relating to this aspect of care are difficult to discriminate and prioritise. The purpose of this current work was to clarify the direction of future support for medicines optimisation in advanced cancer care. Engagement was used to create a dialogue with wider communities, share pertinent knowledge, assess the relative importance of opportunities to improve patients' experiences and generate ideas regarding the implementation of policy, practice, and education to support medicines optimisation in advanced cancer care.

6.2 Methods

6.2.1 Participants and setting

Communities of people with specific personal, clinical, or strategic involvement in medicines use during advanced cancer were considered key stakeholders in this research. Audiences were carefully considered to include as many people as possible who are involved in the complex network of care for people living with advanced cancer demonstrated by previous studies. The selection process also acknowledged the need to reach audiences from these communities motivated to undertake initiatives focused on affecting communal change (The Wellcome Trust, 2021). Stakeholders were people living with or affected by advanced cancer, and qualified or in-training healthcare professionals and strategic leaders from primary care, oncology, and pharmacy. People with current or previous cancer diagnoses or with experience of supporting someone living with cancer were included given their first-hand insight into cancer care and medicines management. In primary care, HCPs providing care to people living with advanced cancer in the community, and those with broader involvement in implementing

guidelines and designing future services, were sought. Stakeholders were identified in oncology as people delivering direct advanced cancer care, as well as non-clinical personnel in strategic, operational, and supportive roles responsible for the implementation of The Recovery Package in practice (Macmillan Cancer Support, 2013). Within the pharmacy community clinicians with expert insight into Medicines Optimisation good practice guidance (RPS, 2013) were also key stakeholders in this work.

Existing events hosted by organisations involving these communities, were identified as potential opportunities to conduct stakeholder engagement. The use of pre-arranged meetings enabled access to a significantly greater number of participants than a discrete event, solely for the purposes of the current study, could allow (Banks and Armstrong, 2012; National Co-ordinating Centre for Public Engagement (NCCPE), 2021). This also meant that resources could be directed towards developing engagement materials, rather than event planning and advertising. Conferences, workshops, and educational events accommodating the target stakeholder communities were identified by the researcher. This involved approaching patient advocacy and governance contacts made through previous stages of the research. Individuals signposted possible opportunities and facilitated networking with event organisers and with other organisations serving these communities.

6.2.2 Materials

Engagement resources were developed to present stakeholders with information, evidence, and interpretive understanding about pertinent areas of domiciliary medicines self-management and asked for their feedback to enable these ideas to be refined and prioritised. To develop the resources, a mapping exercise was undertaken to connect the research findings about people's experiences of domiciliary medicine use (Research Study One), with findings about healthcare context and opportunities (Research Study Two). In this process, research results were reconsidered as a whole and interrogated in terms of the key challenges and areas of distress, or ambiguity, or effort that demand resourcefulness and resilience from people living with advanced cancer; and where HCPs perceive care infrastructure, process, or individuals to have the potential to influence change. Six such examples were identified and are hereafter referred to as a 'medicines optimisation priority':

- **Understanding** what medicines are for
- Developing **practical techniques** for medicines use
- Supporting the impact of medicines on **bowel care**
- Simplifying medicines **supply**
- Minimising medicines **accumulation**
- Maintaining a **normal life** whilst using medicines

Engagement materials were designed to convey each 'medicines optimisation priority'. They were presented visually, in an accessible and interactive way to promote involvement and response from as many event attendees as possible (The Wellcome Trust, 2021). The resources sought to accurately communicate the research in an uncomplicated, stimulating, and enjoyable manner. Collaboration with hosts ensured that the format and content of materials was suitable for auditoria and could be embedded within the predetermined agenda of guest speakers, seminars, or presentations. Materials were produced to incorporate engagement evaluation measures to assess the extent and nature of audience participation with the exhibition. The visual exhibition included the following materials:

- *Photographs* depicting each 'medicines optimisation priority'
- *Pen portraits* describing the photograph and providing context
- *Quotations* demonstrating evidence for that priority across participants
- *Explanatory summaries* providing an interpretive basis of the priority

Photographs taken during Research Study One were catalogued alongside interview data according to associated themes. Photographs were systematically assessed for their suitability in representing each 'medicines optimisation priority' for use in the engagement exhibition. This process included: Quality screening, where all photographs were viewed and the image quality appraised; Organisation, when relevant photographs were identified and grouped according to the associated 'medicines optimisation priority'; Relevance rating, which saw grouped photographs rated based on their visual representativeness of the 'medicines optimisation priority' by PhD supervisors; and Visual impact appraisal, where top rated photographs were considered in terms of their overall impression. Using this approach, three different photographs were selected for each priority. One of the three, considered to have the most visual impact, was reproduced in a poster format. All three photographs for each theme were also printed as smaller picture postcards. Each photograph selected was given a simple description to assist with future reference. All picture postcards had the photograph image on one side, with the reverse stating participant pseudonym, diagnosis and the 'medicines optimisation priority' to which it was attributed.

Pen portraits were prepared to contextualise and personalise each photographic image. These short sections of text provided a narrative summary of the origin of the six poster-sized photographs using data from the Research Study One interviews. Interview transcripts were re-read and coded segments of interview data attributable to that priority were identified. This data was then reworked into synopses capturing individual participant stories. A single pen portrait was composed for display alongside each photograph poster.

Quotations from research participants capturing the six priorities were also presented alongside the photograph and pen portrait. Quotes were identified by returning to the Research Study One database and retrieving specific quotes coded to research themes which the mapping exercises highlighted as linking to a given 'medicines optimisation priority'. Quotes were collated to support each 'medicines optimisation priority' and reflect the breadth of participants' experiences.

Explanatory summaries for each 'medicines optimisation priority' were developed to provide a detailed description for each and enable audiences to understand the underpinning research findings when making decisions about their feedback.

In addition to materials used for disseminating research ideas, materials for evaluating stakeholder feedback were also developed. These included the following resources:

- *Picture postcards*
- *Feedback cards*
- *Fieldnotes*

Picture postcards were colour prints of original photographs taken in Research Study One. As described, three photographs portraying each priority were identified. Therefore, eighteen different picture postcards were produced, for audiences to take away freely. The number of postcards taken at each event provided one measure for evaluating the extent of audience engagement with the research overall and demonstrated audience preference for each priority.

Feedback cards were created to enable audience participants to provide written responses to the engagement resources. Participants were invited to take a feedback card and select their preferred 'medicines optimisation priority', offer a rationale for its selection and give details of ideas about actualises the stated goal of the priority. Feedback cards were a means of evaluating the extent of audience engagement, to rank preferences for each 'medicines optimisation priority' and to understand participants' rationale for selecting a priority and its possible implementation within their role.

Fieldnotes were made during stakeholder engagement, to record pertinent observations about participants' reactions and responses and the environment of stakeholder events. They also were a means to annotate conversations that took place between the researcher and attendees. During individual conversations the audience were invited to reflect on the specific examples provided, discuss more broadly the key concepts from the interpreted data, and introduce their own insights to the presented data. Engagement resources are summarised in full for each priority in Appendix 9.

6.2.3 Data collection

All events were attended by the researcher. Event hosts announced the study to stakeholder audiences and explained the background for the research and summarised the various resources and methods of engagement. Attendees were invited to approach the exhibition and interact with resources. A range of data were collected to enable evaluation of the scope of engagement, the extent of stakeholder interaction, and the outcome of medicines optimisation priority ranking and rationale.

The scope of engagement was assessed by recoding the approximate number of people in attendance at each event. This estimate was corroborated by hosts at each event's conclusion.

The extent of engagement was evaluated by monitoring the number of picture postcards taken away by attendees from each event. The number of feedback cards returned by event attendees was also recorded as a measure of audience participation. Conversations with, and comments to, the researcher were recorded in fieldnotes as a means of capturing a general sense of the receipt of the engagement materials and their level of participation.

'Medicines optimisation priority' was evaluated by monitoring which picture postcards were selected by participants. Recording which picture postcards were taken provided one measure for assessing participant preference towards a particular 'medicine optimisation priority'. Feedback cards also provided data to rank participants' priorities. Feedback cards stated all six priority options and participants were asked to circle the one that was most important to them and return their card. Whilst feedback was anonymous, participants were also invited to state their professional role Conversations with, and comments to, the researcher were recorded in fieldnotes to highlight issues and ideas arising upon participants' being asked to select a single priority.

'Medicines optimisation priority' rationale was also evaluated using the feedback cards. Participants were invited to state in free text their rationale for the selection of a priority.

Medicines optimisation priority' implementation was obtained by the ideas suggested by participants on feedback cards about how to realise the selected 'medicine optimisation priority' within the scope of their own professional remit. Conversations with the researcher referring to relevant clinical or implementation details were recorded as fieldnotes.

6.2.4 Data Management and analysis

A spreadsheet was created in Microsoft Excel to support management of data generated during each stakeholder engagement event. Data recorded by the researcher on paper was transferred into the

spreadsheet after each event. These included tallies of numerical data and fieldnotes. Handwritten data received from participants, such as priority selections and free text comments on feedback cards, were also transcribed into the spreadsheet after each event. All original documents were destroyed after processing. The scope of engagement was judged by the number of persons attending each venue and in total. The extent of engagement with the research was based on the number of picture postcards taken during individual events and overall; and the number of feedback cards received at each event and overall. The priority for medicines optimisation was considered by analysis of overall event data regarding picture postcard selection, feedback card priority choice, rationale for priority choice and suggested implementation strategies. First, the number of picture postcards taken by participants was counted and the 'medicines optimisation priority' with which postcards were attributed was tallied cumulatively. Next, feedback card priorities selected by participants were recorded and their totals at each event and events overall tallied. Then, the professional role of the participants were grouped and their priority selection logged. Data in the form of free text comments written on feedback cards and the annotations of conversations between participants and the researcher, about participants' rationale for priority selection and insights into the implementation of individual priorities into clinical care were then recorded. These were combined and analysed inductively for themes. Comments were statements and sentences, and were systematically reread and organised according to common ideas. Annotations were made in excel to document decisions and analysis relating to the patterns within the feedback.

6.2.5 Ethical considerations

Application to a Research Ethics Committee is not required for public involvement in applied health research (HRA, 2021). This can enable involvement methods such as engagement to be invigorating allowing access to large numbers of people and freedom in methods. However, participatory research itself should still reflect the ethical principles and values of all research (University of Leeds, 2016; National Coordinating Centre for Public Engagement, (NPCCE), 2021). Ethical principles were considered just as they would for a study method requiring formal ethical approval, and several key issues were identified. The individual preference to engage with the materials was respected; including the likelihood that some people may want to attend the event and not participate. There were no incentives, and participation was voluntary. Attendees were not put under pressure to access resources or give their feedback. Gratitude was expressed to all stakeholders who engaged with the research regardless of their contribution. No personal data was collected from participants to ensure they were free to engage anonymously. Collecting data about participant professional titles was voluntary and attendees self-identified. To ensure participant confidentiality was maintained, potentially identifying information provided during conversation with the researcher was not documented in fieldnotes. Any personal information disclosed on feedback card was not transposed onto the electronic record and all original written evidence was destroyed.

6.2.6 Reflexivity

In principle, this stakeholder engagement was a rational, systematic, and iterative process of translating analytical concepts generated from Research Studies One and Two, into clinically relevant statements, which reflected the real-life experiences of people living with advanced cancer. In practice, the activity was unwieldy and challenging. The engagement agenda was compiled as Research Study Two data analysis was still underway, therefore ideas and themes were still being contemplated. The exercise involved consideration of a large volume of data and it was initially difficult to separate out conceptual descriptions from the tangible 'medicine optimisation priorities' presented here. Reflexivity facilitated deep questioning about the purpose of this engagement. This work sought to both validate the findings of the research so far with the wider community of stakeholders and also progress ideas on behalf of people living with advanced cancer who use medicines at home to consider how their experiences can be improved. This realisation helped to expedite the mapping of 'medicines optimisation priorities'. These reflected key experiences that people using medicines report, that people working in practice endorse, and that could be addressed now in practice to make people's self-management of medicines easier. This process required disciplined selection of ideas most relevant to the specific research aims.

6.3 Results

6.3.1 Summary of events and participants

Engagement took place at four separate events attended by stakeholders from different communities, between October 2018 and January 2019. Events are summarised in appendix 10. The audiences comprised CCG clinical staff and researchers with a specific interest] or responsibility for cancer care, strategic leaders, specialist cancer healthcare professionals, patient advocates, people currently and previously receiving treatment for cancer, carers, and clinical, student or academic pharmacists. The events were a range of educational, research and support meetings hosted by local research governance, charity, academic and healthcare institutions. Most auditoria were spacious and accommodated placement of engagement materials in a communally accessible area near event refreshments. This encouraged audiences to look at visual displays. The resources benefited from being in the same room as event programmes, to promote ongoing engagement rather than only during breaks. One event was challenging due to the small venue which provided very limited space to exhibit, and little privacy for discussions between attendees and the researcher. The approach to the engagement with a community cancer support network was modified to reflect the intimate and informal nature of the event. Instead of standing next to resources, the researcher joined the group discussion. Upon receiving the invitation for this event, one forum member was unable to attend but was keenly interested to be involved in the engagement. Subsequent correspondence was exchanged, and a face-to-face meeting arranged to facilitate access to the resources and collection of feedback.

6.3.2 Scope of engagement

Approximately 150 people attended the events in total. Therefore, many people potentially viewed the study exhibition resources and gained access to this novel research evidence. The events hosted audiences from healthcare, research, education, strategy, and patient advocacy, which made them appropriate stakeholders. This was particularly clear from the nature of participants verbal comments to each other and to the researcher during the event, and their free text responses provided in written feedback. Attendees' reactions, personal recollections, and responses were enthusiastic, resonant, and focused, which indicated that the events included people with valuable experience, proximity, and influence. At two events, individuals with senior strategic roles in primary care and specialist oncology services were in attendance. They were engaged with the work and contributed their insight by providing verbal and written feedback. The opportunity was unique in these methods to disseminate the research to influential people and get their input in the future direction. There was some recurrent attendance by a small number of attendees across events. This comprised a small number of non-clinical leaders and patient advocates invited as keynote speakers at multiple events. This overlap was encouraging as it implied that the engagement events were reaching the right network of people with influence in this setting.

6.3.3 Extent of engagement

Forty-one postcards were taken away from the events. Therefore, up to a third of the total audience potentially took a picture postcard away from the event, leading to wider dissemination of the research findings and priorities into wider communities. It was not possible to collect demographic data about who took postcards and it is possible that some participants may have taken more than one postcard. It is also possible that the same individual selected a postcard at more than one event. Forty-eight feedback cards were returned. Therefore, again a third of all event audience members engaged with the priority setting exercise. Participants were provided with only one feedback card. Audience members who attended more than one event were advised to formally engage only once overall. Therefore, this number is a reliable reflection of engagement. Feedback cards were also a means to record participants' professional role. The forty-eight participants who returned feedback cards spanned a range of stakeholder groups and variety of roles within these groups. The distribution of stakeholder role demonstrates the effectiveness of engagement as a method to reach a broad audience including those who may have otherwise been hard to reach. For example, several participants were regional non-clinical leaders for cancer strategy or senior clinical academics. These individuals were unlikely to have been introduced to the current research outside of these events. To assist analysis, participants were categorised according to one of four 'role groups' based on their professional role. Table 9 highlights the scope and extent of feedback and role groups are summarised in Table 10.

Event	Scope of engagement	Extent of engagement	
	Estimated audience	Number of picture postcards taken	Number of feedback cards returned (% of audience)
1	50	17	12 (24%)
2	60	3	16 (27%)
3	10	10	8 (80%)
4	30	11	12 (40%)
overall	150	41	48 (32%)

Table 9. Scope and extent of stakeholder engagement

Professional role	Role group	Feedback cards returned
Management academic strategic	Non-clinical	10
GP, nurses, hospital doctors	Medical/nursing	13
Student, academic & clinical pharmacists	Pharmacy	12
Public, past/current patients, carers	Patient advocacy	13

Table 10. Stakeholder role-group feedback

Discussions occurred across role-groups and covered a range of issues, including specific clinical scenarios relating to prescribing practice, experience of the medicines use process and the engagement method itself. Nine in-depth conversations were recorded for their relevance to the specific aims and objectives of this study, or the wider research. This specifically included participants who introduced novel information regarding issues arising from the research findings, those who contributed to data about implementation of a 'medicines optimisation priority' and those with influential professional roles. Additionally, some of the conversations and contacts made with stakeholder audience members prompted subsequent correspondence after the events, to follow on conversations regarding the progress of the study and potential future application of findings to areas of practice.

6.3.4 'Medicines optimisation priority' setting

Picture postcards taken by participants and the 'medicines optimisation priority' to which they were attributed were tallied, as shown in table 11.

Medicines optimisation priority	Picture postcard	Tally	Total	Rank
Understanding what medicines are for	Tom 'Blood pressure'	2	7	4
	Jack 'IF SICK'	5		
	Karen Calcichew	0		
Developing practical techniques for medicines use	Simon Button	6	8	2
	Lillian Washbag	2		
	Timothy jewellery box	0		
Supporting the impact of medicines on bowel care	Malcolm windowsill	3	6	5
	Jenny bedroom	2		
	Henry kitchen cupboard	1		
Simplifying medicines supply	Margaret inventory	2	3	6
	Timothy 'LAST'	1		
	Isobel bucket	0		
Minimising medicines accumulation	Rosalind cat food	7	8	2
	Eileen drawer	0		
	Malcom kitchen cupboard	1		
Maintaining a normal life whilst using medicine	Brian kitchen counter	5	9	1
	Tony cupboard	2		
	Leonard kitchen counter	2		

Table 11. Picture postcard selection across all events.

The most popular picture postcards were: Rosalind's drawer of medicines, open near the cat's food, which was selected to depict medicines accumulation; Simon's compliance aid, with a button in it to remind him to change his Fentanyl patch, to depict practical techniques for medicine use; Tom's box of amlodipine, labelled with 'Blood pressure', depicting understanding what medicines are for; and Brian's kitchen work surface, depicting him maintaining a normal life. These picture postcards were notably more popular than others and were preferred over other images depicting the same medicines

optimisation priority. Overall, the most popular priority was 'maintaining a normal life while using medicines', closely followed by 'developing practical techniques' and 'minimising medicines accumulation'. Findings are cautiously interpreted due to the small sample size.

The number of times each priority was selected on feedback cards at each event and events overall was tallied. Priority selection is summarised in Table 12. Several participants expressed difficulty in selecting only one priority on their feedback card and some selected more than one priority per card. This accounts for the numerical discrepancy in results, with 64 priorities selected from 48 individual participants.

Medicines optimisation priority	'Medicines optimisation priority' selected					
Medicines optimisation priority	Event 1	Event 2	Event 3	Event 4	Total	Rank
Understanding what medicines are for	7	6	4	6	23	1
Developing practical techniques for medicine use	0	1	1	2	4	5
Supporting the impact of medicines on bowel care	1	1	0	0	2	6
Simplifying medicines supply	6	2	2	1	11	3
Minimising medicines accumulation	2	4	2	0	8	4
Maintaining a normal life whilst using medicine	4	8	1	3	16	2
Total	12	16	8	12	64	

Table 12. Feedback card priority selection

'Understanding what medicines are for' was the highest priority for medicines optimisation in advanced cancer care amongst stakeholders. This was selected twenty-three times at all events, by stakeholders in various professional roles represented in the different audiences. 'Maintaining a normal life while using medicines' was the second highest priority, selected 16 times, and 'simplifying medicines supply' was selected 11 times. 'Minimising medicines accumulation' was selected eight times; four participants selected 'developing practical techniques for medicines use' and 'supporting medicines impact on bowel care' was the least popular priority, selected by two participants who also chose multiple other selections.

The numbers of each future priority selected by different role groups was determined. Sample sizes are small and there were differences amongst participants as to whether a single or multiple priorities were selected. It is therefore not possible to confidently determine whether there are differences in priorities across professional groups. Table 13 summarises the data returned according to professional role.

Medicines optimisation priority	Role group % selection			
	Patient advocacy	Pharmacy	Medical/ nursing	Non-clinical
Understanding what medicines are for	25	50	37.5	41.67
Developing practical techniques for medicines use	4.17	16.67	0	8.33
Supporting medicines impact on bowel care	8.33	0	0	0
Simplifying medicines supply	25	8.33	12.5	16.67
Minimising medicines accumulation	20.83	0	6.25	16.67
Maintaining a normal life whilst using medicine	16.67	25	43.75	16.67

Table 13. Percentage choice of medicines optimisation priorities by role-group

The patient advocacy group had the most even distribution of priority selection. 'Simplifying medicines supply', 'understanding what medicine are for' and 'minimising medicines accumulation' received the highest endorsement. This group were more likely than any other group to select priority 'simplifying medicines supply'. They were also the only group to select 'supporting medicines impact on bowel care' as a priority. This group also had slightly higher occurrences of multiple priority selection than others. Within the pharmacy group the greatest frequency of endorsement was with 'understanding what medicines are for'. Interestingly, the priority 'simplifying medicines supply', which on the surface would seem most applicable to their professional responsibility, had the least importance amongst the pharmacist group of all role groups. Pharmacists were also the only group who consistently selected only one priority. The group with medical and nursing participants was the only group that did not select priority 'understanding what medicines are for' most frequently. They chose the priority 'maintaining normality' with 'understanding' coming close second. This group did not have any endorsement for priorities relating to 'bowel care' or 'developing practical techniques for medicine use'. The non-clinical group results reflected the general trend of the prioritisation in the stakeholder population overall. They endorsed 'understanding what medicines are for' most and had similar interest for the priorities of 'simplifying medicines supply' and 'minimising medicines accumulation'. In

conversations, stakeholders underscored the difficulty in choosing only one priority. This reflected their feeling that everything was important and that they could not pick any one priority over another. Whilst a priority might seem relevant to their own professional role, they remained aware of other roles and scenarios elsewhere in healthcare and so were reluctant to commit to one. Participants described overlap between the priority examples connected by overarching areas of concern, such as practical inconvenience, or emotional burden, which they wanted their selection to affect.

6.3.5 Rationale for a 'medicines optimisation priority'

Participants' notes on feedback cards about their choice provided concise data about their rationale for selecting a 'medicine optimisation priority' in advanced cancer care. Participants also provided verbal explanation about their selection in conversation with the researcher, which was recorded as fieldnotes. Several participants did not give any reasons for their selection of a particular priority on their feedback cards. Others who selected multiple priorities provided a rationale for only one. Notably, many explanations for the 'medicines optimisation priority' choice recited comments from the wording in the textual summaries presented in the visual engagement display itself, rather than introducing new language of independent personal justification. Some participants referred to experiences of supporting their family members with medicines. There were some professional insights. Three overarching themes were generated from participants' rationale for their 'medicine optimisation priority': 'making life easier', 'empowering people', and 'improving outcomes'. Table 14 shows the distribution of sub-themes and overarching themes across the six options.

Making life easier

Many participants rationalised their priority as making medicines use easier for people living with advanced cancer. Participants wanted people's lives to be as straight-forward as possible, as this was seen to benefit their wellbeing and quality of life. Participants from across role groups responded along the theme of 'making life easier'. This theme was reflected in comments grouped as sub-themes relating to reducing the workload, the emotional burden and confusion associated with medicines use.

> *"If patients can't take their medicines practically, there is no point prescribing them"*
> Pharmacist selecting 'Developing practical techniques for medicines use' (feedback card)

Participants recognised that medicines could often become a major focus for people and even seem to rule their lives. They expressed regret about the workload associated with acquiring or using medicines. Reducing work was cited by several participants opting to prioritise simplifying supply. Participants stated that medicines-related lifestyle disruptions should be minimised wherever possible to allow people living with advanced cancer to find their normal rhythm. Participants identified that having

practical techniques could promote maintaining a normal day-to-day lifestyle. Having a normal life was also selected by participants who prioritised the quality of patients' day-to–day experiences. Participants stated that this was fundamental for the care for people living with advanced cancer and perceived a link between this and more effective medicines use. Some participants expressed their focus on reducing the emotional burden of medicines use for people living with advanced cancer. Participants prioritising medicines supply agreed that the complexity of obtaining medicines could contribute unnecessarily to worry for people living with advanced cancer. Likewise, those opting for 'minimising medicines accumulation' reasoned that the difficulty of having multiple medicines at home could be a potential source of stress. Participants selecting normal lifestyle felt that this was imperative to protecting patients' emotional wellbeing.

> *"When life is upside down during cancer, 'normal' is very important"*
> GP selecting 'maintaining normality' (feedback card)

Reducing the confusion associated with medicines use was a common reason for participants' whose priority selection aimed to make life easier. Several participants stated how complicated medicines use could be for patients. They indicated their belief that multiplicity of medicines was a barrier to both practical use, but also understanding medicines and developing knowledge about them. Many participants recalled their personal experience. They could therefore appreciate the challenges people living with advanced cancer faced. During conversations with the researcher, participants referred to their first-hand experiences and professional observations in relation to the complexity of medicines use. Anecdotes about mix-ups, confusion, and stress, emphasised the impact of medicines on life at home and the burden medicines can put on people. Whilst not attached to a priority card selection, these remarks reiterated a commitment to making life easier for people living with advanced cancer.

> *"Friends and family and years in practice indicate to me that people don't want medicines to be the focus of their lives; they want to live their lives without worrying about their medicines"*
> Pharmacist selecting 'maintaining a normal life while using medicines (comment to researcher)

Empowering people

Another theme amongst responses was the importance of giving people who use medicines power in this process. Participants indicated that prioritizing a certain 'medicines optimisation priority' would promote development of informed and independent medicines use. Participants from the professional role groups gave reasons within the overarching theme of empowerment; however, patient advocacy participants did not refer to this concept. Comments about empowering people who use medicines made by participants reflected the perceived significance of education about medicines. Participants

expressed belief in the necessity that people know about the medicines they are given. Selecting 'understanding what medicines are for', participants stated that patients 'should' know what their medicines are for, demonstrating belief in the need for fundamental information.

"before knowing how to use their medicines, patients should understand why they are using them and what for"
Pharmacist selecting 'Developing practical techniques' (feedback card)

Other participants rationalised a connection between having essential knowledge and being equipped to use medicines effectively. Some participants referred to their own professional observations of a gap in people's knowledge about why medicines have been prescribed, what medicines do or what their side-effects are. They expressed their concern about people being able to use medicines safely, with a full understanding of potential harms. In keeping with this idea, some participants went further, and referred to the personal autonomy that accompanies knowledge. Participants selecting 'Understanding what medicines are for' stated that giving information about medicines was one means for people to gain control and responsibility. Empowering people also underpinned the rationale for the those selecting 'maintaining a normal life while using medicines'; this was perceived to put people at the heart of their care and giving them more control. In conversations with the researcher, participants at all four events, from across role groups, demonstrated awareness of the importance of shared decision-making regarding medicines use, which underpins concordant interactions. They also showed a commitment to supporting people who are living with long term cancer, to develop their own personal skill set to enact medicines use. Several clinical and non-clinical stakeholders expressed concern about the growing population of people living with advanced cancer and identified that promotion of self-management would be key to providing a viable service in the years ahead.

Improving outcomes

Some participants demonstrated a focus on measurable outcomes associated with medicines optimisation, which were increasing adherence to medicines and reducing waste. Participants in the pharmacy role-group, or non-clinical strategic role-group were more likely to suggest reasons associated with improving outcomes. Increasing medicines adherence was given as a reason for the selection of a priority. 'Simplifying medicines supply', for example, was a means of helping more people to access their medicines, and therefore getting them to take them. Improving people's 'Understanding what medicines are for', was a means to getting people to take them correctly as directed. Likewise, the support for 'Development of practical techniques for medicines use' indicated that having reliable medicines 'taking' practices could guarantee independent medicines use. Reducing waste was another reason some people gave for selecting a priority. This related to the way that unnecessary medicines accumulation contributes to waste, as well as to the medicines that are not used, due to people not

taking them effectively, and therefore wasted. These themes indicate that stakeholders were focused on delivering solutions which improved the experience of people who use medicines. Participants' rationale for their choice of a particular 'medicines optimisation priority' was consistently orientated around reasons that would improve people's lives at home with medicines, and their encounters elsewhere with medicines. It indicated that stakeholders recognised, from the data present in engagement resources, the complexity and potential burden of this aspect of advanced cancer care management. Their selection of 'medicines optimisation priorities' reflected, based on the data presented and their own experience, where or how they thought those complexities and burdens could be best addressed. In making life easier, many stakeholders believed that reducing the burdens and restrictions on people associated with medicines use was an important way of improving the individual experience of medicines use with advanced cancer. Others prioritised empowering people who use medicines, recognising that medicines users are at the heart of their professional or personal interest in this research, and that they should have more control and agency and might be likely to have or create their own solutions given the right opportunity or support. The final priority theme among stakeholders recognised the need to improve people's outcomes, and their belief that the best way is to help people make the most of the medicines they have.

6.3.6 Implementation of a 'medicine optimisation priority'

Participants proposed broad recommendations regarding healthcare generally alongside specific operational changes, which could potentially support medicines optimisation in advanced cancer care. Data was generated on feedback cards and in discussion with the researcher. Ideas for implementing a 'medicine optimisation priority' generated three main themes: Improving communication with people; improving communication about people; and person-centred service redesign.

Improving communication with people living with advanced cancer

Many participants' ideas about implementing a 'medicines optimisation priority' in practice centralised on instigating and maintaining a dialogue with people living with advanced cancer about their medicines. Participants' suggestions included giving people the chance to talk about their medicines, listening to them, and giving pertinent education and signposting. This encompassed adequate support upon medicines initiation and timely continued evaluation of medicines use. Participants identified existing and novel opportunities to communicate and considered the nature of interactions which could facilitate both giving information and obtaining information about patients' experiences and preferences to influence clinical practice.

> *"Involve patients, to find out what is impacting on their lives and what would help them"*
> Pharmacist selecting 'maintaining a normal life whilst using medicine' (feedback card)

"more consideration given to routines/frequency of prescribing e.g.BD/QDS to make it easier to take"
Pharmacist selecting 'developing practical techniques for medicines use' (feedback card)

Improving communication through counselling was a means to empowering patients with knowledge. Counselling at medicines dispensing was identified by participants as one such opportunity. Several pharmacy role-group participants, prioritizing 'Understanding what medicines are for', rationalised that medicines counselling was a means to providing education about rationale as well as practical use.

"encourage people to ask questions - take control, talk, listen, explain, motivate"
Non-clinical participant selecting 'understanding what medicines are for' (feedback card)

"detailed counselling on medication and why it's important to take medication"
Pharmacist selecting 'understanding what medicines are for' (feedback card)

The most identified opportunity to talk about medicines and exchange information with patients was through medicines reviews. Many clinician and pharmacy role-group participants referred to reviews as a mechanism to communicate with patients about their experience. Medicines reviews were described as a structured opportunity to assess medicine's benefit, identify gaps in understanding, and support more effective medicines use. These were also means to realising other priorities. They might support 'Minimising medicines accumulation' by supporting rationalisation through deprescribing. Similarly, the chance to talk to patients about medicines use at home and possible management strategies was identified as a route supporting patients 'maintaining a normal life' and making life easier.

The lack of time available to pursue medicines reviews and medicines counselling was identified by numerous participants as a barrier to achieving medicines optimisation priorities. Some feedback focused on creating new and different opportunities to communicate.

"Better use of medicine reviews. We do them, and they have benefits and problems, but if I could do a good MUR, suggest useful changes and management strategies and reliably refer the patient to their Dr/Primary Care Pharmacist/Nurse (this is key!) for those recommendation to be enacted that would be great."
Pharmacist selecting 'maintaining normal life while using medicines' (feedback card)

One participant suggested the need to 'make every contact count' regarding medicines. This was explained as taking advantage of the many passing interactions that people living with advanced cancer have in healthcare, rather than necessarily relying on rigid frameworks for communication.

The potential to develop existing clinical roles was also proposed to facilitate better communication. Participants selecting 'Understanding what medicines are for' envisaged scope for enhanced pharmacist input, to provide grounding knowledge about medicines and practical medicines management support. The concept of untapped pharmacist expertise was reiterated during face-to-face conversations with audience members. Several pharmacy role-group stakeholders identified that this was a potential source of support for the practical aspect of medicines use. However, these participants highlighted that the distribution of clinical pharmacists around cancer services and primary care might prevent direct contact with people living with advanced cancer and curtail their influence in supporting medicines optimisation. Speaking regarding their Community Pharmacist colleagues, participants also noted that any direct contact with people in that setting is unlikely to be underpinned by access to the same degree of medical history as clinical counterparts, limiting their potential input.

Feedback relating to improving communication included suggestions that the information provided to patients about using their medicines be more personally nuanced and bespoke. Better dialogue with individuals could contribute to demystifying the processes around medicine use and application of approaches framed to suit their personal needs. During face-to-face conversations, some stakeholders noted the value of the visual photographs in communicating information around medicine use. It was suggested that use of imagery may have some practical role in clinical patient education. Similarly, written feedback indicated the apparent value of sharing experiences through peer-to-peer support, which can help provide or maintain information, knowledge, and skills.

Some participants agreed that additional or alternative written resources could improve individual patient understanding. Annotating packaging was not a new concept to participants, some of whom reported anecdotal observation of benefit. Supplying written lists or summaries to patients was also suggested. Clinicians particularly identified their role in communicating about medicines indication and suggested that improvements to labelling could help, either by changes to labelling on boxes or making supplementary notes on the prescription that could be transcribed. The importance of ongoing assessment within advanced cancer care itself was also identified. Both clinical and non-clinical role-group stakeholders with a background in cancer services discussed assessment tools available in clinical practice. The Holistic Needs Assessment (HNA) was identified by several participants working in cancer services as a possible source of ongoing structure and monitoring. This is an existing standardised mechanism via which medicines experiences might be captured, beyond symptom or toxicity grading.

Improving communication about people living with advanced cancer

Improving communication about patients and their medicines also featured in participants' ideas for implementing their 'medicines optimisation priority'. Exchange of relevant information about patients between healthcare professionals and providers was identified to provide continuity of care around medicine use. Access to a unified care record allowing integration of information between healthcare settings was recognised as a major objective in the future of services. Face-to-face conversations with attendees at each event explored the digital referral and documentation processes used in primary care and gave invaluable insight into the context of some of the issues relating to information-flow and medicines that people living with advanced cancer experience. The incompatibility of software between healthcare settings and resultant discrepancies in features and functions for clinical recording limit prompt exchange of information. Patient advocacy and clinical role-group stakeholders observed the practical consequences of this situation, particularly citing the resultant breakdown in the flow of information during transitions of care. This has implications for staff preparedness and impacts on efficiency, safety and satisfaction.

Feedback card comments identified how sharing contemporaneous patient information between healthcare professionals would make services more streamlined for patients and impact on each 'medicines optimisation priority'. For example, multidisciplinary communication between clinical areas could support the reduction of unnecessary medicines. The ability for prescribers to view accurate records and collaborate with peers was identified as a potential way for prescriptions to be gathered into a single synchronised repeat and hugely simplify medicines supply for many. Accessibility of information could also enable better coordination of the supply chain, by involving pharmacies or allowing linkages with areas of care. Further, inclusion of some diagnostic information in records visible to pharmacy staff could allow delivery of more patient-centred service in the community.

> *"develop value and practice of clear, simple, patient developed + owned information"*
> Non-clinical participant selecting 'understanding what medicines are for' (feedback card)

During conversations, participants from the pharmacy-role group shared their frustration with some aspects of the medicines prescription system and suggestions for how it might improve. They were keen to discuss the value of the medicines list format across healthcare settings. Some suggested it was unhelpful and disjointing the medicines care from prescriber to community pharmacist to person using the medicines. Modifying the design of how medicines-related information is presented, into a more relevant grid or timetable structure, might benefit people who use medicines, but also clinicians and pharmacists. This could support prescribers to make decisions which fit with patient's existing medicines regimes, give pharmacists greater insight and facilitate pertinent counselling and provide

patients with a standardised resource for daily medicines administration. A key conversation also took place with a participant with a clinical background whose role was to lead on development of IT in primary care. The challenges associated with multiple interfaces were discussed and the consequent discrepancy in medicine-related information sharing discussed. In this conversation it was identified that the way medicines are coded and linked to people's records in primary care is a significant influence the way those medicines are subsequently managed and monitored. There was scope for this to be better standardised, and also for this to be an opportunity to pass information between clinicians.

Person-centred service redesign

Another theme amongst participant feedback related more broadly to rethinking how medicines services in advanced cancer care can be designed to work for real people. These suggestions focused on putting people at the heart of future decision making, in order to include their preferences and promote the maintenance of their sense of normality. Participants from across role-groups stated that involving and collaborating with the public through dedicated initiatives was key. This could address improvements in areas of medicines care that matter most to people. The nature of this research study itself prompted audience members to discuss the value of incorporating engagement into service redesign and encouraged stakeholders to acknowledge a sense of responsibility to listen to patient voices.

> *"continue to listen to what people want and support them to live the way they want"*
> Patient-advocacy participant selecting 'maintaining a normal life while using medicines' (feedback card)

One stakeholder from the non-clinical role group expressed insight into the pathways and support structures available within The Recovery Package (Macmillan Cancer Support, 2013) for patients receiving advanced cancer care. They identified that the work-stream associated with Living with and Beyond Cancer (Department of Health, Macmillan Cancer Support, NHS Improvement, 2013) may be an avenue for development of cancer-specific services which specifically support medicines use by people living with advanced cancer. Specifically related to medicines prescribing, participants identified how services could improve to consider the experiences of people using medicines. Many participants responded to the powerful evidence about medicines integration into everyday activity, by suggesting that prescribing should be fundamentally informed by this kind of insight, the reality of what medicines use is like for people living with advanced cancer.

| Medicines optimisation priority | Themes | | | | | | | |
| | Making life easier | | | Empowering people | | Improving outcomes | | |
	Reducing the workload	Reducing emotional burden	Reducing confusion	Giving knowledge	Giving control	Improving adherence	Reducing waste/cost	Enhancing safety
understanding what medicines are for	x	x	x	x	x	x	x	x
developing practical techniques for medicines use	x					x		
supporting medicines impact on bowel care								
simplifying medicines supply	x	x				x		
minimizing medicines accumulation			x			x	x	
maintaining a normal life whilst using medicine	x	x			x	x		

Table 14. Themes and subthemes for rationale for the selection of medicines optimisation priority

Medicines optimisation priority	Themes								
	Improving communication with people				Improving communication about people		Person-centred service redesign		
	Tailoring information	easier access	listening	Enhanced Pharmacist role	Shared information network	Better information display	Involving people	Timely Medicine reviews	Personal routine prescribing
Understanding what medicines are for	x		x	x			x	x	
Developing practical techniques for medicines use			x	x					x
Supporting medicines impact on bowel care									
Simplifying medicines supply	x	x				x			
Minimising medicines accumulation	x					x		x	
Maintaining a normal life whilst using medicine			x				x	x	x

Table 15. Themes and subthemes for implementation of selected medicines optimisation priority

6.4 Discussion

6.4.1 Summary of findings

The findings of this engagement work provide new understanding of stakeholders' perspectives about the priorities for supporting medicines optimisation in advanced cancer care. The evidence illustrates how difficult it is to establish a single priority but in so doing highlights stakeholders' commitment to the importance of the issues relating to medicines use and people's experiences. Small numbers of key stakeholders were engaged and many of the ideas discussed, and issues raised, were closely connected. Given the opportunity to select a specific priority, stakeholders emphasised the importance that people understand what medicines are for and encounter an uncomplicated process for medicines supply. Beyond identifying a priority, three broader themes captured the reasoning and logic behind stakeholder priorities, which were about making life easier, giving people power and control, and improving outcomes. Three further themes relating to how these might be realised in clinical practice were prominent in stakeholder feedback; improving communication with people who use medicines, improving communication between HCPs (about people who use medicines); and re-designing services that are intrinsically person centred.

These findings demonstrate the wealth of additional insights that can be drawn from engaging with other people in the important communities that work for or closely with people living with advanced cancer. While they also highlight the challenge of creating improvements in an area which is so big and spans much of healthcare provision across the NHS, the data collected across the events does highlight stakeholders' opinions about the future direction of practice and research. The aims of the research were to help prioritise issues, understand stakeholders' rationale, and brainstorm options for implementation. This was a small local activity, and inference from the data generated is tentative; however, some clear themes resonated through sharing the previous studies' findings with people and exploring their wider experiences in their own related roles. No single priority was prominent and no new issues or priorities were raised that were not already represented by the data shared during the engagements. This indicated that the significant issues known to key stakeholders were available in this engagement and that the research overall has reflected their encounters with people living with advanced cancer who use medicines. The themes generated from free feedback, written on cards and shared verbally with the researcher highlight compassion for people living with advanced cancer. They care that this process is challenging for people, they want to work within their own capabilities to address that and they want to participate in healthcare that changes that. People's rationale is strikingly simple: prioritising making the process better so that life is easier for people, whose life is limited, and giving people the skills they need to enable effective self-management. In terms of implementing this change, participants recognised that communication was a key factor. In their own roles, they needed better access to people's individual experiences with medicines, and they then needed to be able to better communicate about those experiences with other HCPs, to generate a continuity of care.

One way of measuring prioritisation was through selection of picture postcards. The numbers selected were small, which was partly a consequence of the practical barriers in exhibiting many different examples in unfamiliar or confined spaces. In addition, there were few opportunities to observe stakeholders' choices and communicate with them about their collection of picture postcards when facilitating engagement alone. In addition, no data were collected about the participants who selected the picture postcards, so it is unsafe to draw conclusions about the possible rationale for their choices. The relevance of participants' specific selection to a 'medicine optimisation priority' is not reliably indicative of personal priority. The only judgment possible about picture postcard selection regards the images which most resonated with audiences. Notably, all the most popular picture postcards were also photographs exhibited on a larger scale. It is possible that this may have accounted for increased interest in the stories these pictures represent, but it could also be that this reflects that the photographs chosen to be exhibited in large scale were highly effective at capturing the relevant concepts. The selection of picture postcards does not correlate with the same priorities ranked on the feedback, which indicates that postcard collection was more likely associated with the salience of research images, rather than necessarily the medicines optimisation priority that they represented.

Feedback cards were provided in order that participants could formally select a 'medicines optimisation priority' in response to the data presented. Stakeholders found it difficult to prioritise a single medicines optimisation goal. 'Understanding what medicines are for' was the highest priority, based on the cumulative selections made by stakeholders. Although, after this, 'maintaining a normal life while using medicines' and 'simplifying medicines supply' were also popular choices. Interestingly, the patient advocacy group were more likely than any other group to select priority 'simplifying medicines supply' as being important, and they were the only stakeholders to select 'supporting the impact of medicines on bowel care'. However, overall, there were only slight differences in the overall numbers of stakeholders selecting different priorities.

In addition to selecting a single priority, participants were encouraged to expand on their choice by providing a rationale and insight into the potential implementation of that idea. In their verbal and written feedback, the stakeholders acknowledged that people encounter lots of problems with medicines and there are therefore lots of opportunities, within the current framework of care, where we can deliver support around medicines. Stakeholders identified the need for strategies which involve people who use medicines and enable HCPs to better support them.

Ideas for implementing better support of medicine use related to ways of improving continuity of information and responsibility. Specifically in relation to cancer care, the Holistic Needs Assessment (HNA) was suggested as a tool to support this. HNAs provide key points throughout care and therefore present a good opportunity for improved continuity. They are also specific to cancer care, so might allow a more specialised approach to supporting medicines use by people

with advanced cancer. Similarly, outside of the specialist cancer setting, medicines reviews were identified as an obvious way to better understand people's experiences. This could provide the opportunity not to test knowledge of medicines, but to discuss practicalities and quality of life and consider tailoring prescribing to suit practical medicines use. As stakeholders, HCPs were concerned about people knowing what medicines are for. This knowledge is about why they need to take medicines, but it is also about how to use them. Medicine Reviews were seen to have potential function as a means of joining up these two parts of the process of using medicine.

Another important finding from this research is the use of participatory involvement as an approach to generating ideas and understanding or endorsing new evidence and sharing the responsibility for its future direction. This engagement study was a positive and affirming part of the research, both in its utility in expanding insight and as an interactive and research experience. It provided a powerful way to disseminate research ideas using techniques which may not have been available through other priority setting approaches. It facilitated unintrusive connections with people, which enabled them to adjust their involvement to suit their own comfort. This made the interactions during the engagement authentic and productive. Many of the people involved in this research belonged to an established network which must be involved to enact any change in practice. Some of the research data resonated strongly with delegates across the events, and various imagery appealed to different individuals. More than this, the engagement activity also prompted useful interactions with influential people working in healthcare provision for advanced cancer. While the formal participation with the engagement resources was encouraging, the direct interest and engagement of senior strategic and influential leaders in the field was exciting. As a priority setting exercise this work was not particularly effective, but it did help improve understanding of how or why key stakeholders may prioritise one issue over another. However, the opportunity to give the participants from Research Study One, living with cancer, who shared their homes and experiences, a voice that could be heard beyond the confines of this thesis, or an academic paper, to a wider and potentially influential audience was invaluable.

6.4.2 Strengths and limitations

An obvious weakness of this study was the failure of the method in its utility as a priority setting exercise. The data presented were nuanced and intricate. The priorities were all considered relevant by audiences and their close interlinkage prevented their discrimination. The methods used to establish priorities were inadequate. The selection of picture postcards, for example, could have incorporated means of understanding what drew people to certain research themes and images. Not capturing this data in a brief survey during the engagement was due to practical constraints and a wish to have freedom of dialogue that allowed for more in-depth feedback from stakeholders. However, this absence also presents a real limitation to how that data can be used in the overall understanding. Another major limitation of the prioritisation method was that, after the initial event, feedback card analysis revealed that several participants selected more than one priority. At

subsequent events, the importance of choosing one priority was emphasised. During the first event it had also been necessary to elaborate some meanings, which questioned the fluency of feedback card statements. Prior to subsequent events, the wording of priority statements was modified to reflect these clarifications and capture more detail. It was also noted that across all events many attendees observed the visual resources, but did not engage in a way which could be captured by data collection tools.

A major limitation in the execution of the research methods was working alone. Facilitating all aspects of the engagement presentation simultaneously, which included having conversations with people, supervising feedback card circulation and encouraging postcard selection, was difficult. It became apparent that although many people physically approached the resources and communicated with the researcher, only some of those stakeholders provided feedback. Consequently, some opportunities to talk to people were missed as the researcher could only hold one conversation at a time and could not capture all the details of all conversations. A further limitation in conducting the work was that the format of events restricted the nature of engagement. Engagements used existing events which had pre-determined agendas and venues. It was not possible to change these plans significantly once they were in place. For example, the picture postcards were reliant on adequate space for their presentation. Events did not always have suitable space to accommodate them, and postcards sometimes ended up separated from the rest of the engagement resources. Avoiding this would have led to better data. This was compounded by the difficulty of facilitating events independently, which prevented monitoring picture postcard selection and engaging with stakeholders as they made their choices. More communication about picture postcard availability and fewer options being displayed alongside the photography exhibition could have streamlined this section of the engagement. This would have also generated more meaningful data, attributing postcard selection to priorities of interest, rather than the preferred image.

One other potential limitation of this study is the selection of data that was presented, which was all based on the research findings thus far. The themes generated in studies one and two was generated inductively out of the analysis process, and a different analyst might have identified other themes or issues to present from the earlier studies. For example, there was some critique in verbal discussions that maintaining a normal life in relation to medicines, which was here presented as a single priority, is an over-arching issue that encompasses all of the other aspects presented. This could explain why it is so popular. It is possible another researcher may have used a different description, or that better communication during engagements could have clarified that this priority referred to maintaining aspects of everyday life, rather than being a general statement about quality of life.

An alternative approach such as consensus building could have been used to undertake this activity. This would have helped overcome the lack of clear prioritisation and potentially helped stakeholders to make difficult choices between the various areas where support is needed. However, this engagement did not specifically aim to achieve a consensus; stakeholders came from different perspectives and understanding their differing priorities was important at the outset. It is possible though, that stakeholder's differing priorities and perspectives would also have been captured in reaching a consensus. A strength was that this work undertaken whilst the research process was ongoing, so the engagement did not make claims, but rather talked and shared ideas, and asked for new ones.

Despite the limitations of the chosen method, the study was effective in meeting the core principles of public engagement. The STAR framework (University of Leeds, 2016) was used at the outset of the engagement to guide the study design. Another strength was how many people were able to be reached by the events. A far greater number and diversity of people were involved in this work compared with the previous studies, than might have been included using alternative measures. The engagement activity also prompted several insightful conversations with significant leaders, which provided valuable networking opportunities in relation to future events or potential future collaborations or initiatives. In this sense, the study was successful in engendering trust and building foundations for future relationships with stakeholders. In providing a mechanism for stakeholders to have access to research findings and provide their own insights and reflections, the work facilitated openness with the local community about work being carried out. Introducing the ideas to people from wider communities meant the research could incorporate new perspectives, move ideas into different directions, and inform what issues to take forward. Lots of people from across different stakeholder groups engaged; a third of stakeholders provided feedback cards, up to a third took postcards away with them, and many more people looked at the displays. The engagement allowed evidence to be shared locally, but in a way that accessed people who may have been otherwise unaware. Engagement also provided an effective way to reach people who might not have read an academic research paper and get them to consider the issues and perspectives in the context of their own role with regards to advance cancer. Audience members from across the stakeholder groups were forthcoming with their interest in the study, which was reflected in the highly relevant and pertinent information people provided through their written feedback. Several audience members took their own photographs of the exhibition. This demonstrated that the activity was exhibited to the right groups; attendees were there to observe a cancer agenda, many were prescribers.

6.4.3 Summary and next steps

This engagement work specifically aimed to disseminate research evidence about medicines use during advanced cancer to key stakeholder communities, obtain feedback about these findings and prioritise opportunities for medicines optimisation. Engagement exercises were undertaken to share

and assess the importance of each 'medicines optimisation priority' and generate ideas about implementing suggestions in clinical practice. Meeting these objectives was evaluated via various engagement techniques.

The stakeholder engagement comprised four events attended by 150 people from communities of HCP, patient advocacy and non-clinical groups. A proportion of audience member at each event viewed resources, took materials away, and provided written and verbal feedback. Data were captured by counting interactions with resources, collating written evidence in feedback cards and fieldnotes. Analysis of numerical and textual data indicated the difficulty of prioritising a single idea. The priority indicated by picture postcard selection and feedback card responses did not align. Some priorities were more popular than others. The most popular picture postcard was 'minimising medicines accumulation'. 'Understanding what medicines are for' and 'simplifying supply' and 'maintaining a normal life while using medicines' were all popular feedback card selections. In providing their reasons for picking priorities, participants shared common justifications. The goal should be to make people's lives easier, empower people using medicines. This could be achieved through listening to what people's perspectives of medicines use are, and what they need from the service and communicating more effectively with other professionals.

Although the engagement did not provide clear medicines optimisation priorities, it did help to condense down or refine ideas, and close down others. Participants in this study identify that considering people's quality of life in the medicine use process is paramount. This engagement served as a valuable means of looking at this system and acknowledging that bits of it do not work very well with that in mind, and there are some things to do to achieve these professional, strategic and personal objectives. Public engagement is an emerging part of the research cycle. Using photography to engage was a good way to shift attention and focus onto real people's lives and experiences with advanced cancer. This study highlighted the importance and potential for generating further ideas and insights from even small segments of data. It gave a voice to patients and lent the research transparency and authenticity that much research could benefit from.

Chapter 7. Discussion, Recommendations and Conclusions

7.1 Introduction

The new research presented in this thesis aimed to develop understanding about the experiences people living with advanced cancer have using medicines at home. This knowledge was considered a vital precursor to any theoretical claim or interventional initiative for supporting medicines use amongst this growing population. The research also attempted to move beyond the problematisation of the issues of medicine use, towards potential ways to help people who are currently receiving care for advanced cancer. This concluding chapter presents a summary of the key findings from this research alongside an integrated discussion looking across those findings.

7.2 Overview of this thesis

7.2.1 Knowledge gaps and research aims

Chapter Two presented a robust literature review, conducted at the outset of the research to outline existing evidence. Searches were undertaken to identify peer-reviewed qualitative research about people's experiences of using domiciliary medicines during advanced cancer. This review identified a limited amount of relevant work. Ten studies which met the review eligibility criteria were included in a narrative evidence synthesis (Zeppetella, 1999; Schumacher et al., 2002; Sand et al., 2009b; Stoner et al., 2010; Yeager et al., 2012; Klein et al., 2013; Wickersham 2014; Schumacher et al., 2014a; 2014b; Milic et al., 2016; Campling et al., 2017). The quality of the available research varied. The use of insufficiently rigorous methods or the lack of transparency in reporting limited the value of the contribution of some findings. In addition, many studies had only partial overlap with this specific research focus. There was a small amount of highly credible qualitative research, which provided rich insight into people's medicines management experiences at home.

The outcomes of the first principle of the Medicines Optimisation good practice guidance (RPS, 2013) provided a structure to integrate the research evidence and summarise existing understanding about people's experiences with medicines. The synthesis highlighted how domiciliary medicines use during advanced cancer involves significant self-management responsibility. People have many medicines, for various indications, from many different healthcare providers. Using them involves multiple processes and actions. The coordination of ordering repeat prescriptions, integration of medicines taking into daily routines, and use of reminder prompts for medicines use, are some examples of the kind of activities observed in previous research. The most detail around those requirements and skills was demonstrated in the use of pain medicines and at the transition to supported self-management of medicines at the end of life. However, due to the scarcity of high-quality relevant evidence, the review was not able to provide insight into what people do to manage all of their medicines together and how they feel about it, particularly in the context of living with

long-term incurable disease. There were some useful findings, but the scope of the literature was limited and the evidence could not provide adequate context about the role of advanced cancer healthcare in those experiences. The findings of the review also did not provide insight into what people need to support their medicines experiences. This warranted further investigation.

This absence of in-depth knowledge was the starting point for the empirical research presented in this thesis. Qualitative research was designed which could explore the gaps in understanding. Interpretive Description (Thorne et al., 1997) guided iterative work, grounded in naturalistic principles, to produce findings which maintain relevance to clinical practice (Lincoln and Guba, 1985; Thorne 2016). The approach allowed freedom to respond to the cumulative research findings and develop methods capable of adding towards the generation of a coherent description of what is happening, and what could happen next. The empirical research was undertaken across two interconnected studies, which considered medicines use from different perspectives: the first, with people living with advanced cancer about how they manage their many medicines at home; the second, with healthcare professionals about the clinical context for people's experiences and how they might be supported. Finally engagement with stakeholders was undertaken to set priorities to inform clinical practice and further research. Collectively the evidence in these studies gives new, rich and honest insights.

7.2.2 Empirical research and key findings

Research Study One addressed the immediate gap in understanding about how people self-manage their medicines regimen. This study generated rich evidence about the intricacies of people's everyday experience. In their homes, people re-enacted and explained the dynamic considerations they make and actions they take, to start and sustain personal medicines management systems. The results expand knowledge about people's experiences in the context of a whole medicine cohort, in this specific phase of the continuum of cancer, receiving NHS care. Using medicines at home means taking on work, which is practical, cognitive and emotional and intersects with the broader self-management duties of advanced cancer. The research found three core areas of responsibility to entail: the relational aspects of medicines use, which encompass accepting medicines, and making ongoing evaluations about their value and effect; dealing with the system within which medicines are acquired and undertaking the bureaucracy necessary for medicines encounters and supply; and the daily habitual practice of medicines use in the home. The evidence generated indicated that people demonstrate a resilience in response to this situation by adapting, by weathering disruptions and by making medicines work for them. This self-management effort applies to multiple areas: understanding medicines, developing practical techniques, ensuring sufficient supply, minimising accumulation, and managing the joint physical effects of multiple medicines, which therefore, are all areas where people may benefit from medicines optimisation support.

Like some of the previous evidence located in the literature review, people in this study equipped themselves with knowledge about their medicines, learning their indications, actions and effects and kept a system for ongoing medicines use (Wickersham et al., 2014; Sand et al., 2009b; Klein et al., 2013; Yeager et al., 2012). However, this was not without challenges. Medicines names are unnatural to pronounce and difficult to remember; medicines labels do not correspond necessarily with a functional understanding. People adapt by coming up with their own recognition and reference systems to make their life easier. However, as noted in existing research, this too can come under threat when packaging is changed, or different brands are introduced (Klein et al., 2013; Sand et al., 2009b; Stoner et al., 2010; Schumacher et al., 2014b; Campling et al., 2017). Looking across the whole cohort of medicines, this research shows the extent of such barriers and generated rich visual data to exemplify the specific techniques people develop to overcome this.

To implement a complex regimen, this research showed that people ground medicines use in their daily routine. Central to this approach of fitting medicines into normal life is using them in a personally relevant way, which incurs a minimum disruption to the rest of life and promotes the sense of normality. In the use of a single type of medicine, other authors identified such routinisation based daily activities and use of the physical space to prompt memory or automate medicines use as habit (Schumacher et al., 2014a and 2014b; Wickersham, et al., 2014; Campling, et al., 2017). More broadly, studies concerning medicines use in chronic illness consistently refer to the pattern and process for medicine 'taking' (Bytheway, 2001; McCoy, 2009; Huyard et al., 2019). By undertaking research in the natural environment of their use, this research generated novel evidence about what those techniques look like, such as placing medicines in particular household locations to prompt use in relation to a specific daily activity; using a favoured receptacle; or having a specific visual signal following their administration to help indicate they have been used. The evidence generated illustrated the similarity amongst people's approaches, and yet the unique personalisation of such practice. The accounts generated in this study also expose how, even for experienced medicines users, initiation of a new regular or intermittent medicine, which is less easily embedded into the existing routine, can cause problems. Another key finding relating to this exploration of practical approaches from medicines use, was how people came upon their personal strategy. As reported by studies about pain, people received no practical coaching or guidance about using medicines at home (Schumacher et al., 2002; Campling et al., 2017). Instead, people figured something out, usually following a period of trying alternatives.

This study also found that the responsibility for obtaining medicines and maintaining their adequate supply is a major area of work for the people living with advanced cancer. The convoluted supply process was a primary concern for many people interviewed. They explained their prescriptions often did not marry up and they were left to manage multiple supply streams. They also referred to an inflexible supply chain which was acutely time-bound and even hostile. This is an important observation, for any medicine user, but particularly in the context of living with incurable metastatic

cancer, where people are often advised medicines are imperative, only to then encounter problems in gaining access to them. Research about pain medicines management does report the problem of unsynchronised prescriptions (Schumacher et al., 2014a; Campling et al., 2017). However, exploring overall medicines use in advanced cancer showed that this is a huge issue for people who receive several medicines from multiple prescribers. Klein et al., (2013) stated that people's actions for obtaining medicine were ritualised to the routines associated with medicines administration. This study presents additional evidence about the complexity of how people try and synchronise prescription dates for many medicines and provides novel insight into the specific practices which people undertake to manage their supply.

The current study generated new evidence about the impact of medicines multiplicity. Previous research has reported that using many medicines concurrently, makes it difficult to attribute medicines side-effects with symptoms, especially when experiencing multiple symptoms at the same time (Schumacher 2002; Sand et al., 2009; Yeager et al., 2012; Klein et al., 2013; Schumacher 2014b; Campling et al., 2017). Studies referring to medicines use in advanced cancer identify and report the impact of side-effects on quality of life, and the relationship between side-effects and people's choices about using medicine, yet they do not discuss the impact of side-effects in combination. Whilst the physiological impact of specific types of medicines has been reported, the overall consequences of using many medicines at the same time or over the course of time has not. For participants in this study, this was expressed in medicines effect on bowel health. These findings suggest this is a big concern for people living with advanced cancer that requires personalised support, given the individualised nature of medicines regimens and people's bowel health and habit.

The current research indicated that people make careful, considered judgments about their medicines, which influence how they feel about using them. That people are worried about the physical and psychological impacts of medicines and evaluate the side-effects and benefits, was widely known (Zeppetella 1999; Schumacher et al., 2002; Sand et al., 2009b; Yeager et al., 2012; Klein et al., 2013; Campling et al., 2017). This research provided insight into the complexity of these considerations and how they can change over time depending on disease-related factors such as cancer symptoms, complications, and progression. In addition to the concerns about side-effects, the findings contribute nuanced insight regarding how decisions about using medicines are connected to people's feeling about their own life goals and underlying determination to maintain normality and stability in the face of disruptive, debilitating disease.

A key contribution offered by this study is the degree of detail about the responsibilities entailed by using medicines in this specific healthcare context. This study has given a close commentary about the nature of this self-management work. Though recent articulation of self-management in advanced cancer does acknowledge a medicines dimension (van Dongen et al., 2020) most of the evidence synthesised originates from studies investigating only pain medicines (Bennet et al., 2009:

Gibbins et al., 2014; McPherson et a., 2014; Erol et al., 2018; Liu et al., 2018).This effort is catalogued as monitoring symptoms, bodily changes, treatment effects or disease risks; self-administering medication; adhering to prescribed treatment schedules; and adjusting or discontinuing treatment schedules (van Dongen et al., 2020). Effective pain control is undoubtedly a key concern in the care and self-care of people living with advanced cancer. However, so too are the many other symptoms and scenarios that indicate medicine use. Looking at the collective use of a regimen in this phase of cancer, the current research found that people do feel differently about their various medicines and that use of many medicines involved a plethora of wider activities. Shaping understanding about the self-management of medicines using evidence about pain-control only does not fairly reflect people's experience. It is imperative that the wider nature of medicines use in advanced cancer be represented in future evaluation of self-management.

Summarising people's experiences and needs during advanced cancer in the UK NHS context, Harley et al., (2012) used an adapted Generic Choice Model for long-term conditions (Team DoHCP, 2007). As explained in Chapter One, the domains include 'clinical services', 'self-care and self-management', 'living independently', 'finances', 'psychological wellbeing', and 'support pathways'. Referring to the domains here is helpful in considering how use of medicines intersects with this knowledge and adds depth to the understanding of people's experiences and needs during advanced cancer. The medicines use process is entrenched in cancer clinical services, yet this study has shown that the organisation of these compartments for care often prohibits a streamlined experience. As previously identified, there is a perceived disconnect between primary care and specialists in oncology care and people have variable relationships with their GP (Harley et al., 2012). The self-care and self-management related to advanced cancer is well-articulated for specific symptom clusters. The current study draws attention to the work of administrating prescriptions and handling medicines, which is crucial to implementing a symptom management strategy. The often-laborious work of medicines management was also highlighted, which may potentially exacerbate some symptoms due to the energy and effort required. The research has also shown the complicated or opaque support pathway available for people living with advanced cancer, who perhaps are unclear about where to seek support for medicines management, or do not have ready access to a named key worker who knows their story. Independent living is also a primary concern for people who use their medicines at home and many of the approaches people take are indicative of the determination to promote autonomy and self-sufficiency.

Significant in relation to this work, is the understanding gained about how people develop coping strategies to manage the responsibility for medicines use and deal with the various challenges. In LeBoutillier's (2019) recent conceptual framework of surviving with cancer, the experience is presented as an Adversity, Restoration, Compatibility (ARC) model. This summarises people managing the cancer through coping methods, developing strategies to cope, and doing so in a way compatible with individual their experience. The evidence in the current study resonates with this

commentary on how people cope in advanced cancer. People manage the work of medicine well. Some thrive, they are proactive and weather disruptions, they find solutions to problems. By participating in the research, many expressed a hope to offer their solutions to others. A resilient response has been well documented in people with long-term conditions, and amongst people diagnosed with cancer. There are numerous definitions for what resilience is, but authors broadly agree it summaries a dynamic process, which involves adapting to adversity through disruption which threatens normal function (Solano et al., 2016). Protective factors for resilience include positive mood, self-esteem, self-care, independence, social support, and reduced anxiety, spirituality, moral compass, use of active coping strategies such as problem solving, meaning finding from trauma and reframing of past experiences. In cancer, these factors are thought to influence disease progression symptoms, and mortality (Howell et al., 2007; Chida & Steptoe, 2008; Rasmussen, et al., 2009). Cancer survivorship literature suggests that some people over time develop strength in response to the cancer experience, its treatment and impacts, which manifests as resilience (Coughlin, 2008; Deshields et al., 2016). The findings of this study suggest that the resilience response in advanced cancer applies to the use of medicines at home and facilitates the capacity to adapt and respond to medicines encounters.

Research Study Two acknowledged and aimed to build on the qualitative findings about how people living with advanced cancer experience managing medicines at home. The research added essential evidence about the nature and structure of NHS advanced cancer care by exploring the perspectives of HCPs. The reflections and opinions expressed by the participants in this study endorsed the patient experiences reported and HCPs also made specific, clinically relevant suggestions for how problems may occur as downstream consequences of shortcomings or hurdles in the healthcare setting. Findings were summarised as three themes capturing the predominant issues relating to the clinical context for medicines use and opportunities to improve people's experiences: Insight and information, which refers to the awareness those providing advanced cancer care have about what people's experiences are with medicines, baseline information to inform clinical judgements and general understanding about of what is being asked of people who use medicines; Oversight and ownership, which explains the overall responsibility for the medicines regimen and the optimisation of the medicines people living with advanced cancer are given; and Expertise and resources, which focusses on HCPs ability to support medicines use in their own clinical role and environment. The data presented an overarching concept of fragmentation within the current medicines use process for people living with advanced cancer. Such fragmentation in the care of advanced cancer is known, given the complex needs of people living with cancer are well known to require complicated care spanning multiple settings and it can contribute to ineffectiveness, inequality, and inefficiency of care (Taplin and Rodgers, 2010; Cortis et al., 2017). In the current study, new detail has been generated that relates to the continuity between settings of care, between individual HCPs and between HCPs and people who use medicines.

This research evidence indicates that HCPs often have limited insight and information about people's medicines regimens. This undoubtedly is connected to their lack of opportunity to see the whole collection of medicines physically. However, this is not a particularly remarkable observation and is a fact of ambulatory healthcare generally. What is surprising is that such detachment from people's medicines experiences is so pervasive in this context of care, where medicines are so integral to people's wellbeing and where the nature of care is so grounded in concern for people's quality of life. In this study, individual HCPs either demonstrated being disconnected in their limited interview response; or described the sense of disconnection brought about by not witnessing people's everyday encounters with medicines, or having limited chance to talk to people living with cancer themselves about medicines and medicines-related events elsewhere in care. Consistently in this study, HCPs recognised that unless they were directly interacting with people in an outpatient clinic, they had little opportunity to take time to consider their medicines. This echoes existing evidence about the limited support available for people who are living with advanced cancer but not currently having active cancer treatment in a specialist centre (Harley et al., 2012; Boele at al., 2019). People with long-term diagnoses can go without clinical contact for some weeks or months and so, as this research has shown, feasibly may not have any interaction with healthcare providers about medicines. Like previous observations, the current study also found GPs were not well integrated in the care of people living with advanced cancer and they feel excluded from the follow-up process because of the structure of specialist oncology and their resulting limited contact during cancer surveillance and treatment (Schutze et al., 2018; Christ et al, 2021). These findings were also observed in earlier studies of people's experiences and support needs in advanced cancer (Harley et al., 2012; Boele et al., 2019) in reports that people feel that their GP does not know enough about cancer to support them. This research adds important evidence that GPs themselves do not feel they know enough about what is going on with someone's cancer care and have little up-to-date information about their plan of care. In the context of medicines use, a key outcome of this disconnection between people living with advanced cancer and HCPs in their local community appears to be the increased demand on specialist CNS support provision. CNSs in specialist cancer services in the current study reported feeling inundated with queries from people living independently at home with advanced cancer, yet explained that these people are simultaneously poorly linked into primary care and so it is difficult to enact professional support from their secondary care base.

Another key finding in exploring HCPs perspective related to the challenges they face in efficiently accessing accurate documentation about people. Elsewhere, the shortcomings of local record sharing process have been reported (Redmond et al., 2019; Dinsdale et al., 2020; Christ et la., 2021). The archaic process and substandard infrastructure for obtaining and sharing information has been described in other care settings in relation to medicines (Petrov et al., 2018; Mazhar et al., 2018; Mohiuddin, 2019). By involving a range of HCPs from across the MDT in both primary and secondary care, the current study uniquely highlighted some of the specific issues for HCPs across

settings. In medicines-related care for this population, information such as knowing what medicines look like, whether others have been tried, and if a person living with advanced cancer has insight into their prognosis and therefore whether a discontinuation conversation is appropriate, are all shown in this study to be vital considerations for providing good medicines optimisation support. Whilst HCPs are aware of the value of concordance and are motivated to provided support, lack of access to clinical records to support these conversations and decisions prohibits HCPs from taking on medicines optimisation support. Whilst previous evidence has focussed on the importance that prescribers have such information, the findings of this study highlight the need for access to information across the MDT, so that all HCPs can support medicines optimisation in routine care.

The significance of clinical responsibility for providing oversight for the overall regimen of medicines was a notable finding in this study. The perspectives from HCPs in this study added valuable context about the organisation of care for people living with advanced cancer, and how it prohibits ownership for the whole medicines collection. Whilst individual HCPs can and do appreciate people's medicines needs, and are aware of many of the issues relating to medicines use, they describe feeling restricted, reluctant, or reticent to support them due to this separate way of working and lack of cohesion. No single person is taking responsibility for all the medicines somebody living with advanced cancer has at home. Though oncologists are well placed to provide leadership expertise regarding medicines, they do not routinely see all people living with advanced cancer if they are, for example, not currently receiving SACT and they often work without basic insight into things going on elsewhere in the network of care. Clinical pharmacists have the expertise and broader understanding of medicines optimisation principles to offer responsive oversight; however, they are currently poorly positioned in the care pathway to provide direct support to people. Also, they too are reliant on clinical encounters. Primary care pharmacists are better placed to see and talk to people in the community, but their role and reach depends on local resourcing. GPs, whilst having access to people at home, often have no contact with people living with advanced cancer in their caseload. This perpetuates silos of working, which due to the previously described challenges in communicating about people's medicines, does not result in curatorship. Experiences reported by people living with advanced cancer, such as sequential prescribing, unnecessarily demanding or complicated regimen schedules, and the use of multiple medicines whose combined effects have intolerable physical impacts, are all downstream consequences of this failure to consider and talk to people about their medicines as a whole regimen.

The research also identified how individual HCPs' perception of their own knowledge and skills around medicines optimisation impacted on their provision of support for medicines use. One remarkable piece of evidence from this research was how removed HCPs, and particularly prescribers, are from the physical medicines themselves. Repeatedly in this study, HCPs explained not knowing what medicines look like, or not knowing what brand or dose denomination a

pharmacy would be able to supply. This curtailed any discussions with medicines users about their practical use, because the HCPs do not have the knowledge needed to talk the same language as the people whose medicine use they supervise. This is extremely concerning, given the overwhelming evidence in the first study, that people rely on visual information about medicines to recognise, remember and communicate about them. This is a good example of how so often in this study, HCPs provided evidence about aspects of the system, which are fundamentally outside of their sphere of influence, having an enormous impact on their ability to provide support for medicines use. Recent research found that HCPs caring for people living with advanced cancer differ in their views and approaches regarding self-management and self-management support (van Dongen et al., 2021). HCPs observed self-management to be diverse, dynamic, and challenging. In terms of supporting medicines self-management, the evidence here indicates that some of this challenge and disparity, may be related to infrastructure and organisational factors, which limit HCPs.

The other key contributions from this study are the ideas suggested by HCPs about how to improve support for medicines use amongst people living with advanced cancer. It is important to note that there were discrepancies between HCPs about what the distinct goals of supportive strategies should be. The unclear future path may be an inevitable consequence of the complexity of the issue. In this great, sprawling system, individual HCPs cannot be expected to have a handle on how or where to start to address the issues and will base their ideas on their own clinical remit and insight. Specific local ideas suggested by HCPs included creating more and better structured opportunities to talk to people about medicines, delivering bespoke advice and support, and developing reference resources for HCPs. Other potential solutions identified by participants related to improving integration between various areas of care for cancer in general and are not necessarily specific to the metastatic population. Getting better insight into people's experiences with medicines was central to the ideas HCPs had about supporting medicines optimisation. One suggestion, made by several site-specific oncology CNSs, was the potential to develop the Holistic Needs Assessment (HNA) to improve understanding about people's perspectives of medicines use in routine outpatient oncology encounters. The HNA is one of the key interventions in The Recovery Package (DH, Macmillan Cancer Support & NHS Improvement, 2013; Macmillan Cancer Support, 2013), an initiative to improve outcomes specifically for people living with and beyond cancer. The HNA does have an existing medicines question, yet it does not explore any of the specific aspects of medicines self-management identified in this research. Adapting the HNA to further explore medicines self-management presents a potential opportunity to better assess people's experiences in clinical interactions. It does not however accommodate people living with advanced cancer who do not have regular or routine CNS contact.

Medicines reviews based in the clinical setting were also highlighted as a potential solution to improving insight about medicines experiences and enhancing communication with people about using medicines. Medicines reviews can offer a structured format for discussion between medicines

users and prescribers to optimise the use of medicines and are particularly relevant for people with long-term conditions or who take multiple medicines (NICE, 2016). However, as with any clinical intervention, there remains the issue of how these could be integrated into the existing cancer care pathway without adding additional appointment burden to people living with advanced cancer and encroaching on vital clinical time for HCPs. HCPs in this study did not provide any suggestions about this; however, HCPs awareness of the increasing reliance on community-based provision for advanced cancer resulted in suggestions to support medicines regarding changes in primary care. They considered the potential for other approaches to the review. Practice pharmacy roles were also a potential avenue to enhance provision for medicines optimisation in this population. The Practice Pharmacists who participated in this study explained the specific remit of their role, which often does not necessarily include advanced cancer. However, the nature of their expertise and familiarity with the medicines optimisation agenda indicates they are extremely well placed to support people in the community who are living with long-term cancer and using many medicines independently.

The possibility of adapting the medicines review to accommodate the practical aspect of medicines use was also introduced. Extending domiciliary pharmacy provision to accommodate the broader needs of medicines users, rather than just those who are frail, or with cognitive impairment, would be one positive step. Such a practice facilitates both visual audit of the medicines themselves and enables a practical-focussed review with the medicines user which can assist in embedding medicines use routine and identify environmental and social factors implicating on medicines management (McCormick et al., 2020). Whether this specific service would benefit people living with advanced cancer is not known to have been previously investigated but the evidence in the current study indicates that there is potential space in current cancer services for such a role. Practical coaching around medicines use was identified by one participant as an opportunity to provide direct support for medicines use at home. This HCP's description of their aim to be a 'personal trainer' around medicines really resonates in relation to the accounts of people who use medicines and explain the trial and error they undertake to establish a system and the adaptation necessary to weather disruptions. People may benefit from individualised support, which considers their daily routine and the ongoing encouragement that a coach could offer. How this could be achieved in current clinical practice remains to be seen but the evidence in this study demonstrates that there are multiple HCPs involved in the advanced cancer MDT that would prefer to have more skills and expertise to support people with medicines.

At a service level, multiple participants recommended that improving the relationship between NHS HCPs in primary and secondary care, and community pharmacies is key to better supporting people who use medicines at home. Whilst participants were realistic about the low likelihood of a major overhaul of the remuneration and operationalisation of community pharmacy, they did see potential to make improvement for the benefit of medicines users. A key way this could help,

would be to streamline some of the reordering processes for repeat prescriptions, using electronic systems, to minimise the burden experienced by people living with advanced cancer.

Another broader recommendation from HCPs was the need for better IT systems, which would support streamlined working. This could certainly address some of the challenges of accessing and sharing information and potentially improve collaboration. A strategy is currently underway to integrate NHS IT systems (NHS Digital, 2021). This is a much-needed upgrade which has the potential to benefit all aspects of care. This specific initiative appears to be sharing patient data available from the GP, rather than across and between all settings; however, it still will be an improvement on the current fragmented system. In practice, such vast infrastructural change will take a long time, and the progress of this existing project is unclear. Multiple studies have explored the utility of 'digital care', but the fundamental issue of connected health records remains.

Stakeholder Engagement was designed to move the ideas generated in the research so far forward, to not remain fixed on the problems identified, but to create ideas about possible next steps to instigate improvements. The research was particularly necessary given that there were so many suggested ideas both by people living with advanced cancer and healthcare providers. The engagement conducted with stakeholders was a powerful way of maintaining focus on people's everyday experience, using original evidence to probe and canvas the opinions of others. Public engagement hosted at existing events proved a highly effective dissemination strategy to share this research with a wider audience. Individual events also served as networking opportunities to discuss the key findings with people of influence in the sectors involved in this area of healthcare.

In this work, stakeholders offered their insight about where the emphasis in the future should be, and what the immediate priorities for medicines optimisation are. There was agreement in some areas, and disagreement in others. Overall, the key message was the difficulty in prioritising the focus of intervention in this area. No single priority was identified. However, what the study did emphatically demonstrate is a shared commitment to this issue, through the participants' widespread enthusiasm for the research. A considerable number of people from a range of professional roles wanted to talk about specific solutions and the work opened conversation with well-placed people to offer their understanding and ideas. The participants expressed commonalities in the rationale for trying to make people's experiences better. So, although people did not have the same priorities, they offered similar motivations behind their goal, to make people's lives easier, to give them greater control, and to improve outcomes. Likewise, participants identified similar mechanisms for making that possible, through better communication with people using medicines themselves, between HCPs about people who use medicines, and services that put people at the heart of the design process. The outcomes of the last part of feedback all pointed towards improved communication. This is important because it overlaps with a major finding of the previous study with HCPs, who too identified that communication and access to information

and insight is severely impeded by the existing structure, layout, and systems for healthcare care. There are many areas of disconnect which prevent accommodation of medicines self-management in the longer term, so improving communication is one key area that could have a direct impact on people's experiences of medicines. In addition, stakeholders recognised the need that future services be designed around people living with advanced cancer, to recognise the changing climate of cancer care, and the needs of people living with advanced cancer.

7.3 Moving forward with the knowledge

7.3.1 Understanding people's experiences

This research contributes a conceptual description of how people experience medicines use at home during advanced cancer in the context of UK NHS care. This summarises the core elements of managing the incurable diagnosis, the responsibilities of medicines, and getting on with life. The depth of detail and diversity of this experience has not previously been captured. The RPS Medicines Optimisation outcomes for understanding people's experiences with medicines concentrates on people's engagement with their medicines in everyday life, their beliefs and preferences about medicines, making shared choices, effective medicines-taking, and sharing medicines experiences and impacts (RPS, 2013). New insight from the current study provides a basis for HCPs to have deeper understanding about these and additional areas. Undertaking research in the natural environment of medicines use enabled the detailed personalisation of a medicines management system to be examined.

The first diagram, shown in Figure 17 was developed to visualise this previously undocumented aspect of advanced cancer. It outlines the everyday work of medicines use in the context of living with incurable disease. The diagram attempts to highlight the central reality and impacts of incurable metastatic cancer, key areas of responsibility for the relationship, the system, the habituation, and the mediating 'self-management' work of adapting and adjusting. Specific characteristics of each concept are unique to individuals and their approach: the central concept 'Having cancer that is never going to go away' includes, key features of the experience such as future uncertainty and maintenance of normality; the three surrounding areas are populated by specific activities, so 'Navigating the system' for example includes ensuring a sufficient supply, and "Habituation in the home', incorporates conscious placement of medicines to facilitate their use. The final outer area in the diagram depicts the self-management effort employed by people who use medicines, which in this research was characterised by responding to events and determination to manage medicines in a way that promotes independence. In the diagram, this is depicted as a penetrable region to symbolise the potential for this experience to be supported. This proposed portrayal of the experience is tentative and open to detail and divergence gained in future research.
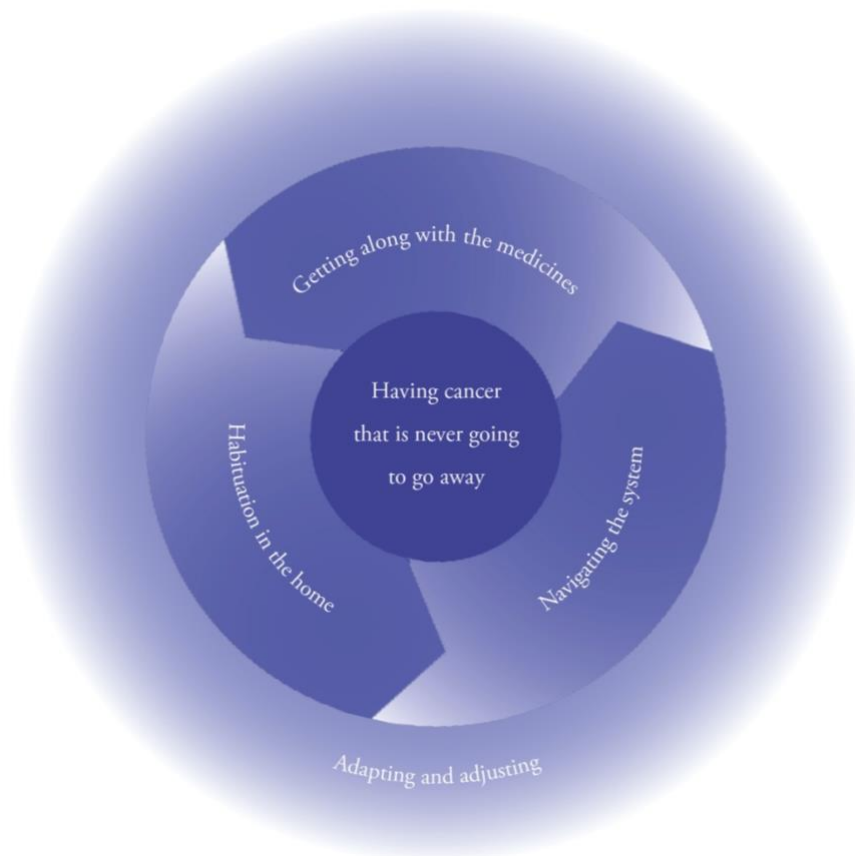
Figure 17. Conceptual description of living with advanced cancer and using medicines at home

7.3.2 Identifying opportunities to support people

This research has helped to develop understanding about what is happening when people use medicines at home. It has illuminated the detail of their self-management tasks, their approaches, and provided some sense of what people's priorities around medicines use are. It has also provided valuable knowledge about the structure of care and how that impacts on people's experiences. It has enhanced understanding about people's roles and how they function within the system and subtle changes in those areas, which may benefit people living with advanced cancer. It has also established that it is difficult for people involved in the key areas of strategy, research, education and care, and people affected by cancer themselves, to prioritise the future direction. The research undertaken and the results make clear that this is an extraordinarily complex area of care. Complexity is layered in several ways due to advanced cancer pathophysiology and treatment, the trajectory of care, the extensive array of advanced cancer clinical services, the incongruent infrastructure to support cross-disciplinary working, the multiple medicines people need, the convoluted processes for their use; and the people involved, who comprise HCPs with various roles and responsibilities and people living with advanced cancer and whose lives are difficult and likely limited.

The research with HCPs helped to explore the context of advanced cancer NHS care. Key concepts were identified which summarise the ability of HCPs to provide continuous support for self-management. The diagram presented in Figure 18 highlights how these concepts form the surrounding conditions that can influence and interact with the individual's experience of medicines use and their self-management endeavour. The original diagram representing the experience of medicines management is here augmented by the factors outlined above, which were discovered or validated through the second study with HCPs. The progression from the first diagram to the second illustrates how the personal regime of medicines management exists within a more complex but discontinuous system. The contextual factors of insight and information, oversight and ownership, and expertise and resources, can all impact the individual experience, as both a barrier to, and a potential positive catalyst for supporting medicines optimisation. Their lack of integration means that they currently do not reinforce one another to cohesively support self-management.
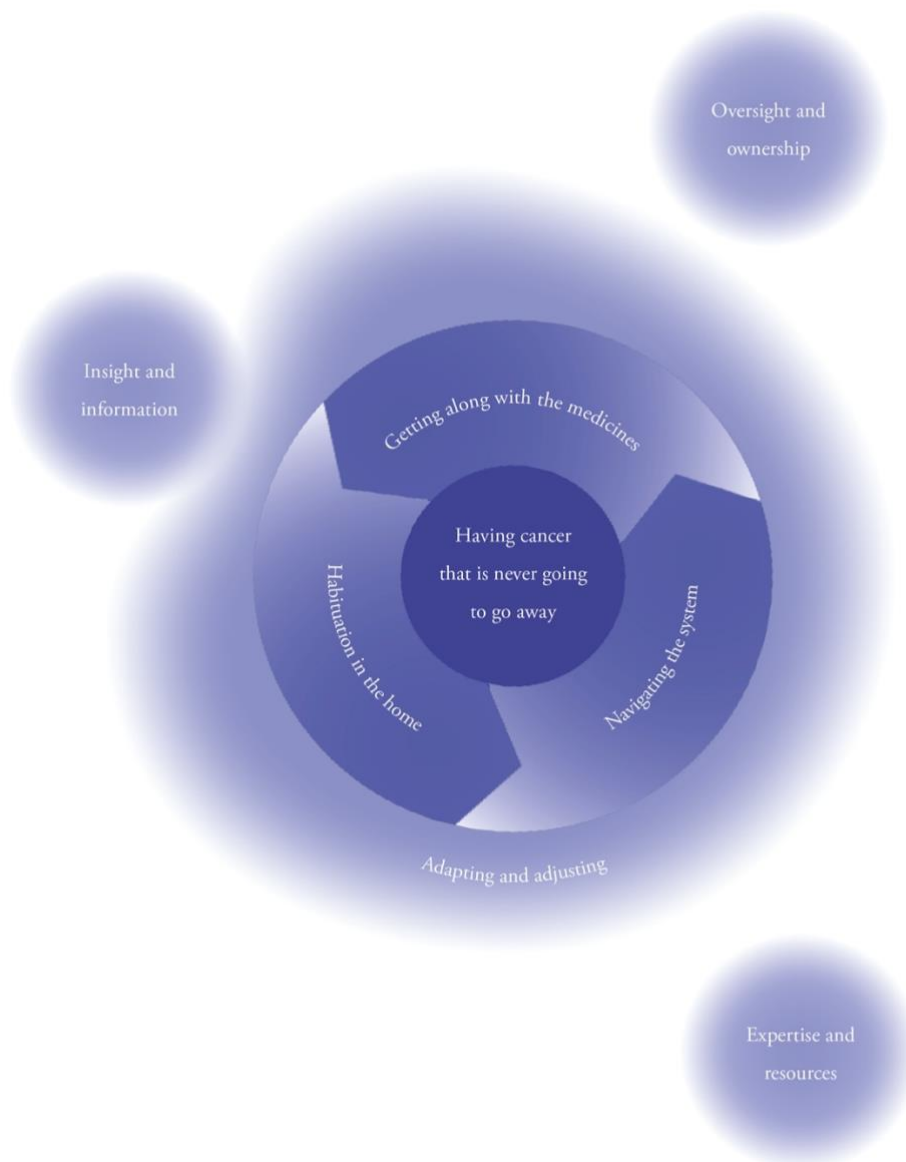
Figure 18. Conceptual description of medicines use in advanced cancer in NHS care context

The research included many HCPs from different settings and consequently many suggestions were generated, either based on what people have tried for themselves or based on proposals from local and wider audiences about the potential avenues to impart change and improvement. The stakeholder engagement failed to generate a singular priority for the direction of future work. However, it did generate clear and collectively agreed motivations for the delivery of support for medicines optimisation. In Figure 19, these ideas are integrated into the conceptual diagram, to demonstrate the potential for these strategies to mediate the support of people's medicines self-management in advanced cancer. This final diagram suggests that improvements in the key areas of communication with, and about people, and through the person-centred design of services, could achieve more coordination and continuity of care. It shows that this could beneficially impact the individual experience of medicines use during advanced cancer, by supporting self-management.
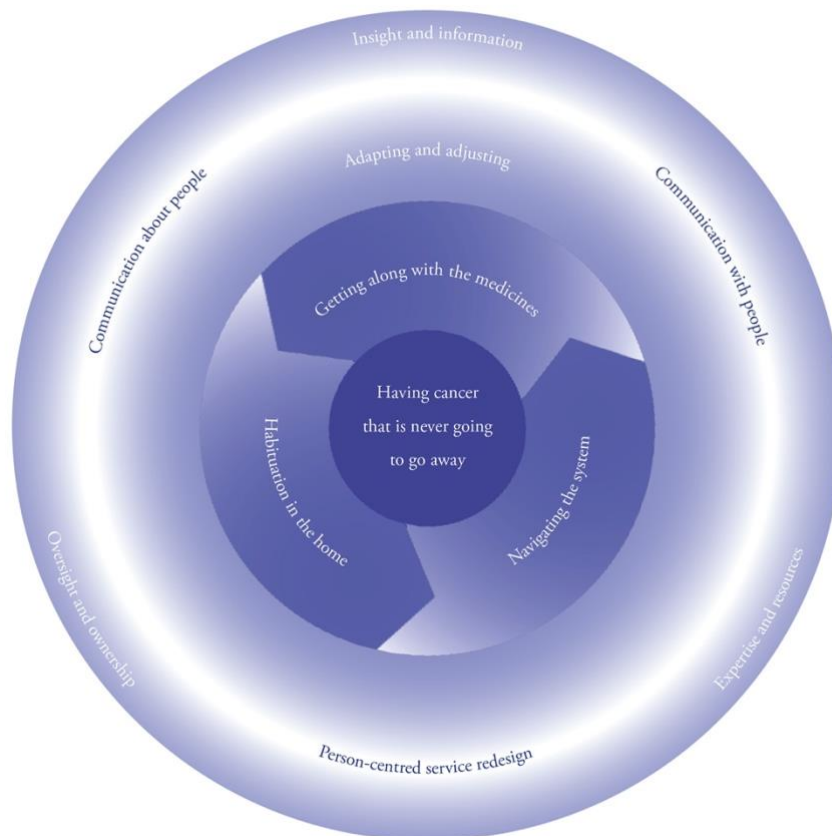
Figure 19. Conceptual description of supporting self-management of medicines in advanced cancer

The research identified numerous potential opportunities in clinical practice to improve people's experience of using medicines at home. Many of these ideas have been highlighted throughout the work across all three studies. Some were small, local level suggestions that do not necessarily involve significant reorganisation, others reflect broader service-wide change. Revisiting those

suggestions for change at an individual, organisational, and cultural level is a good next step in considering how to move forward. Some suggested innovations, provided by study participants, which could be considered in future work are described below.

Annotating medicines labels was a simple method identified by numerous participants, which aided their practical familiarity with medicines. Handwriting supporting information onto the medicine packaging, about what that medicine is for, helps people use medicines by enabling them to fit into a daily routine, or introduce them and facilitates conversations about them. An outcome of pilot interviews was that people could not talk about what they did with medicines easily, without having them to hand. This physicality of medicines is important in how people relate and remember and communicate about them. This is in stark contrast to how HCPs are accustomed to referring to medicines in their absence and without any sense of their appearance, relying entirely on terms describing their indication or pharmaceutical name. Annotation is a simple and free means of addressing some this difficulty. It is important to also note that some HCPs in Research Study Two voiced concerns about encouraging this practice, given the potential for people to transpose incorrect or misleading information. The findings of Research Study One, however, do not back-up that concern. It remains a valid consideration, but indicates that re-education of HCPs, so that they feel less anxious about condoning this practice would be beneficial. Providing HCPs with the insight into people's everyday practice and demonstrating that annotation is valuable would address this current gap in HCPs understanding and willingness to endorse such a technique.

Medicines schedules present another simple solution for assisting people to integrate their medicines into a workable daily routine. Except for the use of trial systemic-anti-cancer therapy, no participants had experience of being supported with written tools. Some HCPs referred to their own independent practice of designing and issuing timetable-type paperwork to people to support their implementation of a medicines schedule. It was observed that the prescription format of a medicines list, whilst theoretically accurate and useful for medicines reordering, serves little practical purpose for people when they are using medicines at home. The list is not indicative of the temporal and integrated nature of medicines use. There is therefore clear scope for the use of a standardised medicines schedule across NHS cancer services. This would be a tool akin to the medicines list but presented in a schedule format to include vital detail about the timing of medicines administration and any specific instructions. Engagement with people who use medicines and HCPs could facilitate the design of such a template. This could then be used as a shared document, used by people used at home to assist implementation of their regimen; and by HCPs, for them to be able to offer guidance and ensure future prescriptions integrate well into the existing routine. Obviously, the complexity of care interactions and their existing siloed documentation process, illustrates the likelihood that initiation of such an additional document or tool would only add to the current administrative labyrinth. For such a schedule to be of most value, would require it to be accessible to people using medicines, and all relevant MDT members and kept up to date.

Consequently, the implementation of such a resource, regardless of the simplicity of the tool itself, depends entirely on the existence of an effective electronic platform for information sharing.

Compliance aids are a recognised means to potentially improve practical medicines management. Some people in this research were already using privately sourced devices and had established a routine for replenishing them. The use of these devices generated mixed reaction from HCPs, who were concerned that they do not always work, as some medicines do not fit in or may even become less effective when stored in such a way. However, participants in the first study were enthusiastic about their utility and the opportunity it gave them to remain in control of their medicine organisation. A 'blister pack', or multi-compartment compliance aid (MCA) is another means of supporting medicines use. These are designed to contain individual doses of medicines in separate compartments for each occasion medicines are required. The first study did not include any people who used these, as receipt of any professional support with medicines was a recruitment exclusion criterion. HCPs in the second research study, raised the suggestion that some people with complex medicines regimens may benefit from a MCA. Other participants were critical of MCAs, due to the readiness with which they are given in lieu of alternative attempts to explore people's experiences with their medicines and highlighted that they can take control away from people. Overall, the evidence indicated that they could be considered a useful intervention for some people, but need to be carefully considered and implemented, with drawbacks and positives fully considered. This echoes guidance about the use of MCAs (RPS, 2013b).

Tailored assessment tools were herein identified as a way that HCPs can explore medicines-related issues with people. The HNA offers the potential to execute this readily in clinical encounters. In its current version there is not adequate inclusion of medicines given their enormous role in people's lives. For example, the assessment does not necessarily link assessment of symptoms with the use of medicines. This represents a genuine opportunity to integrate medicines self-management and the physical implications. But is also raises the question, whether HCPs conducting assessments would know what to do with the information generated and how, for example, to escalate issues relating to medicines use. It is also unclear how the information gained in an HNA could be effectively transmitted to other HCPs involved in the MDT, given the barriers to communication in advanced cancer care that this research has reported.

Coaching offers an opportunity to provide practical guidance around medicine use in the home. The potential for the success of this approach was initially introduced in the literature review, where the qualitative work of Schumacher et al., (2002; 2014a and 2014b) in the exploration of an RCT coaching intervention for pain was considered. The suggestion that the practice pharmacist with a domiciliary remit could embark on such an initiative is logical given their placement and expertise. However, the reality of commissioning and implementing such a specialist service is currently unclear. There is tentative work to highlight that pharmacists can be successfully trained in a

coaching approach and that it can enhance care and coaching for medicines optimisation is becoming a reality in UK community clinical practice for older people with complex comorbidities (Barnett et al., 2017). However, its specific application to the complexity of advanced cancer and the domiciliary aspects remains untested. The evidence generated in this research shows that advanced cancer has unique clinical conditions, which indicated that more exploratory work would be needed to consider how a domiciliary service could work in this context.

A Key Person for advanced cancer is one suggestion arising from integrating evidence generated in this research. Having overall responsibility for medicines to a named HCP is one way that some of the discoordination and lack of continuity might be addressed. The point is, that a named individual or role takes responsibility for the whole cohort of medicines. That individual would need to establish a therapeutic relationship with people and offer tailored advice and support according to their needs. In Research Study One, three participants who were in receipt of Specialist Community Palliative care were unique in their experience of medicines oversight. They felt supported, had a direct point of contact, and, importantly, perceived someone to have a grasp of all aspects of their care. However, Specialist Palliative Care is a service for people with complex and poorly controlled symptoms; it is not necessarily appropriate for all people living with advanced cancer. Yet the model used for community-based, person-centred holistic support is clearly valuable and could inform the development of a similar service for people living with cancer as a chronic condition. This is particularly relevant, given that those who do have access to a site-specific CNS, report it is an opportunity discuss problems and symptom management; however, many people with advanced cancer do not have access to a CNS (Harley et al, 2012). Greater provision for CNS roles in cancer care is needed, as CNSs in the current study report that much of their working time is spent addressing issues from people in the community. As such, it may be appropriate to consider an extension of the CNS role in community services and practices.

Information Technology is clearly a major obstacle in the provision of good medicines optimisation care. The information technology infrastructure supporting the administration of medicines prescription and documentation would benefit from development. There are several issues at play which impact on HCPs ability to access and record basic information about people and their medicines. This limits the way they can support people, particularly if they do not see people face-to-face. Currently, different care settings use different patient records systems, and these are typically not integrated or accessible to all key providers of care. Schutze et al., (2018) explain that HCPs in primary care lack confidence to take a significant role in the long-term follow-up of cancer patients and that the development of electronic platforms to share information between GPs and specialists, to better integrate primary and secondary health care, would certainly be of benefit. Integration of systems and easier visualisation of care across settings could make support for medicines much easier, more efficient, and comprehensive. Such a system could include a 'live' prescribing interface so that information is accurate and up to date and could include the rationale

for prescribing decisions, that would be beneficial to other care providers who may also have to make prescribing decisions or support patients to take their medicines optimally.

In addition to these suggested practical and infrastructural changes, the evidence in this research also indicates key cultural shifts are necessary to improving the support for self-management of medicines by people living with advanced cancer. This firstly relates to a basic acknowledgement of the fundamental work that medicine use entails. When we ask people to use their own medicines at home, we ask them to take on a complex, multifaceted and sometimes laborious responsibility. Future action in supporting medicines use and medicines optimisation should keep this fact at its forefront. The current evidence also indicates the need to better embed the emphasis of medicines optimisation on supporting medicines use as a process, not just its outcome, amongst HCPs. Achieving both goals requires the provision of essential education to HCPs involved throughout the cancer care trajectory, about the normal everyday practices of medicines self-management that people undertake. HCPs need insight into what the expectation for medicine use translates to in the home, and about the techniques and approaches which people find helpful. This would undoubtedly help HCPs relate to the experiences of the people in their care, but also empower HCPs to encourage people living with advanced cancer to find out what works for them.

In the context of medicines use, the Recovery Package is relevant because it focuses on person-centred care and the growing importance of self-management given the new trajectories of care for advanced cancer. The Recovery Package (DH, Macmillan Cancer Support, NHS Improvement, 2013), introduced in Chapter One, is a strategy to support people living with and beyond cancer. It aims to give support that enables people to live as actively and independently as possible. Giving people the information and support they need to be empowered to manage their own lives and medicines is integral to this. The strategy recommends personalised approaches, effective holistic follow-up care, and a better-integrated model of care. Needing medicines creates work, and people living with advanced cancer typically get on with that work, but there is much scope to help with this effort through tailored self-management support. The work undertaken here supports recommendations made in other cancer care contexts, that interventions for medicines use by people living with advanced cancer could consider the development of protective factors for resilience. These should ideally be community based, in order to promote long-term self-management (Harrow et al., 2014; Seiler and Jenewein 2019.

The findings of the current study align with conceptual models described in the Burden of Treatment Theory (May et al., 2014). As previously discussed, the Burden of Treatment Theory explores the relationship between people receiving healthcare for chronic illness, their social networks, available healthcare services, and the proactive work involved in self-care. This is an important model to consider when designing interventions to provide self-management support for medicine taking, as it illustrates the complex and dynamic factors that affect successful medicine

taking and identifies sources of burden for patients. Research Study One, for example, showed that many patients are proactive in putting systems in place to support medicine taking, which in the Burden of Treatment Theory would be regarded as 'agency'. Individual agency is not a constant element, however, and several factors such as increased symptom burden, changes to medication, or altered routines, can easily increase work for patients and disrupt 'agency'. Research Study One also highlighted a reliance on family members and wider support networks, including healthcare professionals. The network of support around patients is called 'Relational Networks' in the Burden of Treatment Theory. For many patients, individual agency is supported by strong relational networks, but this will vary between patients and is subject to change over time, so cannot be assumed. Maintaining relational networks can also be burden of work for patients. Research Study One demonstrated that individual agency and strong relational networks may not always result in successful medicine taking, and several organisational and bureaucratic barriers to medicine taking were identified. This is recognised in the Burden of Treatment Theory as 'control' whereby healthcare organization, protocols, and bureaucracy can cause insurmountable barriers to medicine taking and place a heavy burden of work on patients and their relational networks. Research Studies One and Two both highlight the lack of control that many patients have over their medicines and the burden of work involved in maintaining medicine supply. May et al (2014) state that the future development of healthcare services should consider changes necessary to improve patient experiences of treatment burdens and they recommend interventions address the dysfunctional structural elements of healthcare. They argue that future interventions should:

a. Improve relational networks and equip people to navigate system controls and opportunities. These are likely to improve effective healthcare utilization.

b. Help people to establish co-operation and social capital to address functional performance and improve resilience. This would increase individual capacity/agency to undertake healthcare tasks.

c. Facilitate controls of cognitive and practical tasks delegated to patients and their relational networks and monitor their effects. These are likely to improve capability to perform healthcare tasks.

d. Develop collective competence for doing practical tasks, provide help and exploit local resources. This aims to reduce inappropriate demands on healthcare services.

7.3.3 Embedding change

To address some of the issues identified and suggestions made in this research would require development of a complex intervention. These are interventions with multiple interconnecting components, which require multiple layers of change. In creating such an intervention, it is essential to understand the complexity within which the research is situated. The conceptual model created in this research about people's experiences with medicines during advanced cancer helps to provide the foundations for understanding this complexity. By undertaking this essential groundwork,

which has involved the right people and explored the rich issues underpinning this really complicated area, this research can tentatively inform the possible development of such interventions. The model has helped visualise the different areas of the self-management experience, which different interventions could address, but also clearly shows the importance of considering the context of life with advanced cancer from the perspective of the medicine user in the approach to the intervention design. The research shows there is a lot of work to be done and the complex findings from this research have confirmed it is not a straightforward undertaking. However, this work provides a helpful starting point

Developing and implementing complex interventions is demanding and particularly challenging in primary care (Murray et al., 2010; Lau et al., 2016). Normalisation process theory (NPT) is recommended as a way of developing and implementing interventions. NPT is a set of social processes to help support the consideration of implementation of a complex intervention, whilst designing it, to ensure procedures are feasible in the clinical practice setting; and to operationalise new practise interventions in healthcare (May et al., 2009b; Murray et al., 2010). NPT describes four constructs for different mechanisms required to implement a new practice, these are Coherence, Cognitive participation, Collective action and Reflexive monitoring (May et al., 2009b). NPT represents one means by which the ideas generated in this research, could be used to inform the development of a complex intervention.

Despite the wealth of opportunities suggested in this thesis to inform the development of future interventions, it is worth stopping and thinking about whether these individual strategies would really tackle anything. Instead, they may just be patching over problems and generate additional silos of working. It seems likely that they could be tinkering around the edges, and inadvertently give some HCPs more to worry about and even more to do, whilst not comprehensively addressing the bigger issues. This raises the question about whether widescale reform of advanced cancer care is what is actually needed. Advanced cancer has changed, and its requirements are different; the system we currently have was not ready for this. Advanced cancer has outgrown the system it started out in, and it is no longer suitable for people's complex needs. We are in unchartered territory. A novel approach to the delivery of cancer services for this population would recognise people's independence and desire to live as normally as possible, consider the community location for much of the population, be responsive and accessible, and well connect the expert insights of specialist HCPs.

7.4 Strengths and Limitations

A key strength of this research is that it addressed a major gap in understanding, which had been identified by the literature review. The empirical work undertaken in this thesis has added significant detail to our understanding about how people manage medicines at home during

advanced cancer; what the NHS healthcare context is for those experiences; and what might help to improve the support of their experiences. The use of methods grounded in the individual perspectives of people living with advanced cancer provided a suitable and effective approach to generating this knowledge. The research sought first-hand accounts from people, and that data was used to inform and build materials used in the subsequent research. Consequently, the research has maintained proximity to the original accounts and everyday realities of people living with advanced cancer.

The methodology specifically helped to support execution of these methods. An approach informed by Interpretive Description supported the grounding of the research in naturalistic techniques, which considered the subjective perspectives of medicines users themselves and the social, environmental and healthcare system contexts for medicine use. Crucially, this work embraced the knowledge of clinical cancer nursing and allowed it to guide the generation of data and development of concepts which specifically related to clinical practice. An added strength of this work is the inclusion of other healthcare professional perspectives which was facilitated by the study design. The recruitment of people providing care has helped to generate specific findings relevant to UK cancer care. Previous research has not provided insight into this organisational basis for medicine use and the data here has proved invaluable as a tool for the consideration of changes and improvements which can support people's experiences. Using engagement to disseminate research findings and explore other perspectives about this work also benefitted this research. It allowed the researcher to share study findings with others and start conversations about maintaining momentum in research in this field. This approach to creating a dialogue with others strengthens this research as it incorporates greater diversity of opinions and insights, which are key considerations prior to undertaking any complex interventions.

A key limitation of this research is that it is a small, local study. Consequently, the findings are few and contextual. The small numbers of participants means that inferences and conclusions about these results are tentative. Participants were recruited from one geographic area and therefore some of the specific process and practices identified by people may not be transferrable to other settings. In addition, the absence of ethnic diversity in this sample of people living with advanced cancer means that the study cannot explore cross-cultural similarities and differences. The participants in the study were mostly older, retired people. Whilst advanced cancer amongst the older adult population is more common, it would be valuable to consider the impacts of the medicines use experience for people who are younger, in employment, and potentially have dependent families and caring responsibilities. The nature of the experience documented here implies that the challenges of managing medicines are potentially greater for people with additional responsibilities. In addition, although the participants in the initial sample had varied cancer diagnosis, some prevalent primary cancers were not represented by this work. It is important that future work considers the potential for specialist self-management needs amongst people with other diagnoses.

Other shortcomings of this work relate to the methodological limitations of the chosen approach. Whilst the exploratory nature of the studies has generated rich, nuanced data, findings need to be confirmed via other research approaches in more depth, before moving forwards to developing interventions. Future research should be based on the use of other methodologies to test if any of the suggestions identified by this qualitative work could be useful in practice. These would involve both additional qualitative and new quantitative work, to validate the findings discussed, further investigate gaps, and continue to explore opportunities for making an impact in the real world.

7.5 Summary and conclusion

This thesis has presented research aimed at improving understanding about people's experiences of medicine use during advanced cancer and identifying potential ways to support people. The work undertaken has generated new evidence demonstrating that using medicines at home during advanced cancer is a complex activity, involving multiple areas of responsibility. People living with advanced cancer demonstrate resilience in response to this essential requirement, through the development and implementation of self-management techniques which promote their independence. In so doing, they weather disruptions and overcome obstacles, which are worthy of our attention. The research also generated new evidence demonstrating NHS HCPs current detachment from the everyday issues of medicines self-management during advanced cancer, due to their own limited understanding of the requirements of medicines use, and the apparent fragmentation of the advanced cancer care pathway which restricts proximity to people and their medicines experiences. HCPs recognise key areas in care which could be addressed to try and improve their support for people who use medicines at home, yet the evidence also indicates the need for comprehensive systemic change to improve continuity in advanced cancer care. Finally, the research generated new evidence about how these key ideas and opportunities to support people resonate with the wider community. Stakeholders are motivated to address support for medicines optimisation, which is grounded in the determination to make things easier for people and empower them, through improved communications, and services which put the medicines self-management experiences and needs of people living with advanced cancer at their centre.

These findings have substantially improved knowledge in this area and they provide a firm foundation for future work. Further research is required to validate and expand our understanding, which, combined with the knowledge generated here could inform the design and improvement of clinical practice to deliver real benefit to people living with advanced cancer.

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Appendices

Appendix 1. Search Strategy: EMBASE

1	cancer*.tw.	2540804
2	neoplasm*.tw.	158786
3	malignan*.tw.	738430
4	1 or 2 or 3	3042418
5	metasta*.tw.	723397
6	advanced.tw.	655107
7	stage IV.tw.	40029
8	terminal*.tw.	430612
9	5 or 6 or 7 or 8	1707222
10	4 and 9	780345
11	chronic cancer.tw.	701
12	exp advanced cancer/	130008
13	10 or 11 or 12	814118
14	medication*.tw.	544909
15	medicine*.tw.	769997
16	prescription*.tw.	174736
17	exp prescription/ or exp prescription drug/	217209
18	14 or 15 or 16 or 17	1459767
19	patient* experience*.tw.	105982
20	lived experience*.tw.	9277
21	life experience*.tw.	8689
22	personal experience*.tw.	13618
23	patient* perspective*.tw.	16422
24	self manag*.tw.	32201
25	self care.tw.	26427
26	exp self medication/	8136
27	exp self care/	80078
28	19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27	242146
29	13 and 18 and 28	735
30	limit 29 to english language	709

Appendix 2. Research Study One: Participant Information Sheet

UNIVERSITY OF LEEDS

School of Healthcare

Participant Information Sheet

Exploring the experience of medicines management for people living with advanced cancer

You are invited to take part in a research study which will explore the experience of living with advanced cancer and managing medicines. Before you decide if you would like to participate, it is important that you understand the purpose of the research and what taking part will involve. Please read this information carefully and take your time to decide if you would like to take part. **Many thanks for taking the time to read this information.**

What is this study about?
Advanced cancer, describes cancer that has spread (metastatic) and can not be cured.
People with advanced cancer often self-administer many prescribed medicines at home including pills, injections, patches, inhalers and liquids. Some people also take other remedies which they get from the chemist, health shop or internet. The medicines might:

- ☐ treat the cancer e.g. chemotherapy
- ☐ alleviate the symptoms of cancer e.g. pain
- ☐ treat other medical conditions e.g. diabetes, heart disease, depression
- ☐ prevent specific medical conditions e.g. blood clots
- ☐ ease the side-effects caused by other medicines e.g. anti-sickness
- ☐ improve overall health e.g. vitamin tablets

This can often result in a complex collection of medicines. Little is known about the how people cope with this. This study aims to find out about the practical strategies and attitudes people have towards managing their medicines, in order to improve the support and information given to other people with advanced cancer who have lots of medicines.

Who is doing the study?
This research study is being carried out by a registered nurse and PhD student in the School of Healthcare at the University of Leeds. The PhD is being supervised by Professor José Closs, Dr Clare Harley, Dr Nic Hughes and Dr Claire Easthall.

What will happen in this study?
The researcher will interview people at home, about where their medicines come from, how they are organised and how it feels to manage them. The researcher will also take photographs of medicines and any aides used to help manage them.

What will taking-part involve?
If you decide to take part, the researcher will arrange to interview you at home at a convenient time. You will be given a copy of a Participant Consent Form to read and you will go through this form together, so that you can ask any questions. You will be asked to sign the Consent Form to confirm that you agree to take part in the study and that the data you provide can be used by the researcher. The interview will last for around 1½ hours and the sound will be recorded using a Dictaphone. You will be invited to show the researcher your medicines and you will be asked questions about how you manage them. If you have given your permission, photographs will be taken of your medicines using a digital camera. You

Participant Information Sheet
Version 3.0 28/06/16
Kathryn Chater
IRAS 197305

will be shown the photographs straight away and photographs that you do not like will be deleted. If you decide that you do not want any photographs to be taken, you can still take part in the study by doing the interview only. What you have to say will still really help.

Will my contribution to the study be confidential?
If you decide to participate in this study, you will be asked to share your name and contact details so that an interview can be arranged. This information will remain confidential. All of the data that you provide to the study, including your medical background, social circumstances, interview answers and photographs will be anonymised, so that they cannot be linked to you. You will be given a false name, which will be used by the research team instead of your real name at all times. If during the interview you discuss something that causes concern about your safety, this may be shared with your medical team. After the interview, you will receive copies of the photographs, so that you can check you are happy that they are used. The interview will be transcribed and saved with all other data on the University of Leeds server, which is secure and can only be accessed the research team.

What will happen to the results of the study?
The anonymised data will be analysed and shared with the research team and presented:
   - in the PhD thesis
   - in published articles in journals, books or online
   - in academic posters and presentations at conferences
   - at public exhibitions
   - in future research

What are the advantages of taking part in this study?
Participating should be a positive experience. It provides an opportunity for you to help others by expressing your opinion and raising important issues about your medicines.

What are the disadvantages of taking part in this study?
No immediate risks are anticipated in taking part in this study. It is possible that talking about certain issues will cause you to feel emotional. There is a lot of help available to you, so please do tell the researcher if you would like some support.

Can I withdraw from the study?
You can withdraw from the interview at any time. You might want to have a rest, or stop altogether. You do not need to explain why you want to stop. If you decide that you do not want your interview or photographs to be included in the study, your data can be destroyed up to a fortnight after the interview. After this time, your data will be included in the study.

Who has reviewed this study?
The NHS Research Ethics Service [have granted] ethical approval, which means that the study meets regulatory and governance requirements.

To **take part** or for more **information** contact the research team at
The University of Leeds   email: hcs5k2c@leeds.ac.uk   telephone: 0113 3431374

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IRAS 197305

Appendix 3. Research Study One: Consent Form

UNIVERSITY OF LEEDS

School of Healthcare

Participant Consent Form

Exploring the experience of medicines management for people living with advanced cancer

I have read the Participant Information Sheet explaining this study dated 4/5/16. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in this study is voluntary and that I can withdraw without giving a reason. I understand that if I withdraw, I can choose whether any data that I have already provided is kept or destroyed.	
I understand that I can withdraw any data that I have provided up until two weeks after the interview, after which time my data will then be included.	
I understand that all personal information that I give to this study will remain confidential, be stored securely and only accessed by the research team.	
I understand that any data I provide to this study will be anonymised. However, I understand that if I discuss something that indicates I am at risk of harm, this may not remain confidential.	
I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records	
The Interview I agree to take part in a digitally audio-recorded interview for this study. I agree that the anonymised interview can be shared with the research team and used: ☐ in the PhD thesis ☐ in articles published in journals, books or online ☐ in academic posters and presentations at conferences ☐ at public exhibitions ☐ in future research with other researchers	
The Photographs I agree that digital photographs can be taken of my medicines and medicine-related items. I agree and that anonymised photographs can be shared with the researcher team and used: ☐ in the PhD thesis ☐ in published articles in journals, books or online ☐ in academic posters and presentations at conferences ☐ at public exhibitions ☐ alongside anonymised quotes from my interview in future research with other researchers	

Kathryn Chater	**Participant**
Signature	**Signature**
Date	**Participant Name**

One copy of this Consent form will be retained by the researcher, one copy will be given to the participant and one copy will be placed in the participant's medical records.

Appendix 4. Research Study One: Interview Topic Guide

Introductions

Consent

Demographic details

Please could you start by telling me what an average day for you is with your medicines?

- When do you take them?
- How many medicines do you take?
- What is the routine?
- Do you have to consider things like where you are going/what you are doing?
- Do you find yourself giving it a lot of thought?

Can you tell me about the aspects that change from day-to-day?

- Are there some medicines that you use differently day to day?
- What about days when your health has changed for the better or worse?

Can you tell me about your different medicines?

- You can talk me through them if that helps
- Can you tell me about what the different medications are for?

Can you tell me a bit more about what it is like to manage all these medicines?

- Fitting them into your day?
- Taking them under all circumstances?
- Carrying them around with you?
- Responding to how your body feels?
- What you do if things change; if one is stopped or changed or a new one added?

Can you tell me about how you keep a track of everything, and all your medicines?

- Do you have a system?
- Are they arranged in a certain way?
- How do you remember to take them?
- How do you feel about needing to remember to take them?

Please could you show me how you remember to take them?

- Do you write it down or set any reminders?
- Do you worry about remembering?

Please could you show me how you keep your medicines?

- Is the way they are arranged significant?
- Are they all in the same place?
- What if you are going out?

Earlier in the interview, I asked you about an 'average' day. Can you tell me about the days that are not average – the days that are different?

- Why are things different?
- What happens?
- How do you feel?
- How does it have an impact on your medicines?

Are all your medicines from the same place?

- Are they all on prescription?
- Who gives you what?
- Who handed you them?
- What about alternative treatments?

What happens when you run out?

- Are there any problems in getting them?
- Who do you interact with about your medicines?

Can you tell me a little bit more about how you feel about your medicines?

- What do you think affects the way you feel about them?
- Have your feelings changed over time?

What would you like to change about your medicines?

Do you have any advice for other people?

Is there anything else that you want to talk about in relation to your medicines?

Appendix 5. Research Study Two: Participant Information Sheet

UNIVERSITY OF LEEDS

School of Healthcare

Participant Information Sheet

Exploring Medicines Optimisation in Advanced Cancer
Phase 2: Clinical perspectives on medicines management and advanced cancer

You are invited to take part in the above research study. Before deciding if you would like to participate, it is important for you to understand the purpose of the research and what taking part involves. Please read this information carefully before deciding whether to take part. Please contact the researcher if anything is not clear, or if you would like more information. **Many thanks for taking the time to read this information.**

What is this study about?
This study is **Phase 2 of a PhD project**, which is exploring Medicines Optimisation for people living with advanced cancer. Medicines Optimisation refers to patients getting the best out of their medicines. This is relevant because evidence suggests that medicines use is sometimes sub-optimal. People with advanced cancer self-administer many medicines; to treat cancer and alleviate its symptoms, prevent complications and ease the adverse effects of medicines themselves. Additionally, medicines may also be required for co-morbidities. Research is limited investigating what this experience is like for patients and therefore how they could best be supported. This PhD project seeks to address this gap in understanding and generate knowledge which will promote Medicines Optimisation.

Phase 1 of this PhD, explored the patient experience of managing medicines. Interviews were conducted with people living with advanced cancer to understand their attitudes and approaches to managing medicines. Photographs were taken of their strategies and solutions for medicines management. The aim of Phase 2, is to explore the perspectives of healthcare professionals who support people living with advanced cancer in either Primary or Secondary care, specifically in relation to medicines management. Clinicians who have some role in the prescribing, management, dispensing and review of medicines will be sought, to give insight into their role in supporting medicines management.

Who is doing the study?
This research study is being carried out by Kathryn Chater, a registered nurse and full-time PhD student in the School of Healthcare at the University of Leeds. The PhD is being supervised by Dr Clare Harley, Dr Claire Easthall and Dr Nic Hughes.

Why have I been approached to take part in this study?
Participants in this study are people who provide care to patients diagnosed with advanced cancer and have a role in the prescribing, management, dispensing and review of medicines. This includes General Practitioners, Consultant Medical Oncologists and Oncology Registrars, Nurse Consultants, Clinical Nurse Specialists, Staff Nurses and Pharmacists. You have been invited to participate in this study because of the relevance of your current clinical role.

What will taking-part involve?
You will be asked to participate in an audio-recorded interview, lasting 30-60 minutes. During the interview, you will be asked to talk about your clinical role in supporting people with advanced cancer to

manage their medicines. You will also be shown photographs taken in the Phase 1 study, depicting patients' experiences of medicines management, to prompt the discussion.

Participation is voluntary. If you decide to take part, the interview will be arranged for a convenient time. The interview will be carried out by the researcher in person, at your workplace or over the telephone. At the time of the interview, you will be given a Participant Consent Form to read and discuss with the researcher. Your consent will be documented prior to commencing the interview.

What are the advantages of taking part in this study?
Participating should be a positive experience. It provides an opportunity for you to reflect on your clinical practice and raise issues relating to advanced cancer care and medicines management. This PhD project will hopefully contribute towards advancing cancer practice.

What are the disadvantages of taking part in this study?
In order to take part, you will be asked to give up approximately 30-60 minutes of your time. All efforts will be made to minimise the impact of taking part on your work.

Can I withdraw from the study?
You can withdraw from the interview at any time, without providing an explanation. If following the interview, you decide that you do not want your interview data to be included in the study, this can be destroyed up to a fortnight after the interview. After 2 weeks, data will be analysed and included.

Will my contribution to the study be confidential?
If you decide to participate, you will be asked to share your name and contact details so that you can be contacted about the study. This information will remain confidential, will be used only for study management purposes. All personal information and study data will be stored on the password-protected University of Leeds server, which is secure and can only accessed the research team.

You will be given an ID number, which will be used by the research team instead of your real name at all times. The audio-recording of the interview will be transcribed by the research team. The data that you provide will be anonymised and the original interview recording will be deleted. If during the interview you discuss something suggesting a risk of harm to yourself or someone else, or an illegality, the researcher has a duty of care to share this with academic and clinical supervisors.

What will happen to the results of the study?
The anonymised data will be analysed and the results will be shared and presented in the following ways:
- in the PhD thesis
- in published articles in journals, books or online
- in academic posters and presentations at conferences
- at public exhibitions
- in future research

Who has reviewed this study?
University of Leeds School of Healthcare Research Ethics Committee approval has been granted, which means that the study meets governance requirements.

To **take part** or for more **information** please contact:
Kathryn Chater   **email: hcs5k2c@leeds.ac.uk**   **telephone: 0113 3431374**

Participant Information Sheet
Version 1.0 31/01/18
Kathryn Chater
IRAS Project ref: 242795

Appendix 6. Research Study Two Consent Form

UNIVERSITY OF LEEDS

School of Healthcare

Participant Consent Form

Exploring Medicines Optimisation in Advanced Cancer
Phase 2: Clinical perspectives on medicines management and advanced cancer

	Confirm agreement to the statements by initialling the box below
I confirm that I have read the Participant Information Sheet explaining this study (Version 1.0 dated 31/01/18). I have had the opportunity to consider the information, ask questions and they have been answered satisfactorily.	
I understand that any information that I provide to this study, including person details will remain confidential, be stored securely and only accessed by the research team.	
I understand that my interview will be audio-recorded	
I understand that the interview be transcribed and anonymised. However, I understand that if I discuss something that indicates a risk of harm to myself or others, confidentiality may be breached.	
I agree that the anonymised information I give can be used in: • the PhD thesis • articles published in journals, books or online • academic posters and presentations at conferences • public exhibitions • future research with other researchers	
I understand that my participation in this study is voluntary and that I am free to withdraw from the study: • Up to 2 weeks post-interview • Without having to give a reason for withdrawing • that any data provided will be destroyed I understand that it will not be possible to withdraw my data after 2 weeks of the interview taking place	
I agree to take part in this study	

Participant Signature	Date
Name of Participant	
Researcher Signature	Date
Name of Researcher	

Consent Form
Version 1.0 31/01/18
Kathryn Chater

Appendix 7. Research Study Two: Interview Topic Guide

Introductions   **Photo**

Consent   **Ref:**

Clinical role and context

- How long have you been qualified [as a doctor/nurse/pharmacist]?

- What is your current post?

- How long have you been in your current post?

- In what context and capacity are you currently caring for people living with advanced cancer?

- What experience do you have in advanced cancer care?

- How are you involved in supporting patients with medicines?

Having cancer that is never going to go away – exploring experience

- What factors relating to advanced cancer do you think influence people making the most of their medicines?

- What are the similarities or differences with other chronic conditions?

- How does uncertainty of prognosis impact on medicines interactions?

Having cancer that is never going away – identifying opportunities

- What support sources are available or recommended for medicines management?

Getting along with the medicines – exploring experience

- What are your observations about how people feel about their medicines?

- How do you address and respond to patients' attitudes about medicines?

- How are patient expectations about benefits assessed?

- How are concerns about consequences addressed?

Getting along with the medicines – identifying opportunities

- What practices could support patients' understanding medicines indication?   1

- How can medicines accumulation be avoided?   2

- How can adverse effects be discussed openly?   3

- What information is relevant on external packaging?   4

- Is annotation encouraged? Could it be?   5

- What else can patients do to help themselves?   6

Navigating the system – exploring experience   **Photo**
Ref:

- How do you interact with the other prescribers involved?

- How is consistency of information maintained between clinicians?

- Who should be the point of contact about medicines? Cancer and otherwise?

- What are the implications of many points of contact?

- Who should people with cancer be encouraged to routinely talk to about their   6

  medicines?   7

- How do you tailor conversations about medicines to individuals?   8

- What dialogue occurs between GP/oncologist/pharmacist?   9

- What governs decisions about hospice involvement in medicines care? Is there an   10

  intervention/escalation protocol?

- Do you know where medicines will come from?

- Do you know how medicines will be replenished?

- Do you know any pitfalls with repeating prescriptions?

Navigating the system – identifying opportunities

- How can patients participate in medicines decisions?

- What other measures could enhance how or when patients feeling are known?

- How could roles be developed?

Habituation in the home – exploring experience

- How do you talk to your patients about their practical approach to medicines?   11

- How do you assess medicines practical use?   12

- What do you think about the directions given with medicines?   13

- What do you think about medicines that fall out of routine?   14

- When introducing new medicines, how do you consider the pre-existing   15

  system/approach?   16

- What do you understand about where medicines are stored?   17

- Can you explain how you assess eating issues with the need to consume food with   18

  some medicines?   19

- How do you encourage/emphasise specific administering directions?

- When you are aware that patients ignore recommendations, how do you assess the

  reasons for and the significance of this?

Habituation in the home – identifying opportunities   **Photo**
Ref:

- What could you practice to counter some of the hurdles to following directions?

- Can you identify ways that people can be encouraged to remember?

Adapting and adjusting – exploring experience

- How are information-needs assessed? 21
- How and where should people obtain information? 22
- Do you know of any initiatives to support learning about medicines? 23
- Do you know what all these medicines look like?
- How do you familiarize patients with new medicines?
- How do you refer to medicines during interactions?
- Do you think patients should learn pharmaceutical terms?
- What information and discussion about use of alternatives is provided?
- Should alternatives be acknowledged and/or encouraged?

Adapting and adjusting – identifying opportunities

- What kind of initiatives and interventions would you like to see?
- What can give people confidence to take their medicines?

Is there anything you would like to add?
**Slideshow**

Appendix 8. Full list of photographs included in photo-elicitation slideshow

Interview Topic Guide Photo Ref	Question theme/subtheme	Description
1	Getting along/tolerating	Holly Calcichew
2	Getting along/many	Isobel bucket
3	Getting along/knowing	Tom Blood pressure
4	Getting along/Knowing	Leonard drawer
5	Getting along/side effects	Jenny Movicol
6	Getting along/knowing	Jack 'IF SICK'
7	System/Supply	Margaret inventory
8	System/Accumulation	Rosalind cat food
9	System/Accumulation	Eileen drawer
10	System/ managing supply	Henry 'LAST'
11	Habit/storage	Jack kitchen cupboard
12	Habit/dispense in advance	George kitchen table
13	Habit/dispensing in advance	Henry jewellery box
14	Habit/system	Malcolm windowsill
15	Habit/Practical techniques	Malcolm compliance aid
16	Habit/organisation	Jack I can't believe it's not butter
17	Habit/routine	Timothy kitchen counter
18	Habit/Practical techniques	Tony Oramorph
19	Habit/outlier	Simon button
20	Habit/placement	Rosalind coffee table
21	Resourcefulness/alternative	Henry energy drink
22	Resourcefulness/alternative	Christine blackgold /mushrooms
23	Resourcefulness/alternative	Christine supplement price

Appendix 9. 'Medicines Optimisation Priority' resources

Understanding medicines: what medicines are for
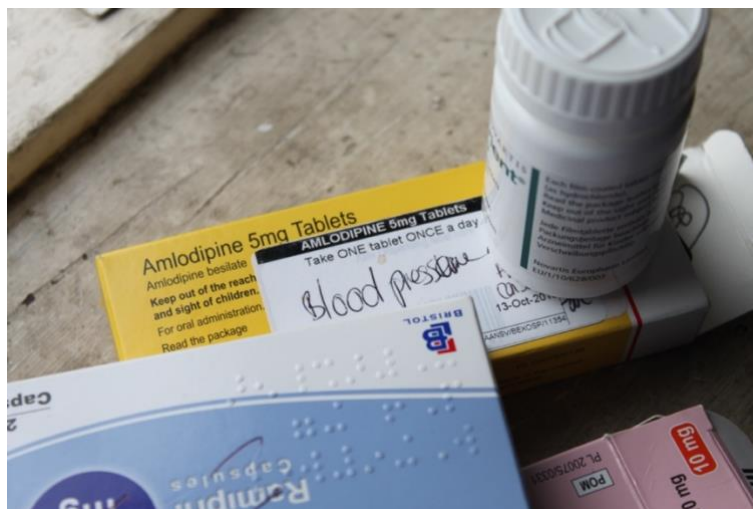
Large photograph (841 x 1188 mm)	
Pen portrait	This photograph was taken in the home of Tom, a farmer living with advanced renal cancer. This photograph shows how Tom writes the indication of each medicines on the outside of each box in order to recognise his medicines and what they are for.
Example quotation	*"There's a steroid tablet that I take…that's something to do with [the cancer]. That's a long term one is that. That's been a long term thing from me first getting cancer…I don't know at all what steroid tablets is supposed to do apart from they're pretty important, you know?"* Tony, advanced prostate cancer
Explanatory summary	People living with advanced cancer want to understand what their medicines are for. This means knowing why medicines have been prescribed and what medicines will do for them. People find it difficult to learn the pharmaceutical names for their medicines so develop alternative ways to become familiar with them. Recognising medicines based upon their purpose is one example. The reason why a medicine has been prescribed, is often absent from the external packaging. People annotate their packaging with information that is useful for them, enabling them to recognise their various medicines.
Picture postcards	Tom Blood pressure Jack 'IF SICK' Karen Calcichew

Developing practical techniques for medicines use

Large photograph **(841 x 1188 mm)**	
Pen portrait	This photograph was taken in the home of Simon, a hardware store assistant, living with advanced prostate cancer. The photograph shows Simon's compliance aid containing a button, which symbolises the time that he should change his analgesic patch. Simon experienced difficulty remembering to change his patch every 72 hours. He tried using a calendar but found this to be ineffective, as the patch often falls off prematurely in the shower or at work, altering subsequent patch-change schedule.
Example quotation	*"I would say - this will help whoever - always have your medicines in one place. Never have them dotted around. Always have them in one place."* Jenny, advanced colorectal cancer
Explanatory summary	People living with advanced cancer need practical techniques in order to manage their medicines effectively. People receive a lot of information about the medicines themselves, but they do not routinely receive education, advice or guidance about how to practically manage medicines at home. Often, people embark on a trial and error approach, before establishing systems that suit them. People develop their own practical techniques to manage their medicines, finding innovative solutions to overcome problems.
Picture postcards	Simon button Lillian washbag Timothy jewellery box

Supporting the impact of medicines on bowel care

|	
Large photograph **(841 x 1188 mm)**	
Pen portrait	This photograph was taken in the home of Malcolm, a retired engineer living with advanced prostate cancer. This photograph shows Malcolm's extensive supply of the anti-diarrhoeal medicine, Loperamide. Malcolm is enrolled in a prostate cancer trial and self-administers oral anti-cancer therapy daily. Diarrhoea is the main side-effect. Malcolm is also prescribed several other medicines for pain and pre-existing comorbidities, which cause constipation. Malcolm describes managing his bowels as a constant balancing act.
Example quotation	*"I've also got Movicol, because I got constipated after the anti-sickness pills…and then it turns the other way."* Isobel, advanced bile duct cancer
Explanatory summary	The medicines that people living with advanced cancer use often affect their bowels. The combined effects of different medicines, mean that maintaining bowel health can be challenging. People spend lots of time and energy thinking about this and trying to address it. Things can be particularly difficult for people experiencing bowel-related late effects from previous cancer treatments, such as pelvic radiotherapy or surgery. For people with gastric-related cancers, bowel regularity is a source of ongoing anxiety.
Picture postcards	Malcolm windowsill Jenny bedroom cupboard Henry kitchen cupboard

Simplifying medicines supply
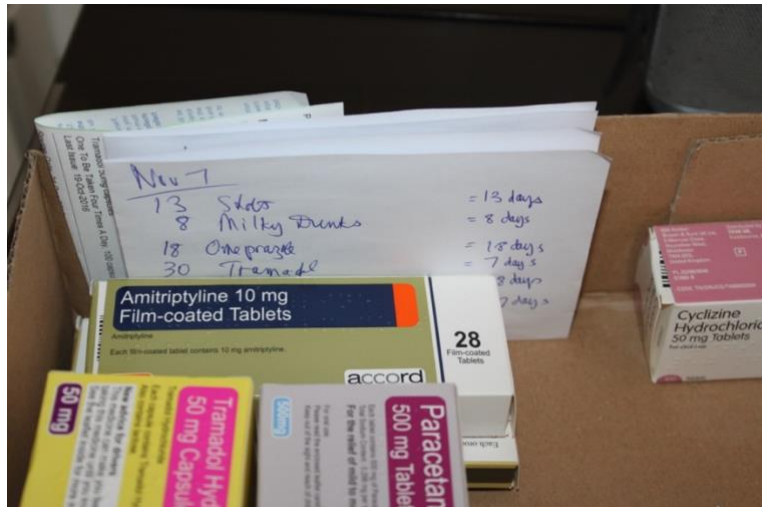
Large photograph (841 x 1188 mm)	
Pen portrait	This photograph was taken in the home of Margaret, a retired academic living with advanced neuroendocrine cancer. The photograph shows Margaret's meticulous medicines inventory, which reflects her ongoing endeavour to maintain an adequate supply of her various medicines.
Example quotation	*"They haven't put it on my regular prescription at the GP's. So I have to go in, fill in the white slip, hand it in, go back in three days, take it into the pharmacy, they have to order it, wait another three days. So I have to be organised."* Rosalind, advanced breast cancer
Explanatory summary	People living with advanced cancer manage many medicines. They often have multiple prescribers and obtain medicines from various different sources. Repeating prescriptions are rarely synchronised. Keeping track of medicines can be time consuming and stressful. People develop systems for monitoring their supply and remembering to reorder repeat prescriptions.
Picture postcards	Margaret inventory Timothy last Isobel bucket

Minimising medicines accumulation

Large photograph **(841 x 1188 mm)**	
Pen portrait	This photograph was taken in the home of Rosalind, a retired scientist living with advanced breast cancer. This photograph shows that Rosalind has accumulated many medicines. The collection includes medicines to treat cancer, manage cancer symptoms, alleviate treatment side-effects and other unrelated conditions. She is currently taking only some of these medicines regularly.
Example quotation	*"So then you start … you've to take tablets to counteract that and tablets to counteract that…I've got a full system in 'ere! Look! Bloody loads of these!"* Malcolm, advanced colorectal cancer
Explanatory summary	People living with advanced cancer are prescribed many medicines due to their complex and changing health needs. The result can be a vast collection of medicines in the home. Some of this accumulation is inevitable. Medicines are prescribed for one indication, but cause side-effects that require treatment with the use of another medicine and so on. Medicines are prescribed pre-emptively to mitigate toxicities, and then are not always required. The regular starting and stopping of medicines creates unfinished supplies. Sometime medicines mount up unnecessarily. Medicines for long-term conditions often continue to be prescribed, despite no longer providing therapeutic benefit. Sometimes, people stockpile medicines out of concern that they might run out.
Picture postcards	Rosalind cat food Eileen drawer Malcolm kitchen cupboard

Maintaining a normal life whilst using medicines

Large photograph **(841 x 1188 mm)**	
Pen portrait	This photograph was taken in the home of Brian, a joiner who is living with advanced renal cancer. This photograph shows Brian's medicines in their usual storage place in the kitchen. Brian is enrolled in a renal cancer trial and self-administers oral anti-canter therapy daily. Brian and his wife are the guardians of their young grandson and keep chickens in their back garden. Brian is self-employed and works as his health allows. He enjoys regular rounds of golf.
Example quotation	*"I still do everything; me cooking, me washing, me ironing. I think a lot of people think when you've got cancer you stop doing things people do. But like, I go out for a drink with me mates, we go dancing. I go walking, I do me own housework, I go to work. Next Friday we finish work early 'cos it's Christmas do?'"* Christine, advanced lung cancer
Explanatory summary	Having as normal a life as possible is important to people living with advanced cancer. People achieve this by exercising, socialising, working and participating in family life. People often have to make significant lifestyle changes in order to accommodate medicines due to the practical administration of some medicines or the tolerance of subsequent side-effects. People prefer it when medicines fit into their world, allowing them to sustain existing roles and activities.
Picture postcards	Brian Kitchen counter Tony kitchen cupboard Leonard Kitchen counter

Appendix 10. Engagement event summary

Event	Host	Agenda	Delegation
Primary Care Earlier Diagnosis of Cancer Research	R&I team	Presentation of current research Launch of new local strategic plan	AHPs, GPs, practice nurses primary care applied health researchers; CCG employees and support staff; patient advocates; strategic managers
Cancer Programme Partnership Update	NHS Trust/CCG	Presentations from workstream leaders	Clinical and local government leaders; patient advocates; cancer programme clinical and non-clinical employees
Cancer Patient Forum Christmas Event	Macmillan Cancer Support	Informal meeting of forum members	Patient advocates; engagement employees
Royal Pharmaceutical Society Pharmacy Research	A University	Presentation of doctoral and post-doctoral pharmacy research	Pharmacy students, lecturers, researchers, MHRA representatives