# Shared decision-making between people with experience of psychosis and mental health professionals: A discourse analysis.

Alice Didrichsen Staniford

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The University of Leeds

School of Medicine

Academic Unit of Psychiatry and Behavioural Sciences

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#### **Abstract**

Ideas about shared decision making (SDM) began to emerge in the 1970s as a challenge to the tradition of paternalism in healthcare. Theoretical models have focused on delineating this process and identifying discrete stages including exploration of service-user preferences, deliberation in relation to possible interventions and an emphasis on interactional, two-way communication processes that prioritise collaboration. There are particular challenges in terms of enacting the principles of shared decision-making with those with more complex mental health needs including experience of psychosis. Types of experience (unusual beliefs, intrusions, suspiciousness, changes to cognitive processes) along with issues of capacity, consent and the legal framework of the Mental Health Act (MHA; 1983) make it more challenging to implement these principles, even though they are laid out in best practice guidelines, and consistently correlate with positive outcomes for service-users.

This study focused on the construction of SDM in routine clinical practice by video-recording consultations involving decisions between service-users with experience of psychosis and mental health staff in a community setting. This was with a view to moving beyond exploration of the experience of SDM to look at the enactment of these ideas in practice. Three separate clinical meetings were recorded, which captured seven decisions related to different aspects of care and treatment. The final sample comprised 3 service-users, 1 carer and 5 professionals. Participants then watched the recording with the researcher, and reflective interviews were conducted to facilitate exploration of their experience in the meeting. The study proceeded from a social constructionist perspective, drawing from the principles of Discourse Analysis, more specifically Discursive Psychology. Analysis focused on constructions of psychosis, key features of participant talk and discursive and rhetorical features in order to examine impact on SDM.

The findings highlighted different ways of sharing opinions, directing or redirecting the dialogue, expressing agreement or disagreement and the challenge for staff in terms of promoting choice whilst also fulfilling legal and clinical responsibility. The findings also pointed to some important differences between physical and mental health SDM, and supported previous findings indicating that dominant discourses of psychosis impact collaboration at the micro-level of interactions between speakers in individual meetings. Based on these findings, I offer some reflections on implications

for clinical practice, including consideration of idiosyncratic and decision-specific approaches to SDM with this population that account for the nuanced experience of psychosis. I also make some suggestions for directions for future research, including repeating the study in acute inpatient settings.

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# **Abbreviations**

SDM: Shared Decision-Making

NICE: National Institute of Clinical Excellence

**DA**: Discourse Analysis

**DP**: Discursive Psychology

FDA: Foucauldian Discourse Analysis

**CMHT**: Community Mental Health Team

**CPA**: Care Programme Approach

**ICS**: Intensive Community Service

MHA: Mental Health Act

MCA: Mental Capacity Act

# **Chapter 1: Introduction**

Ideas about shared decision-making (SDM) began to emerge in the 1970s alongside increased interest in service-user centred care and challenge to the unequal distribution of power between service-users and clinicians (Haug & Lavin, 1981; Charles & DeMaio, 1993). SDM "recognises a patient's right to make decisions about their care, ensuring they are fully informed about the options they face" (Coulter & Collins, 2011; p2). It emphasises the need for clinicians to relinquish a paternalistic, expert position and allow service-users to share in decision-making by bringing their lived experience of a particular condition (Adams & Drake, 2006). This marked a shift away from exclusive focus on symptom reduction and towards consideration of quality of life and values-based outcomes. Along with making healthcare more responsive to the needs and wishes of service-users, some argue an SDM model is financially advantageous because service-users can identify treatments to suit individual preferences. This avoids funding universal interventions, which service-users may not be interested in pursuing (O'Connor et al, 2009).

These ideas have been studied extensively in physical health settings, but there is less research on how the principles can be integrated into mental health care (Duncan, Best & Hagan, 2010). This study aims to make a unique contribution to the literature by exploring how decisions are made in routine clinical practice in a sample of service-users with experience of psychosis. As discussed later in the chapter, enduring discourses of illness and incapacity alongside the impact of unusual experiences pose many challenges to SDM with this population, which may not appear in other areas of physical and mental health. This is important in thinking about ways to embed SDM across the spectrum of healthcare, and address issues of implementation with populations with complex needs.

The following chapter begins with an outline of the SDM literature across physical and mental health settings and how the experience of psychosis might impact on the enactment of these ideas in practice. This is followed by a discussion of societal discourses around psychosis, and consideration of how these also impact on opportunities for SDM. By situating this study within the broader research and clinical context, I provide the rationale for the current project and associated research question and aims. Please note, the acronym 'SDM' is used throughout this document for the purpose of consistency and ease of reading. I am aware that this captures a very

specific sort of decision-making, which relates to the models and methods of measurement highlighted below. As I proceed with the introduction and reflect on the difficulties applying these ideas across complex populations, my intention is to highlight the challenge of embedding these broader ideas and principles in mental health services and with people who experience psychosis. As such, although I continue to use the term 'SDM', I intend to capture other familiar synonyms from policy and clinical practice including: 'person-centred care', 'patient-centred care', 'patient empowerment' and 'collaborative care' (Royal College of General Practitioners, 2014).

## 1.1 SDM background

SDM models emerged from changes to the conceptualisation of the clinician role in healthcare (Charles, Gafni & Whelan, 1999). Traditionally, there was an assumption that clinicians held the knowledge and skills needed to weigh up the risks and benefits of different treatments and identify the most appropriate interventions for service-users. However, with advances in medicine and an upsurge in treatment options and associated side effects, there was increasing uncertainty about clinician ability to make decisions on a patient's behalf. There was also increased awareness of inconsistency in prescribing practices amongst clinicians, and a move towards greater accountability and advocating for service-user choice and control. Shared decisionmaking models began to emerge, with an emphasis on information exchange which: "ensures that all relevant treatment options are on the table [...] and that both the physician and patient evaluate these within the context of the patient's specific situation and needs rather than as a standard menu of options whose impact and outcomes are assumed to be similar for clinically similar patients" (Charles et al, 1999; p654). SDM is distinguished from informed decision-making, which by contrast is associated with provision of information by an expert clinician to facilitate independent decisionmaking by service-users. In SDM the emphasis is on a two-way process that is, by definition, interactional (Charles, Gafni & Whelan, 1997; Braddock, Fihn, Levinson, Jonsen & Perlman, 1997). This work has continued apace across the spectrum of physical healthcare including one-off health decisions and management of a variety of long-term conditions (including screening and diagnostic testing, major surgery) and illnesses (including breast cancer, cardiology, urology, obstetrics, diabetes and dementia) (Coulter & Collins, 2011).

Whilst attempts have been made to integrate the principles across services, there have also been some on-going challenges. These relate to difficulties with

definition, measurement and evaluation, but also with service culture and enduring power imbalances in the clinician-service-user dyad. These relational issues can make service-users underestimate the value of their contributions to SDM and act as a barrier to engagement with the process, either because of perceived unsuitability or lack of volition (Joseph-Williams, Elwyn & Edwards, 2014; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). These issues will now be explored in turn.

#### 1.2 Definitions of SDM

Ideas about SDM are set out in national policy (e.g. Right Care Shared Decision Making Programme, 2013), but some have criticised the lack of clarity in definition across clinical practice and research (Makoul & Clayman, 2006; Moumjid, Gafni, Bremond, & Carrere, 2007; Coulter & Collins, 2011). Makoul and Clayman (2006) conducted a systematic review of publications which included a description of SDM. They found substantial variation, with 31 separate concepts used to define SDM. Only two elements (patient preference and values and options) appeared consistently in over 50% of articles where a definition of SDM was offered. The authors sought to synthesise common elements from the review to provide a conceptually useful definition for clinical practice. These included presentation of options by the clinician, opportunity for shared exploration of pros and cons, articulation of service-user perspective on values, concerns and expectations in relation to different options and regular review to ensure mutual understanding of the issues. Although this review was extensive, it included studies published between 1980-2003, which limits current application. Interest in this area has since increased, and the number of articles offering working definitions of SDM has expanded considerably (Martin & DiMatteo, 2013). Researchers at Leiden University Medical Centre in the Netherlands are currently working on an updated systematic review (Gartner, Bomhof-Roordink, Smith, Stiggelhout & Pieterse, in press). Nevertheless, this remains an important study in that it was the first to offer a working conceptual definition of SDM in order to bring clarity and rigour to the area both in terms of research and clinical practice.

In 2011, the King's Fund published a document entitled 'No decision about me without me' (Coulter & Collins, 2011), which again addressed some of the confusion around operationalising SDM and suggested ways to embed the core principles in the NHS. Consistent with the findings from Makoul and Clayman (2006), key elements included ensuring SDM conversations informed service-users about their condition, supported them to understand and articulate their preferred treatment outcome, described and facilitated understanding of different options and associated risks in

order to arrive at a decision based on mutual understanding of this information (Coulter & Collins, 2011; p12).

Despite attempts to bring clarity to this area through the publication of policy documents and guidance, problems with definition are likely to continue. Reaching a consistent definition of SDM makes an assumption about the existence of the construct as an objective entity, which can be defined by a set of tangible criteria. The meaning of 'SDM' is likely to be shaped by the current social and political context and by the aims of those implementing the principles. Indeed, Kasper, Légaré, Scheibler, & Geiger (2012) argue that traditional understandings of SDM erroneously assume a positivist definition and overlook the social and interpretive aspects of communication. This supports the need for research that looks at the process of decision-making in an exploratory way, accounting for the experience of all parties in the exchange.

## 1.3 SDM implementation

Aside from initial challenges with definition, a further difficulty is how to embed the ideas in clinical practice. Coulter and Collins (2011) suggested that SDM should be 'the norm' in the NHS and The Health and Social Care Act (2012) reiterated this by laying out a requirement for NHS boards and commissioning groups to involve service-users in decisions relating to their care and treatment.

At a conceptual level, Elwyn et al. (2012) developed a model of SDM which aimed to provide guidance on 'how to do SDM' in clinical practice. This step-wise model included discrete stages (choice talk; option talk and decision talk), which aimed to move people from 'initial to informed preferences,' (Elwyn et al., 2012; p1361). The first stage involves alerting service-users to the fact that different options are available, and providing 'high-quality information' to help them evaluate them. This is followed by a period of 'deliberation', where clinicians and service-users explore the pros and cons of different options and discuss what might be most important to them in light of the information shared. These processes are consistent with earlier models of SDM (Charles et al., 1999; Towle & Godolphin, 1999). The authors acknowledge this model simplifies complex psychological and emotional processes but suggest its parsimony offers direction for implementation in practice. "No decision about me without me" (Coulter & Collins, 2011) also offers a chapter entitled 'what does shared decision-making look like?' which provides guidance on how consultations might exemplify SDM (e.g. exhibiting empathy, normalising serviceuser experience, validating preferences).

#### 1.3.1 MAGIC programme

One of the most significant attempts to apply SDM in practice was through the Health Foundation's 'Making Good Decisions in Collaboration' (MAGIC) programme, which was based on the Elwyn et al. (2012) model of SDM. The initiative was launched in August 2010 across breast surgery, primary care, obstetrics, urology and ear, nose and throat services. It aimed to support teams in primary and secondary care to embed SDM in everyday practice. The programme involved 270 staff across a range of professions in two UK NHS hospital Trusts (Newcastle and Cardiff), thus providing a large sample with robust ecological validity. The inclusion of multiple departments, one-off decisions and management of long-term conditions was also a strength. Over a period of 18-months, staff were provided with skills training workshops with an emphasis on 'how to do' SDM with service-users, given guidance on using decision support tools, and supported to establish opportunities for service-user involvement through patient forums.

A subsequent 18-month evaluation was conducted in 2013. This showed that the "programme increased awareness and knowledge of the principles and practices of SDM" (p63) and increased the use of decision aids as a way to facilitate service-user involvement. Although support for the ideas was evident, the evaluation also found that some senior clinicians continued to object to SDM because they believed it too 'time-consuming' or inappropriate for certain clinical situations. Most recently, Joseph-Williams et al. (2017) wrote about the 'lessons learned' from the programme and key challenges facing the implementation of SDM across services. Consistent barriers to SDM included lack of time, staff perception that the principles were already being followed and a belief that certain clinical situations or particular service-user characteristics were inappropriate for sharing (Charles, Gafni & Whelan, 2004; Gravel, Legare & Graham, 2006; Legare, Ratte, Gravel & Graham, 2008; Joseph-Williams et al, 2014). Unfortunately, it is somewhat unclear from these publications what constituted unsuitable clinical situations, or what particular service-user characteristics were perceived as inappropriate for SDM. Nevertheless, the review captures the challenge of addressing cultural and organisational norms and preconceptions about SDM, and perhaps helps explain the on-going prevalence of what is seen as paternalism.

In terms of recent developments, NICE recently established a 'Shared Decision Making Collaborative' (NICE, 2016), drawing together a number of organisations including Universities, professional bodies and research journals. It is hoped participating groups will share their experience and knowledge, make recommendations about how to encourage a culture of SDM across the spectrum of

healthcare through changes to leadership and establish a way of developing and evaluating decision aids. An action plan was published in 2016 (NICE, 2016), which allocated discrete tasks to the different organisations involved. A progress review was scheduled for June 2017 (unpublished at time of submission).

#### 1.4 SDM outcomes

Ultimately, on-going attempts to implement these ideas have been driven by research suggesting this model of practice leads to a number of positive outcomes for service-users. These include increased service-user satisfaction, adherence to treatment, realistic appraisal of risks and benefits and reduction in numbers of people who opt for invasive or expensive treatment options, which has positive financial implications for services (Joosten et al., 2008; O'Connor et al., 2009). These outcomes have been found consistently across comprehensive systematic reviews spanning multiple physical and mental health difficulties and types of decision including screening, surgery decisions and management of long-term conditions, which increases the validity of the findings.

That said, there continues to be some mixed findings in terms of linking SDM to specific improvements in health outcomes (Shay & Lafata, 2015) and more has been written about justifying SDM on ethical and moral grounds. This makes sense if we think that SDM is often used in situations where there is no obvious 'best' treatment, but seeks to help service-users consider their circumstances and values to identify interventions that allow them to retain optimal quality of life. This might not be synonymous with changes in symptomatology. Consistent with this, Stacey et al. (2011) found SDM increased levels of participation, improved understanding of health conditions and allowed people to confidently select interventions that aligned with their values.

#### 1.5 SDM measurement

In thinking about evidence for the potential benefits of SDM, there are important considerations in terms of measurement. Scales have been developed to measure SDM in clinical practice, including the OPTION Informed Decision Making instrument (Elwyn et al., 2003), the Perceived Involvement in Care Scale (PICS; Lerman et al., 1990) and the Combined Outcome Measure for Risk Communication and Treatment Decision-Making (COMRADE; Edwards et al., 2003). The most recent review identified 27 different measures from a range of perspectives, and identified that a

large proportion of self-report measures focus on service-users' experience of their involvement in decision-making (Scholl et al., 2011). There also seems to be a focus on the decision process, with fewer measures also looking at decision antecedents and outcomes. Scholl et al. (2011) identified that few measures have been robustly tested using factor analytic approaches, and there is limited evaluation of the psychometric properties across different populations and clinical settings.

Adams and Drake (2006) suggest that research in this area is 'fraught with difficulty' because of inherent differences in the questions being posed and difficulties defining and measuring relevant variables such as communication style and relationship quality. Standardised measures offer a way of facilitating assessment and research into SDM, but one could argue the components targeted by the different tools might not fully capture the concept. As such, whilst it is important to have ways of measuring the presence or absence of SDM and to explore service-users and clinicians perspectives on SDM process and outcomes, it is also important for this research to be supplemented by qualitative studies exploring the nuances of the subjective experience of SDM. One way of doing this is with survey and interview studies, which move closer to the experience of SDM. Research drawing on these methodologies will be explored later in the chapter.

# 1.6 Is SDM for everyone?

It seems important to acknowledge the possibility that not all service-users will want SDM (Levinson, Kao, Kuby & Thisted, 2005). As a researcher, I conducted this study in the current social and political climate, which emphasises collaboration and service-user centred care. As such, I (and likely others who have written on this area) will have constructed meaning through this lens, drawing on the narrative of empowerment and service-user involvement as positive and important. Using this construction, the need for robust SDM measures and policy emphasising implementation, positive outcomes and ways of working to achieve these seems taken-for-granted.

Conversely, some research has found that some service-users would prefer clinicians to take the lead role in decision-making in relation to intervention (McKinstry, 2000; Levinson et al., 2005). McKinstry (2000) showed 410 participants (adults and children attending surgical appointments) video vignettes of different styles of decision-making (shared and directive) across scenarios including acute problems (bleeding mole or sprained calf), chronic conditions (rheumatoid arthritis),

mental health (depression) and lifestyle (smoking). They found service-users expressed greater preference for clinician-directed decision-making in all scenarios apart from smoking and depression. The authors suggested that people experiencing serious illnesses seek reassurance and may wish to defer responsibility for the decision outcome to clinicians. Whilst the study had a large sample size and included a range of clinical scenarios, participants watched the video vignettes in groups of four, which means people may have been influenced by other participants, or experienced pressure to conform to the majority opinion. Also, asking participants' preference by watching staged video recordings is arguably different to the real-life experience of being a service-user, and thus participants' preferences may not translate to personal experience of consultations.

Whilst the findings here could be understood as an example of service-users seeking guidance and reassurance at times of uncertainty, they could also be explained by our socialisation to the power of medicine and narrative of superiority of the opinions of clinicians. This is supported by consistent findings that preference for a directive approach increases with age (McKinstry, 2000), which makes sense given that older generations are likely to have had greater exposure to paternalistic discourses and health care systems characterised by compliance and deference to doctors.

Some studies have also found that service-users believe they lack the relevant knowledge and intelligence to make decisions about their care. Service-users experience pressure to conform to socially-sanctioned roles and to not seem 'difficult' by disagreeing with clinicians (Joseph-Williams et al., 2014; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). This highlights the impact of the prevailing view of professionals as expert and powerful, how people understand their roles in decision-making and perceive the value of their contribution. Furthermore, other research has found that demographic variables including age, gender, level of education and socio-economic status influence desire for involvement. People from poorer backgrounds typically opt for a more passive role in decision-making (Murray, Pollack, White & Lo, 2006; Say, Murtagh & Thomson, 2006). This is important when considered in conjunction with the outcomes research because it implies certain groups may be less likely to access treatment options that are congruent with their preferences and values.

Taken together, these findings suggest that although there has been investment in embedding SDM across a range of physical health care settings and types of decision, there remains a challenge in applying these ideas in groups where there are more

complex social issues (e.g. low SES, poor education). Mental health service-users are more likely to face these sorts of disadvantage compared to other groups (Bentall, 2014), and as such there is a need to explore opportunities for people from vulnerable populations to access and benefit from the identified advantages of SDM.

### 1.7 SDM and psychosis

There is less research into SDM in mental health settings compared to physical health, but interest in this area is increasing (Wills & Holmes-Rovner, 2006; Simon, Wills & Hartner, 2009). NICE guidelines stipulate that those using mental health services should be "actively involved in shared decision-making and supported in self-management" (NICE, 2011). However, research has identified low levels of SDM in the context of mental health care (Loh et al., 2006; Goss et al., 2008; Beitinger, Kissling & Hamann, 2014) even though service-users want to participate in treatment decisions (Hamann, Cohen, Leucht, Busch & Kissling, 2005; Klein, Rosenberg & Rosenberg, 2007; Adams, Drake & Wolford, 2007).

In terms of those with experience of psychosis, NICE guidelines suggest that service-users should equally be afforded the opportunity to participate in collaborative planning in relation to their treatment (NICE, 2014). However, the way western society typically constructs psychosis and responds to those with such experiences impacts on the implementation of SDM in practice (Colombo, Bendelow, Fulford & Williams, 2003). Arguably, the frameworks of understanding offered by services and enduring medical paternalism do not create the conditions for collaboration to occur. Some of the experiences typically associated with psychosis may also impact on how service-users participate in decision-making conversations. These issues are explored in depth below.

# 1.8 Psychosis as illness

In Western society, the experiences associated with psychosis (e.g. hearing voices, holding unusual beliefs, experiencing strong or overwhelming emotional states, feeling confused) have often been understood within a medical framework. Emil Kraeplin coined the term 'dementia praecox' in the late 19th century, later replaced with 'schizophrenia' by Eugen Bleuler in 1911. Both made sense of these experiences as severe 'mental illness' caused by genetic and biological abnormalities. Kurt Schneider later introduced the concept of 'first-rank symptoms' of 'schizophrenia', which included 'delusions', 'hallucinations' and 'thought disorder'. These were later

renamed 'positive symptoms' as distinct from 'negative symptoms' of the 'disorder' which include 'blunted affect', 'avolition' and 'anhedonia' (see Jablensky, 2010 for a historical overview).

Western medicine continues to draw on these early ideas. Current diagnostic manuals define 'schizophrenia' as the presence of two or more 'symptoms' (including 'delusions', 'hallucinations', 'disorganised speech', 'grossly disorganised or catatonic behaviour' or 'negative symptoms') alongside 'social/occupational dysfunction' over a period of six months or longer (International Classification of Diseases, ICD-10, World Health Organisation, 1992; Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-V, American Psychiatric Association, 2013). These systems use language which defines 'delusions' as 'false beliefs' and suggests 'hallucinations' are 'sensory experiences without basis in reality'. This is problematic because it only offers one understanding of these experiences, and unquestionably talks about these concepts as if they are truth. A social constructionist stance would question this 'taken for granted' knowledge and suggest certain versions of reality are given priority or credence by social and political structures and their associated power (Burr, 2007). For example, psychiatry has long been a powerful institution in the field of mental health with clinicians being responsible for the diagnosis and treatment of those considered unwell (Rogers & Pilgrim, 2014). This medical approach makes an assumption that the diagnosing clinician's appraisal of reality is the true version, and that the service-user is wrong by virtue of suffering from a mental disorder. This highlights a central paradox in terms of SDM, namely that this approach focuses on the development of a shared understanding of a current problem, and a collaborative approach to addressing or ameliorating it. Whilst we understand 'schizophrenia' as causing inability to think in the way that others do and losing touch with reality, this renders the judgement or decision-making capability of those with these experiences impaired. Do we then reach the crux of the argument here; that SDM is feasible for physical illnesses, but not for 'schizophrenia'?

Some have argued against the 'right' of the medical profession to define reality (Friedson, 1970). In terms of 'schizophrenia', this is only too apparent. Understanding these experiences as a mental disorder caused by biological imbalances in the brain justifies a chemical intervention to address this discrepancy. First course treatment of 'schizophrenia' in the Western world includes prescription of antipsychotic medication, which changes neural transmission processes in a bid to reduce psychotic symptoms. However, many people continue to hear voices and hold unusual beliefs

even after prescription of neuroleptic medication, which has prompted people to question the validity of this understanding of 'schizophrenia' (Bentall, 1988; 1993).

Furthermore, different cultural or spiritual beliefs about the origin or meaning of unusual experiences may mean that taking medication becomes a redundant response because this treatment makes an assumption that the cause of the experiences is a biological or chemical abnormality, which may not be shared by the service-user (Keynejad, 2008). A significant disadvantage of the medical understanding of psychosis is that it limits any scope for the experiences to be viewed as positive or meaningful. It also fails to account for cultural differences in understandings of psychosis. In some cultures, hearing voices or having visions not shared by others is seen as privilege or a valuable spiritual experience (Larsen, 2004). Indeed, medical discourses only allow for understanding psychosis as an illness that people inevitably want to eradicate (Thornhill, Clare & May, 2004). Meaningful collaborative conversations provide an opportunity for clinicians to understand the complexity of service-users relationships with their unusual experiences and potential ambivalence associated with elimination (Deegan, 2007; Casey & Long, 2003). Rogers and Pilgrim (2014) suggested 'the field of mental illness is highly contested' (p23) and emphasised the need to consider and question the assumptions and social and historical context of the speaker when analysing a contribution to any discussion on 'mental illness'. There has also been increasing challenge to the reliability and validity of psychiatric diagnosis, with suggestions of poor construct validity and low levels of inter-rater reliability between clinicians (Bentall, 1993).

Colombo et al. (2003) looked at implicit models of mental health difficulties across professionals in an MDT and the impact on decision-making. The authors conducted interviews using a clinical vignette relating to a service-user whose presentation was consistent with a diagnosis of psychosis. Responses were coded against different explanatory models including medical, social and cognitive-behavioural. They found the medical construction of mental health difficulties was strong amongst a variety of professionals (including social workers, psychiatrists, CPNs). This positions service-users in a 'sick role' in which it is the responsibility of the clinicians to 'make them better' and therefore creates pressure for service-users to accept suggested interventions. Colombo et al. (2003) suggested that by drawing on implicit medical models of understanding mental health difficulties, a power imbalance is set up whereby the service-user can only engage in meaningful discussion with their clinician if they are willing to adopt this 'sick role' and be treated within this framework of understanding. This inherently prevents any mechanism for SDM

because it imposes a one-way treatment process on service-users. Consistent with this, Deegan and Drake (2006) studied SDM in terms of the dominance of ideas about adherence in mental health services and suggested a model of compliance is "rooted in medical paternalism and at odds with principles of person-centred care" (p1636). The study by Colombo et al. (2003) provided a helpful contribution to the literature by including participants from a range of occupational backgrounds, where other research typically focuses on the views and experiences of psychiatry. It also looked beyond some of the questions posed by other studies (e.g. do clinicians support SDM, does this vary by decision type?) to explore the impact of different constructions of mental health experiences, which provided a deeper understanding of this area.

## 1.9 Implications of the medical discourse

The dominance of medical discourses of psychosis has also shaped the way that society responds to people who report these experiences. Historically, treatment of people with a diagnosis of 'schizophrenia' was brutal and inhumane (Scull, 2015). Whilst there have been some changes with time, even now, the most vivid representation of a person with a diagnosis of psychosis portrayed within the media is of someone detached from reality, unable to make their own decisions, incoherent and perhaps dangerous (McLelland, 27 June 2015; Morrison, 2012). This understanding justifies some of the interventions that can be implemented under the Mental Health Act (1983), which allows people with psychiatric diagnoses to be detained involuntarily for assessment and treatment. As above, first line treatment for 'schizophrenia' includes antipsychotic medication, which can be administered without consent to those detained under the Mental Health Act (1983) if they refuse to take it voluntarily. Again, this is entirely at odds with the philosophy of SDM, which is about the clinician and service-user sharing unique perspectives, both of which are essential to arrive at the best decision in relation to any treatment. Ideas around capacity and administration of certain interventions without consent remove the need for the service-user consultation in this process, which makes SDM more challenging to achieve.

Alongside the framework of the Mental Health Act (1983), the Mental Capacity Act (2005) allows decisions to be made on a person's behalf if they are deemed unable to do so due to an "impairment of, or disturbance in, the functioning of mind or brain" (p2). To demonstrate capacity, a person must be able to: understand and retain information relevant to a decision, weigh up this information and communicate their

decision. According to the Act, people are assumed to have capacity unless formal assessment proves otherwise.

Again, in relation to the construction of psychosis, one can see how this might be problematic. Understanding psychosis as a biological disease that leads to risk, irrationality and loss of touch with reality makes it easier to justify clinical decision-making without a person's involvement; they are suffering from a 'malfunction of the brain', and thus it is appropriate for other people to make decisions for them.

Alongside this, service-user disagreement with diagnosis or refusal of a certain aspect of treatment is often constructed as a 'lack of insight into the illness', indicative of enduring psychopathology and further evidence of incapacity (Cairns et al, 2005; Owen et al, 2009). The MCA emphasises that capacity is decision-specific, and there is evidence that service-users with psychosis can have capacity to make a variety of decisions, even when actively experiences intrusions (Dunn & Roberts, 2005; Jeste, Depp & Palmer, 2005). However in practice, studies have found that psychiatric diagnoses (e.g. schizophrenia) lead to an assumption of global lack of capacity (Grisso & Applebaum, 1995; Ganzini, Volicer, Nelson, Fox & Derse, 2004), which represents a barrier to service-user involvement on a decision-specific basis.

As such, the organisation of mental health services and legal frameworks could prevent the power shift needed to make clinical conversations more collaborative. There are aspects of the system that operate in relation to those with a diagnosis of psychosis which arguably contribute to the enactment of power over service-users. For example, those living in the community on a 'Treatment Order' or 'Conditional Discharge' are subject to a number of stipulations (e.g. continuing to take medication, living at a certain address), which could lead to readmission to hospital if they are breached. These practices draw on the medical discourse of 'schizophrenia' as illness through the implication that without pharmaceutical intervention, there will be a relapse that requires further detention in hospital. The potential for involuntary readmission locates power entirely with clinicians, as overseen by Mental Health Review Tribunals (MHRTs). It is important to acknowledge that the decision to detain or treat without consent is taken in circumstances where there are perceived issues of risk either to the service-user or to others. With this critique, I do not intend to imply that such decisions are not necessary or justifiable, but to highlight how the social construction of psychiatric diagnoses, capacity and the legal aspects of mental health care are often directly in opposition with the tenets of SDM. This presents a challenge when trying to embed the philosophy of collaboration and patient-centred care in certain areas of mental health service provision.

A study by Stacey et al., (2015) looked at how legal restrictions in mental health services can be reconciled with the values of SDM. This research recruited from in-patient settings in the England, and thus the findings hold cultural relevance and application to this legal framework. The authors suggest that models of SDM need to account for "issues of power, hierarchy and legally sanctioned coercive practice" (p34). This study makes an important contribution to the literature in light of the previouslymentioned paradox that seems to sit at the heart of the debate around SDM in relation to mental health care and specifically service-users with experience of psychosis. This is seemingly the first study to consider ways to embed SDM in environments where power and discourses of incapacity and legitimate coercive treatment practice can override enactment of the principles of collaboration.

Stacey et al. (2015) conducted focus groups with service users and clinicians from a range of disciplines (including occupational therapists, psychiatrists and social workers). They used critical narrative analysis to explore "how groups positioned themselves in relation to decision making processes and identities that they adopt" (p34). Across all groups, participants reported that the current mental health system makes SDM difficult, particularly in relation to compulsory treatment. The findings highlighted divergence between professional groups in terms of identity and responsibility, which resulted in the construction of a 'them and us' narrative. The authors commented on how different groups positioned themselves in relation to other professionals, the decisions being made and the way this related to their position in the overall hierarchy of power.

The study found service-users were largely marginalised and felt they were positioned outside of the hierarchy of power at times when decisions were made. Service-users also reported that power hierarchies create a "need to conform", and the authors suggested that placing service-users at the centre of care remains "political rhetoric" rather than reality in clinical practice. All groups located psychiatrists at the top of the power hierarchy. Psychiatrists "spoke of their position with an air of resigned paternalism", and said they were compelled to take responsibility because of lack of willingness from other professionals. Nurses identified themselves as 'enforcers' of decisions made by psychiatrists in implementing coercive practice.

The use of profession-specific focus groups in this study represents a relative strength in that it protects against some of the potential for the over-representation of dominant voices or the impact of power hierarchies between group members. This increases the likelihood that the views of all groups are represented. That said, it might also create potential for groups to develop a shared identity by virtue of

belonging to the same profession, such that differences in opinion between members might be minimised, or there may be pressure to conform to the majority opinion because of a sense of shared narrative in the group (Tajfel, 1974). Further, the focus groups in this study were facilitated by members of a values-based network, and followed a semi-structured interview protocol. As such, the views and beliefs of the facilitators may have impacted on the way the groups were conducted such that areas of disempowerment and lack of equal influence and involvement were emphasised.

#### 1.9.1. A SDM framework for mental health: The 3 Is model

In response to their initial findings, Stacey et al. (2015) proposed an alternative model of shared decision-making that seeks to create a "genuine power-sharing partnership" (p36). The '3 Is Model' suggests all participants in a decision-making process should be 'informed, involved and influential' but these positions will shift depending on the "context, capacity and desire to influence" (p36). Being 'informed' means seeking out and valuing the knowledge of different parties in relation to the decision-making process. For service-users, this means sharing the lived experience of a particular condition, and for staff it means sharing knowledge gained from experience of working in a service, and awareness of organisational factors. 'Involved' means being open to different perspectives and prepared to update and adjust decisions based on information gathered from each other. Being 'Influential' means having respect for different views even when these are not shared. This part of the model addresses the need for professionals to support service-users' decisions even if they perceive them as unwise. The authors suggest that service-users can only have 'influence' if they "genuinely hold power and accountability for decisions" (p36). Stacey et al. (2015) suggested that supporting all parties to have influence does not always mean equal power, but that everyone has the opportunity for their views to be considered. Whilst the working definitions of the 3 Is have face validity, it is unclear from the article precisely how the authors operationalised these concepts. Nevertheless, this model offers a useful way to think about SDM and recognises the power imbalances that impact on the enactment of collaboration in practice.

In sum, the dominant ways of understanding psychiatric diagnoses and the broader legal context suggests a need for professionals to assume an expert role and make decisions for service-users at times when they are deemed unable to do this. This contradicts the principles of SDM because it locates the responsibility for decision-making with the professional. The on-going conceptualisation of psychosis as 'illness' perpetuates a paternalistic approach whereby certain interventions are legitimised by

the discourse. The 3 Is model sought to address some of the potential challenges with implementation (Stacey et al, 2015), but it remains unclear what this conceptual framework might look like in practice.

### 1.10 Experiences of psychosis and SDM

The dominance of medical discourses around psychosis and subsequent impact on SDM is further complicated by the fact that some of the experiences typically associated with psychosis make it challenging to facilitate collaboration (Tusaie & Fitzpatrick, 2012). Those who are suspicious or mistrustful of others may find it difficult to engage in conversations with clinicians, which could make it harder to facilitate a collaborative dialogue (Hamann et al., 2006). This makes it even more important to explore these issues specifically with service-users with a diagnosis of psychosis. Whilst the challenges associated with capacity and consent are influential across the spectrum of mental health diagnoses, it seems some of the idiosyncrasies associated with the experience of psychosis may pose unique challenges to the enactment of SDM. This is explored in brief below.

It has been suggested that those with unusual beliefs have a greater propensity for 'jumping to conclusions', whilst Bentall et al. (2001) found that those who experience paranoia were more likely to attribute experiences of misfortune to deliberate spiteful acts by others. It seems these cognitive biases are more likely to be present in those with early experiences of adversity (Read, Bentall & Fosse, 2009), with a growing body of evidence establishing a strong link between childhood trauma and psychosis (Janssen et al., 2004; Read et al., 2005; 2014). Victimisation, bullying and experiences of being powerless in particular have been associated with later development of suspiciousness and paranoia (Bentall et al., 2012). Such experiences could make it hard for people to engage in SDM conversations because of beliefs about others as untrustworthy and threatening. This might increase the likelihood of information being interpreted as malicious, or make service-users wary about sharing their views with professionals. This could be especially relevant if service-users have had distressing experiences of involuntary admission or enforced treatment previously (Loft & Lavender, 2015), which creates valid concerns about what will happen to any information they share. Furthermore, unusual beliefs besides suspiciousness or differences in understanding of experiences might make it more challenging to reach the shared understanding of the presenting problem which sits at the centre of some SDM models (Charles et al., 1999; Elwyn et al., 2012).

Another difficulty working towards SDM with this population relates to the reliance on verbal expression in order for information exchange to occur. Chan and Mak (2012) suggested this could be challenging in light of differences in expressive language that are seen in those with experience of psychosis. Studies have shown that changes to thought processes, working memory and organisation of speech can make it harder for those with experience of psychosis to communicate an intended message in conversation (Langdon, Coltheart, Ward & Catts, 2002). Speech may be more tangential or may disintegrate, thereby making it harder to communicate ideas to others (Mazza et al., 2008; Lysaker & Lysaker, 2001; Frith, 2004). Chan and Mak (2012) suggested this disruption to linguistic and communication skills could be understood in terms of differences with metacognitive processes. They emphasised how flexibility in perspective taking and the ability to monitor the thoughts and feelings of others is integral for effective communication. There is evidence that the capacities associated with metacognition (e.g. perspective-taking, ability to reflect on mental state of self and others, ability to use knowledge of mental states in interpersonal exchange) are compromised in those with experience of psychosis (Lysaker et al., 2011; Lysaker & DiMaggio, 2014). Therefore, it makes sense that collaborative conversations might be harder to achieve when these capacities are affected, and increases the demand for exploration of ways to achieve a shared process of decision-making when working with service-users with these difficulties.

Chan and Mak (2012) also explored the concept of insight in relation to metacognition and SDM with those who experience psychosis. 'Insight' is often defined as 'awareness of different facets of illness and the need for treatment' (David, 1990; Amador & Flaum et al, 1994) and 'lack of insight' has been linked to neuropsychological changes, specifically differences in the structure of neural matter (Shad & Keshavan, 2015). In other studies, professionals have identified lack of insight to be an 'absolute barrier' to SDM (Shepherd, Shorthouse & Gask, 2014). Chan and Mak (2012) suggested this rests on a 'medical model of insight', which centres on the willingness of service-users to accept and endorse a medical understanding of their experience (i.e. that they are suffering from an illness and thus need to comply with recommended intervention). As discussed earlier in this chapter, this is consistent with the current societal construction of these experiences and creates a vicious cycle of disempowerment whereby questioning of the interpretation of psychosis as illness is taken as further evidence of psychopathology. Chan and Mak (2012) suggested that a metacognitive approach to insight means considering an individual's ability to develop an integrated sense of their own experiences and form a coherent narrative.

They suggested acquisition of insight should be seen as the development of a narrative of personal experience, within whatever framework of understanding is most relevant to the service-user. Professionals thus have a responsibility to engage in dialogue that is consistent with service-user understanding of their difficulties, only introducing new or alternative explanations in situations where this is likely to reduce distress. Chan and Mak (2012) emphasised that professionals need to meet service-users 'where they are at' (p540) and match SDM to meet capabilities of service-users at any given time. A strength of this article is the focus on specific processes and how these contribute to difficulties enacting SDM. This also offers suggestions for interventions (for example, metacognitive therapy), which could facilitate SDM. It is also helpful in challenging the dominant understanding of insight and questioning the need for service-users to share the same explanatory framework as professionals.

In sum, the processes outlined above, which are often changed in those with experience of psychosis (cognitive and language and metacognitive capacity) could make engaging with SDM more challenging. It might be difficult for service-users and professionals to engage in information exchange or deliberation to develop a shared understanding of any problems, and therefore share in decision-making in relation to the most relevant intervention. Most decisions are made in a framework of current NHS mental health services, which operate largely within this medical paradigm. As such, there is a need for greater exploration of how to make conversations about decisions collaborative at times when service-users' experiences might make this more challenging to be consistent with the philosophy of collaboration set out in policy. This is the focus of the current study.

# 1.11 Current status of SDM research in psychosis

Hamann et al. (2006) suggested the field of psychosis is well suited to the introduction of SDM because there are usually multiple treatment options available and a range of side effects across different interventions, which can have a substantial impact on service-users' quality of life. A survey of 352 psychiatrists found high levels of endorsement of SDM, but only in relation to certain decisions (Hamann et al., 2009). SDM was considered advantageous in relation to work therapy, future housing, and psychotherapy, whilst decisions around hospitalisation, prescription of medication and diagnosis were best left to the clinician. Consistent with the discussion earlier in the chapter, the participants in this study suggested lack of decisional capacity was a reason not to apply SDM. Other research has similarly found psychiatrists express

concerns about involving service-users in decision-making at times of apparent loss of decisional capacity (Seale, Chaplin, Lelliot & Quirke, 2006). These studies focused on the views of psychiatrists, thus precluding the application of the findings across other professional groups. This perhaps reflects the discourse of hierarchy outlined by Stacey et al. (2015) and the prevailing view that psychiatrists hold most of the power in decision-making compared to other clinicians.

In contrast to the view that lack of capacity necessarily precludes SDM, Hamann et al. (2006) conducted a RCT in a German psychiatric in-patient facility to explore whether SDM was feasible in the acute phase when decisional capacity may be considered impaired. The intervention condition involved provision of a decision aid to prepare service-users for a subsequent planning talk with their psychiatrist. They found that it was 'feasible for most service-users to share in important decisions with their physicians' (p271) and improved participant knowledge about unusual experiences and attitudes towards treatment. A real strength of this study was the broad inclusion criteria, which meant that all service-users with diagnoses of psychosis admitted during a specified time period were approached, regardless of the nature of their unusual experiences. This allowed the findings to show that SDM can be achieved even when people are acutely distressed, as long as the approach is adapted (Carpenter et al., 2000). One of the more concerning findings was the view of doctors and nurses working in the hospitals, which indicated they thought many service-users were 'too ill' to take part in the study. In their write up, the authors emphasised that psychopathology of psychosis did not preclude SDM for those who did participate, so much as 'negative symptoms' or a lack of interest in participation.

Consistent with the physical health literature, studies have found that SDM in mental health settings leads to better health outcomes, increased adherence to treatment and higher levels of service-user satisfaction (Adams & Drake, 2006; Hamann, Leucht & Kissling, 2003; Malm et al., 2003; Loh et al., 2007). Outcome measures used in these studies often fits more with biological and medical discourses relating to psychosis. For example, 'Knowledge about experiences' in the study by Hamann et al. (2006) was measured by a questionnaire asking service users what they knew about 'their disease and its treatment' (p269). This highlights a key problem with the research in this area in terms of how the impact of SDM is measured. The value of collaboration in decision-making demands ways of measuring SDM that take into account outcomes that reflect service-user frameworks of understanding. For example, service-users may not see long-term compliance with medication or reducing the experience of voices as one of their goals for treatment.

This reflects a more general clinician-focus in SDM research, with attention on what clinicians can do to make conversations more collaborative and decisions shared. There has been less written about how service-user behaviour impacts on the exchange, which seems somewhat paradoxical in light of the focus on collaboration and active involvement of service-users. Hamann et al., (2016) conducted the first study into service-user role in collaboration in mental health consultations. This was explored through a series of focus groups comprising either service-users with experiences of psychosis and depression or psychiatrists. The discussions were transcribed and analysed using content analysis. All participants identified a need for service-users to speak freely with clinicians about current experiences and fears and a need for trust within the relationship. Another theme was preparation and participation, which included expression of preferences, awareness of potential options and expression of views about different possible interventions. Of note, the language used by the researchers was consistent with a medical construction of mental health difficulties, which reflected the acute psychiatric service from which they recruited. The impact of this can be seen in the results. For example, the theme 'openness and honesty' (which was generated from both service-user and clinician focus groups), included 'admitting and facing up to having a mental illness'. Importantly, the study found differences between psychiatrist and service-user interpretations of ambivalence towards active participation in decision-making. Psychiatrists suggested 'mental illness' limited service-user interest in active collaboration, whilst service-users said previous experience of enforced treatment and powerlessness made them less likely to express preferences because of a belief that the clinicians' choice of treatment would ultimately be enforced regardless. This highlights the importance of clinicians encouraging service-users with mental health difficulties to think about their preferences and scaffolding and supporting this process where helpful.

Whilst this study was important in providing the first exploration of service-user behaviour in SDM consultations in mental health services, the use of focus groups means that the data represents participant perception of the consultation experience. In this way, focus group, survey and interview data all provide accounts of peoples' experience and opinion, but SDM as enacted in clinical practice might look different from how people talk about these experiences once removed. This requires a different way of conceptualising talk, with an emphasis on language as active and constructive.

#### 1.12 Social constructionism and talk as data

This project approaches the topic of SDM in mental health services from a social constructionist epistemology, which suggests social and psychological phenomena are intrinsically influenced by historical, cultural and social context. Certain ways of understanding are given legitimacy over others, and these dominant discourses can be identified in talk. Talk is thus considered the site where meaning is constructed and where ways of understanding are negotiated (Potter & Wetherell, 1987). Robertson, Moir, Skelton, Dowell and Cowan (2011) refer to the SDM encounter as a 'discursive event'. That is to say, when clinicians and service-users interact, their talk is not just a mirror of inner processes or reflective of a tangible reality, but rather may reflect a current interpersonal aim, for example to persuade, justify, blame etc. (Potter & Wetherell, 1987). This project seeks to explore naturally occurring talk as the site of action in order to explore what speakers are doing with their language in a particular clinical exchange involving decision-making. Ways of talking varies within and between SDM encounters, which suggests the relevant question may not always be 'what does this person think about SDM', but rather 'how is a decision being made in this particular clinical encounter?' This is important in relation to the issues outlined above in terms of how clinicians and service-users negotiate decision-making at times when different psychological and emotional experiences might make this more challenging.

#### 1.13 Studies of talk in healthcare

Georgaca (2013) identified that "actual interaction between mental health professionals and users in clinical settings has scarcely been examined by discourse analytic studies" and there is a place for exploration of "the negotiation processes taking place between client and professional" (p4) in these settings. This seems particularly important when considering the power held by mental health professionals and thus the need for exploration of how talk constructs meaning in mental health settings and services.

One study videotaped consultations between psychiatrists and service-users with psychosis to explore the nature of interactions in this dyad using conversation analysis (McCabe, Skelton, Heath, Burns & Priebe, 2002). They found that psychiatrists avoided answering service-user questions if they related directly to psychotic experiences (e.g. 'why do people not believe me when I say I am God?'). Exploration of the transcripts revealed hesitations in clinician speech and evidence of laughter, which

was thought to indicate embarrassment. In the commentary accompanying this journal article, Skelton highlighted the importance of research using such qualitative design in 'getting under the surface' of issues that might be 'obvious' (in this case, 'doctors having trouble talking to patients with psychotic illness'). Skelton said the article illustrated what happens when rules of conversation are unclear, and emphasised the importance of context. For example, conventional rules of conversation dictate that a question is followed by an answer, but Skelton suggests the doctors in this study were unsure of their role and the context of the clinical encounter. It seemed they were unclear whether to offer service-users a tangible answer to these questions, which could explain the pauses and hesitations, which follow service-user utterances. This is important in thinking about SDM. Central to models of SDM is the idea of informationsharing, particularly service-users sharing their lived experience of a particular mental health diagnosis, which is likely to be harder if clinician talk is organised in ways to prevent this. This study made a unique contribution to the literature by focusing on the features and qualities of interaction between professionals and service-users with psychosis. Recruitment from UK services was also a strength in terms of thinking about broader cultural relevance.

Robertson et al. (2011) used discourse analysis methods to explore SDM in general practice consultations in Scotland. Using a Discursive Action Model, the authors explored rhetorical and discursive devices and the impact of these on the decision-making process. For example, in one extract, the clinician's use of hesitancies and qualifiers was described as 'rhetorically persuasive' in showing a process of 'thinking through' different treatment options in order to invite agreement from the service-user. Robertson et al. (2011) identified speakers 'use of first person pronoun deployment to elicit service-user agreement.' Techniques traditionally used to facilitate partnership (e.g. the use of 'we') seemed to be drawn on to encourage agreement with the professional rather than to aid collaboration. The use of 'we' was also used by Doctors to mitigate responsibility and allocate some responsibility for the choice of intervention to the service-user. Of note, Robertson et al. (2011) recruited GPs who had previously engaged in training specifically aimed at cultivating a positive therapeutic alliance, and were specifically interested in service-user participation in decisions, so their practice may have been different to other clinicians.

Robertson et al. (2011) suggest previous research in this area has been limited by exclusive focus on one party in the exchange (i.e. the clinician OR the service-user) and methods have not allowed for analysis of decision-making as a 'joint-production'. Interestingly, one could argue that research into SDM itself sometimes neglects the

basic tenets of the philosophy of collaboration through this focus on what one person in the conversation is doing. Again, adopting a social constructionist stance encourages dialogue to be seen as a constructive and context-bound process where meaning is negotiated through the talk of the participants. The current study is interested in the process of decision-making as a dynamic process involving (at least) two speakers through which talk is the tool for achieving the social goal (i.e. arriving at a decision).

## 1.14 Summary

To summarise, models and understanding of SDM have been evolving since the 1970s. Developments have been made in conceptualisation and measurement, but certain challenges remain. Factors associated with organisational and cultural norms, as well as enduring expectations of paternalism across stakeholders mean that the aim for SDM to be 'the norm' in all NHS services is yet to be realised. These issues are only more prominent in mental health settings. The experience of psychosis, questions of decisional capacity and legal parameters compound existing discourses of illness. There are also on-going issues associated with power and paternalism and the effects of vulnerability to social disadvantage. Whilst existing literature has explored the experience of SDM across different stakeholders, and identified barriers and facilitators, there remains a need for further qualitative research, which looks at how these conversations happen in practice. The 3 Is model by Stacey et al. (2015) has addressed some issues, and this study sought to extend this further by exploring what sharing might look like in clinical practice.

The current study seeks to extend the existing literature base by exploring the discursive landscape of conversations involving clinicians and service-users with experience of psychosis. It is hoped this will generate new understanding and knowledge about SDM in mental health services by looking to interactions between professionals and service-users in a population where powerful and enduring discourses, legal frameworks and service-user experience all potentially impact on the enactment of collaboration.

# 1.15 Research question and aims

Research question:

 How are decisions negotiated in routine clinical practice between service users with experience of psychosis and professionals?

#### Research Aims:

- To examine how the language of service-users and clinicians shapes opportunities for collaboration in routine clinical conversations.
- To examine collaboration in decision-making with consideration of roles held in the conversation.
- To examine how service-users and clinicians reflect on these conversations and how this relates to the primary analysis.

# **Chapter 2: Method**

This chapter provides a rationale for the chosen research method and an overview of recruitment, data collection and analysis.

#### 2.1 Qualitative research methods

Qualitative research methods are considered most appropriate for open-ended, 'how' questions (Willig, 2001), which fits with the research question and aims of the current study. A qualitative approach also reflects the limited existing exploratory research in relation to SDM with this population. From the literature reviewed whilst designing the project, it appears this is the first study to analyse conversations between clinicians and service users with experience of psychosis in a way that allows for exploration of SDM from a critical perspective. The focus of this study is on the practice of SDM and collaboration rather than measuring presence or absence or looking at tangible outcomes. This again requires a qualitative approach, and more specifically, a social constructionist stance.

Social constructionists question 'taken-for-granted' knowledge (Burr, 2015) and encourage critical observation of the material world. A social constructionist approach holds there is no single, accurate version of reality, but that different truths are shaped by current social, historical and political context. In terms of mental health, a social constructionist approach involves questioning the way we conceptualise these experiences and the practices that follow. In relation to the current study, this involves questioning how speakers construct the concepts of SDM and collaboration and how the language used shapes meaning.

Certain qualitative methods would not have been suitable for answering the research questions, and would have led to a different approach to the data. For example Interpretive Phenomenological Analysis (IPA) would focus on how people make sense of the experience of SDM, proceeding from an epistemological stance that assumes intrapsychic experience can be accessed through language (Smith, Jarman & Osborn, 1999). Thematic analysis might look for patterns in the way different people talk about SDM (Braun & Clark, 2006). By contrast, this study seeks to examine SDM by studying language and discourse as the location where this phenomenon is practiced. Discourse Analysis is thus the most appropriate method because of the epistemological

assumptions about the productive nature of talk. In the following sections, I explore different discourse analysis methodologies and my rationale for taking a particular approach to the data.

# 2.2 Discourse analysis (theoretical background)

Discourse Analysis (DA) emerged from changes in the conceptualisation of language. Traditionally, there was an assumption that language provided access to discrete cognitive entities such as thoughts, feelings, attitudes and beliefs; DA offered a critical approach to these ideas and a shift towards understanding language as action-oriented and a means of constructing particular versions of the social world (Willig, 2001). A number of different approaches to DA have now developed, but they share an assumption that language is central to the construction of reality.

Two distinct types of DA pertinent to psychology are Foucauldian Discourse Analysis (FDA) and Discursive Psychology (DP) (Georgaca, 2012). Whilst these approaches are alike in their criticism of cognitivism and an assumption that language is used to construct reality, they have different theoretical underpinnings that make them relevant for addressing different research aims.

#### 2.2.1 Foucauldian discourse analysis

FDA was influenced by post-structural writers including Michel Foucault. From this position, 'discourses' are understood as "systems of statements that construct an object" (Parker, 1990) and research from this position focuses on the way that language shapes our social and psychological worlds (Willig, 2001). Carabine (2001, p267) suggests we "think of discourse as the way an issue or topic is spoken of" in that it can "define what is truth at a particular moment". Foucault said that dominant ways of seeing the world and talking about objects and events privilege certain groups, and legitimise certain actions and powerful social practices (see Willig, 2001).

#### 2.2.2. Discursive psychology

In contrast to the broad societal level approach of FDA, DP has roots in Conversation Analysis (CA) and a focus on everyday interactions between individuals. CA is largely used to explore routine conversation and the orderliness of talk, with a focus on how speech relates to particular conventions (e.g. turn-taking). DP developed from Austin's speech act theory and ethnomethodology and the proposition that words can have different meanings depending on the context in which they are uttered (Potter & Wetherell, 1987). Potter and Wetherell (1987) suggest people use language

to "construct versions of their social world" (p33) depending on current personal and social objectives. Linguistic 'building blocks' mean that there are always multiple ways to represent reality (Wiggins & Potter, 2008).

In this framework, discourse analysts seek to identify social aims evident in peoples' language (e.g. using it to persuade, accuse, blame, justify). Potter and Wetherell (1987) write about this extensively in their book 'Discourse and Social Psychology, Beyond Attitudes and Behaviour'. In this text, they critique the assumptions of earlier social psychology, for example the idea that standardised measures (e.g. questionnaires) can be used to access speakers true thoughts and feelings (for example asking people to rate their 'attitude' towards 'immigrants' on a series of likert-scale questions). They argue this assumes a shared understanding of the concept being explored (e.g. 'immigrants') and the existence of this as a static object. Inconsistencies in responding patterns are treated as 'noise' from a traditional social psychology approach and attempts are made to limit variation through methodological adjustment (Parker, 1990). By contrast, discourse analysts do not see inconsistency in speaker accounts as problematic. Rather this is considered an area of interest and opportunity to explore what people are trying to achieve with their speech across different contexts (Potter & Wetherell, 1987). From this position, discourse analysts conceptualise entities defined by social psychologists (e.g. attitudes, social categories, representations of the self) as potential linguistic devices. For example, a discourse analyst might ask how someone uses 'trait' theory (e.g. I'm an extrovert) to achieve something in a social exchange (e.g. to justify, to blame) rather than seeing this as an enduring internal structure, which can be measured or quantified.

In terms of the current study, these ideas can be applied to SDM in terms of conceptualisation as a static and tangible entity with consistent defining properties. Previous research has looked at SDM as binary (for example, do people do it or not?). This assumes a shared definition of SDM and the ability for categorisation (e.g. psychiatrists do not do it, but social workers do). Rather than measuring the presence or absence of SDM, this research seeks to explore SDM from a DA position. This approach requires a focus on the linguistic and discursive devices used by different speakers and consequent impact on collaboration. This makes a DP approach particularly helpful.

Edley (2001) presents three 'key concepts' to guide analysis from a DP position:

- 1. 'Interpretive repertoires' are defined as "recurrently used systems of terms used for characterising and evaluating actions and events" and thus represent "relatively coherent ways of talking about objects and events in the world" (Edley, 2001; p149). Edley suggested it is important to identify interpretive repertoires because they provide some indication of different ways that certain concepts can be spoken of, and by implication, ways that they cannot. The terms 'interpretive repertoires' and 'discourses' are often used interchangeably in the literature, and Edley (2001) suggested the difference is more about indicating with which DA tradition the research aligns (interpretive repertoires hail from DP, whilst discourses align with FDA) rather than any other qualitative distinction. Discourses tend to be more 'monolithic' whilst interpretive repertoires include a myriad of rhetorical devices and ways of talking about an object or event at a more individual level. Consistent with a DP orientation, I use the term 'interpretive repertoires' throughout analysis to describe consistent ways of talking between speakers, but also draw from the term 'discourses' to refer to any broader, 'monolithic' ideas that can be seen in participants' talk.
- 2. 'Ideological dilemmas' refer to the "inconsistent, fragmented and contradictory" beliefs and ideas that can exist in a single cultural context (Edley, 2001). This again challenges the assumption that individuals' talk reveals consistent and coherent cognitive structures (e.g. beliefs or attitudes). Identifying ideological dilemmas enables the researcher to explore the impact of a speaker drawing on contrasting repertoires at different points in an account (Radley & Billig, 1996).
- 3. Subject positions are types of identity made available by certain repertoires or discourses. That is, the way people construct and represent themselves in their talk is shaped by current 'discursive regimes' (Edley, 2001).

There has been some debate about whether FDA and DP should be seen as distinct schools of analysis. Wetherell (1998) suggests is it possible, and indeed preferable to draw from elements of both. Willig (2001) states that looking to discursive devices (DP) helps us explore what people are doing with their talk and how speakers construct and negotiate meaning, whilst FDA then allows us to ask WHY they might be drawing on certain devices or ways of talking, what versions of knowledge this might legitimise, or which powerful institutions this benefits.

Although my position in relation to the power of medicine and the medical conceptualisation of psychosis drew me to the ideas of FDA, it was important to keep returning to my original aims in designing this project. Indeed, this study is not asking what discourses can be seen in speech, but rather how decisions are made and specifically how SDM is constructed, which would be better served by a DP approach. The challenge was that I kept returning to the question of whether this could be done without commenting on how the context and wider social and political factors shape these conversations. Indeed, clinical conversations do not occur in a vacuum, and I was aware that the current organisation of mental health services, prevailing medical model and the perpetuating discourse of paternalism would impact all speakers in the exchange.

In terms of the research question for the current study, I was ultimately interested in how speakers at micro level manage interactions involving decisions, so the principles of DP are used as the primary theoretical framework for approaching the data. That said, like Willig (2001), I see that this micro level interaction will be intrinsically linked to and influenced by broader, powerful discourses. As such, whilst the primary analysis in this study is informed by the principles of DP, comment is also made on wider social, historical and political context and evidence of any broader discourses represented in the talk of participants.

To summarise, analysis in the current study was guided by the research questions and by the data collected. Focus was on the action-orientation of the talk at times when decision-making was happening. Where relevant, comment was made on interpretive repertoires, ideological dilemmas and subject positions, as well as the participants' use of rhetorical and discursive devices and associated effects.

### 2.3 Naturalistic data

From the outset, I was keen to capture naturally-occurring clinical conversations between service-users and staff to explore SDM. Whilst interviews or focus groups would have allowed exploration of participants' experience or views about SDM, this would have provided more insight into how staff and service-users construct their behaviour once removed, rather than providing direct access to the phenomenon of interest. Potter (2010) suggests "the magic of naturalistic data is not that it offers purity but that it breaks out of the analysts' agenda into the extraordinary richness of the outside world" (p12).

Although naturalistic data reduce the influence of the researcher, participants have still "provided informed consent, are aware of the recording and consequently modify their actions in a range of ways" (Potter, 2002; p540). As such, whilst the meetings recorded as part of this project would have gone ahead in the absence of the research, it is important to acknowledge that participants' behaviour will have been affected by the presence of the researcher and recording equipment. Furthermore, use of naturally-occurring data does not remove my influence as a researcher in terms of my approach to data collection and analysis. This is where explicit awareness of one's own biases and their impact on the process of data collection and analysis is essential in thinking about how these might influence interpretation (Willig, 2001). This is further considered later in the chapter.

# 2.4 Video-recording

I also considered the best way to capture clinical conversations involving decisions. I chose video over audio recording because it captures non-verbal elements of an interaction (e.g. body language and facial expressions), which can facilitate a richer exploration of the data (Jewitt, 2012).

From the outset, I was aware the prospect of being video-recorded could be daunting, particularly for service-users with experience of psychosis who might be suspicious or mistrustful or services (McCann & Clark, 2005). This issue was discussed with service-users during the process of project design at a local service-user research forum. Attendees thought video-recording was feasible in principle, providing a clear rationale for this was given to participants. Through this consultation process, it was decided that participants would also have the option of being audio-recorded, should they express an interest in participating but object to video-recording (in practice none of the participants requested this).

Likewise for staff, I was aware that being video-recorded might feel exposing, and this could impact on those who would be willing to participate, or indeed influence those who would introduce the study to service-users in first place. This was discussed at initial meetings with clinical leads and with care co-ordinators when setting up the project, and I emphasised my aim of exploring the dyadic process of SDM, rather than scrutinising individual practice of particular clinicians.

### 2.5 Reflective interviews

The second part of the study included an opportunity for participants to reflect on the conversations by watching the recorded conversations with me. This part of the study was included to facilitate a richer exploration of the data and also supports the concept of collaboration that is central to the whole project. This part of the design was inspired by a similar study about the construction of self-determination between staff and services-users with learning disabilities (Brown, 2014), which included an opportunity for all participants to reflect on their experience of a recorded consultation. Reflective discussions with staff and service-user participants were conducted at different times to avoid influence of the other participant on the content of the reflections. This part of the method was guided by the principles of Interpersonal Process Recall (IPR; Kagan, 1980) in which clinical encounters are recorded and then watched again later. This approach suggests that during sessions, clinicians are often preoccupied with their internal experiences, meaning that dynamic and interpersonal processes are often missed. Kagan (1980) suggested that in IPR, the clinician should be considered the person with the knowledge and authority to glean a deeper understanding from the recording, with the observing party taking a curious and non-judgemental position to facilitate this. This part of the design aimed to allow participants to explore their thoughts and feelings during the recorded conversation. In keeping with Kagan's philosophy, I approached this part of data collection assuming the participants' were in a position to offer an expert perspective on the interaction.

Jewitt (2012) suggests that video-data is more able to "reawaken memories and experiences" of an event and thus it was hoped participants would be able to access thoughts and feelings about the recording more readily with a video-recording prompt. This process has been regularly used in education settings to allow teachers to reflect on decision-making in the classroom ('Stimulated Recall'; Calderhead, 1981). Criticisms of the approach in the literature include queries about the validity of thoughts recalled after the fact. For the purpose of this research, and consistent with the social constructionist epistemological position, this was not considered problematic. Indeed, the emphasis was on exploring how participants talked about the recording in the reflective conversations, rather than aiming to get a sense of their 'genuine' thoughts and feelings at the time. Again, the focus was on the action-oriented nature of talk in this scenario, in line with the methodological principles of DP. Lyle (2003) suggested the value of a stimulated recall interview is enhanced when this is conducted soon after the original recording. With this in mind, I tried to minimise the

time between the original recording and subsequent reflective conversation, and this was completed within 3 weeks in all cases.

#### 2.5.1 Interview data

The data gathered from these reflective conversations represents interview data. I did not use a specific interview schedule in order to allow the dialogue to be shaped by participant responses. I did however use a number of prompts at different points during the recording with a focus on participant experience of the meeting, thoughts and feelings both at the time and looking back, provision of a chance to articulate anything that might have not been said, or anything they would have preferred to say (please see Appendix 5 for list of example questions). As a researcher and indeed concurrently an NHS clinician, I was aware of the inherent power in my role and how this might influence the relationship with service-user participants, particularly in this part of the study. McCann and Clark (2005) emphasised that interviews can potentially be stressful for those with experience of psychosis, and interviewers must be mindful of the ethics of undertaking research with vulnerable populations.

McCann and Clark (2005) also suggested the environment is important when conducting qualitative research interviews with those with experience of psychosis, and a private and relaxed atmosphere without unnecessary distraction facilitates engagement and puts service-users at ease. With this in mind, careful consideration was given to the location of feedback sessions, and where possible the researcher went to the service-users' home to conduct the reflective interview. As a researcher, I was mindful of the potential stress associated with the interview process, and took steps to make participants feel relaxed and comfortable. I allowed time at the start to explore what it might be like to watch the tape back, and emphasised participants could stop the interview at any time. I also paid attention to the nuances of participant experiences of psychosis, being mindful of the potential for suspiciousness or mistrust. I took steps to be as transparent as possible about the research process, giving participants control over different aspects of the interview where appropriate (e.g. ability to press a button to stop the tape).

McCann and Clark (2005) offered a protocol in anticipation of participants experiencing stress during research, which I used to guide the interview process. This includes provision of basic emotional support, allowing service-users to decide whether to continue and if needed, making a referral to appropriate services for support. Service-users were informed they were largely in charge of deciding how long

the reflective conversation should last (Holloway & Wheeler, 2013) and these were generally shorter than interviews with staff members, keeping in mind the impact of unusual experiences and medication side-effects on concentration and fatigue (McCann & Clark, 2005). Cowan, Harrison and Burns (2012) emphasise the importance of keeping questions concrete and concise and being willing to repeat or rephrase to maximise the quality of responses gathered. Again, this relates to the assertion that experiences associated with psychosis may impact on interpretation of questions and communication of response. These considerations were all held firmly in mind when approaching the reflective conversations, particularly with service-users.

More broadly, it is also important to acknowledge my influence on participant responses in the follow-up interviews. Before meeting with participants, I watched the recordings and identified the sections where the conversation seemed to be focused on a decision. I noted the time points that this seemed to start and finish, and then played these sections of the recording at the follow-up interviews. I was aware that the initial meetings had been quite long, and I was conducting interviews with clinicians who were pressured for time, and with service-users who (as above) might experience some challenges with concentration because of the nature of their experiences. I wanted to ensure that the interviews focused on the parts of the meeting that were most pertinent to the research questions. This is consistent with the interpersonal process recall literature, which allows for the researcher to preselect sections of the data that are considered most relevant (Cashwell, 1994). It also meant that there was consistency between participants within a data set, as they all watched and reflected on the same parts of the recording. Within these sections, I had noted down a number of points that I would be interested in seeking each person's perspective on in advance, and paused the recording accordingly. Participants were told that they could also pause the recording at any point, and shown how to do this using the equipment. In practice, participants did not actively use this to stop the recording. More often, a participant would start commenting on a particular part of the recording, at which point I would pause the video to allow for further exploration.

Ultimately, the points at which I paused the video determined the parts of the recording where additional participant perspective was sought. The questions I posed will also have influenced the nature of the reflections provided. In addition, the context of the interview and my presence as a researcher will have affected the thought and feelings that the participants were able to share. In order to maximise validity, I have tried to be transparent about my role and the potential impact I had on the data throughout this report.

## 2.5.2. Summary of data gathered

The table below provides an overview of the length of both the initial meetings and subsequent reflective interviews. As above, one of my first tasks after the meetings was to watch the recordings and identify the sections that seemed most relevant to the research questions. I did this by establishing what decisions were being discussed, and finding the first and last times a speaker appeared to make reference to this. I had written notes and impressions from the meeting to assist. When I later received the transcripts of the recordings, I repeated this task of identifying the most relevant sections of the meeting. This was an iterative process, which involved referring back to my original notes and the parts that I had identified to take to the follow-up interviews. These sections of transcript were used as the focus of the analysis. This process is also captured in the list of steps for analysis in section 2.9.

Length of Recording	Meeting	Follow-up interview
Data Set 1	57mins	Service User: 52mins Psychiatrist: 1hr 33mins
		Care co-ordinator: 51mins
Data Set 2	43mins	Service-user: 50mins
		Care Co-ordinator: 1hr 23mins
Data Set 3	50mins	Service-user: 55mins
		Care co-ordinator: 36mins
		Support worker: 38mins

Table 1. Length of meetings and interviews

# 2.6 Sample

The final sample included service-users involved with participating Community Mental Health Teams (CMHTs), and clinicians who took a primary role in identifying and approaching potential service-user participants.

#### 2.6.1 Inclusion and exclusion criteria

Service-user participants. Within these parameters, I aimed to recruit service-users with experience of psychosis. In order to facilitate communication, I had to use the language of the mental health system, and thus sought to identify service-users with diagnoses such as 'schizophrenia', 'bipolar disorder', 'schizoaffective disorder'

and 'manic depression'. However, I did not use these diagnoses as specific inclusion or exclusion criteria. As discussed at length in the introduction, understandings of psychosis have changed in recent years (particularly within psychology) with a move away from diagnostic labels and towards holistic formulation. As such, anyone who had experience of hearing voices, unusual beliefs or other experiences typically associated with psychosis (e.g. significant change to mood or thought processes) was eligible for the study.

I also considered other demographic characteristics including gender, age, length of time experiencing psychosis and length of contact with services and length of relationship with staff member. Whilst some of these variables will likely affect SDM, again I thought this would be an interesting area to comment on in the course of analysis rather than something to determine participation. In keeping with the theoretical background of DA, it was not considered necessary to recruit a homogenous sample of participants; variation amongst participants was considered an advantage in terms of maximising the clinical relevance of the findings.

Staff participants. I sought to recruit NHS staff members actively involved with service-user participants. I was aware that the data gathered would be influenced by the relationship between the staff member participant and service-user. However, given that government and NHS policy suggests SDM should permeate all clinical interactions, again I did not think this was a variable that needed parameters in terms of inclusion criteria. Rather, it seemed participant dyads with a range of characteristics would be advantageous in increasing the richness and variety of the data.

*Staff and service-user generic criteria*. All participants:

- Were aged 18 years or over
- Had the capacity to consent to participate
- Had sufficient ability to converse in spoken English

Types of decision: Again, given that policy and guidance suggests SDM should be embedded across healthcare decision-making, I did not apply any specific criteria to the types of decision that I was interested in capturing. Whilst much of the research has looked at medication decisions (arguably consistent with dominant discourses of psychosis as illness), I was interested in the way participants' talk contributed to the process of SDM. As such, I included clinical conversations related to any decision about on-going care or treatment.

### 2.6.2 Sample size

The recruitment process for this project was time and labour intensive. During the 18-months of project design and development, the services involved went through a restructure and transformation process. This seemed to impact significantly on staff availability and well-being, and I was aware that I was trying to involve clinicians from busy CMHTs under increasing pressure. In addition to this, I was aware that I was trying to access clients from a population where unusual experiences and issues of capacity potentially make it harder to recruit. The results chapter provides an overview of the number of clinicians and service-users approached in pursuit of participants. Ultimately, three consultations and eight follow-up interviews were recorded. This produced a significant amount of transcript data and numerous examples of decisions. This was considered sufficient data to answer the research questions. In support of this, Potter and Wetherell (1987) suggest that the success of the discourse analysis is not contingent on sample size, but rather the richness of the data in relation to the research aims.

# 2.7 Recruitment procedure

Consideration of recruitment sources was led by the research questions, but also had to account for the time-limited nature of the project and the issues associated with capacity and consent in terms of recruiting from this population (discussed further below). I considered a number of standard decision-making forums across mental health services (e.g. CPA, ward round), and ultimately concluded that community mental health teams (CMHTs) would offer the best chances of successful recruitment, along with a varied pool of decisions.

Four local CMHTs were identified and approached. This was led by contacts of the field supervisor who held a clinical position in one of the teams and so had an established relationship with them. The operational manager introduced the study to the locality managers, and I attended meetings with the senior clinicians at two localities to discuss the project. They were happy to support recruitment through their teams.

I attended team meetings, outpatient clinics and approached people informally in the CMHT offices to ask clinicians to identify people on their caseload who met the inclusion criteria outlined above. Where appropriate, they were asked to introduce the research to these service-users and give them a flyer (see Appendix 3). If a service-user expressed an interest in participating, they were either provided with my study phone

number, or consented to being contacted directly. I then spoke with service-users to provide more information about the research and go through information sheets (see Appendix 2). In keeping with the principles of SDM, service-users were actively involved with identifying a forthcoming conversation where a decision was going to be made. I asked service-users if there were any decisions being made at the moment with clinicians from the team, and if there were any meetings coming up where these might be discussed. Where there was more than one possibility, we explored the pros and cons of recording one meeting over another, and I encouraged the service-users to decide which meeting they would most like to record. With the service-users' consent, I approached the clinician(s) who would be involved in this conversation to establish whether they would be willing to participate. For one data set, this was the clinician who had identified potential service-user participant in the first place. For another, it involved the clinician who identified the service-user plus another care co-ordinator from the CMHT. For the third, it involved a support worker who was already aware of the study and another care co-ordinator. I then met with the service-user to go through a consent form. The time between the initial and second contacts gave service-users time to re-read the information sheet and make a decision about participating without the risk of coercion due to the my presence. I liaised with the service-user and clinician(s) to arrange to attend when the agreed meeting took place, and conversations were recorded using video-recording equipment and transcribed using a contracted agreement by an approved transcriber from the University of Leeds.

Shortly after the initial recording, I met with staff and service-user participants to watch the video and engage in a reflective discussion. Participants were encouraged to pause the recording at any point to offer thoughts and feelings about the interaction, and I likewise stopped the video to ask participants to reflect on different parts of the exchange. These reflective interviews were audio recorded, and again subsequently transcribed under contracted arrangement.

# 2.8 Ethical considerations

### 2.8.1 Ethical approval

Ethical approval was granted by Yorkshire & Humber Leeds East Research Ethics Committee. Approval was also sought and received from the Research and Development Office at Leeds and York Partnership Foundation Trust (See Appendix 1). Several ethical issues were considered in applying for approval for the study, and these are addressed in sequence below.

### 2.8.2 Capacity and consent

It was essential to carefully consider issues relating to capacity and consent given that those with experiences of psychosis represent a potentially vulnerable group. The Mental Capacity Act (2005) states that capacity is decision-specific, and always assumed to be present unless assessment indicates otherwise. Every effort should be made to help an individual achieve capacity, and this can include drawing on a variety of materials. With this in mind, I took draft versions of my participant information sheets to a local service user research network meeting ahead of ethics application submission, where they were reviewed for coherence. The service user representatives said they thought these materials were appropriate for the population being approached. Flory and Emanuel (2004) suggest that the best way to promote understanding is for researchers to spend time with participants to discuss the study. Consistent with this, I spoke with everyone who was interested in the study to explain in detail what participation would involve.

### 2.8.2.1 Obtaining consent: service-users

Through liaison with care co-ordinators, I only approached service-users deemed to have capacity to consent to participate. When meeting with service-users, I sought to ensure that they understood what the study demanded of them, were able to weigh up the potential pros and cons of participating, and could understand, retain and communicate this before the consent forms were signed (see Appendix 2 for consent forms). Following the initial recording, participants had the opportunity to withdraw from the study until five days afterwards.

In acknowledging that capacity to consent is decision-specific and can fluctuate over time, this process was revisited regularly during the study. Prior to the reflective interview, I contacted the care co-ordinator again to check service-users continued to have capacity to consent to the study. I revisited the process of consent with service-users before watching the video, emphasising the option to stop the interview at any time. Again, participants were given up to five days after this recording to withdraw from this part of the study.

#### 2.8.2.2 Obtaining consent: staff

Ahead of making a decision about participation, I either met with staff or emailed them an information sheet and consent form. As with service-user participants, consent was revisited at regular intervals throughout study, including ahead of the reflective interview. Again there was an opportunity to withdraw until

five days after the recording had taken place, both for the initial video recording and the audio-recorded reflective interview.

### 2.8.3 Confidentiality and data security

Participants were informed that their participation in the study would remain confidential unless they disclosed any significant risk issues. Where indicated, it was agreed the researcher would (where safe to do so) discuss this with the participant and inform them that contact would be made with their care co-ordinator.

All identifiable information was removed during the process of transcription and extracts were only shared with supervisors following this anonymisation process. Participants were given pseudonyms for the purpose of the write-up. As such, I was the only person with information about the true identity of participants. Participant consent forms and contact information were all held securely in a locked filing cabinet in the Leeds DClinPsy admin office. All data files relating to the study were stored in accordance with University of Leeds regulations, and I stored the video recordings on the enhanced secure drive of the University server. Encrypted memory sticks were used for any data transfer, including transfer of the transcripts to the DClinPsy secure hard drive. All thesis data is retained by the course for 3 years, after which electronic and paper records are destroyed. Video files from this study will be deleted once the project has successfully passed through the examination process.

## 2.9 Analysis

In conducting the analysis, I followed the principles of Discursive Psychology as outlined by Potter and Wetherell, (1987). I have outlined the steps I took with the data below. These were not always followed sequentially, but are presented in this way here for coherence. Where possible, data sets were dealt with consecutively to limit the influence of the different meetings on my perspective and interpretation of the data.

- 1. I made field notes during and immediately after the initial video-recording, particularly in relation to any strong emotional responses I had.
- 2. Shortly after, I watched the videos and noted down my initial thoughts and feelings about the data. I made a note of the decisions being discussed in the conversations; these were sometimes different to the decisions predicted in advance by the service-user and clinicians.
- 3. Due to the volume of data gathered in the study, professional transcribers were employed under a contracted arrangement. Upon receiving the transcripts, I watched the recordings again and made any amendments and additional

- notations. This included any actions in the video (e.g. nods, hand gestures, facial expressions). I then read and re-read these transcripts a number of times (Potter & Wetherell, 1987).
- 4. In accordance with the 'coding' stage outlined by Potter and Wetherell (1987), I identified sections of text that seemed most related to SDM. In a discourse analysis of SDM by Robertson et al. (2011), the authors developed a checklist outlining the key stages and competencies of SDM (Elwyn et al., 2012; Charles et al., 1999) and used these to search transcripts systematically for relevant extracts. This included checking service-user understanding, references to choice, expressing an opinion, exploring values, fears and concerns and other criteria for SDM. I adopted a similar approach here, although I did not use a specific checklist to allow for inclusion of nuanced parts of the dialogue where negotiation or decision-making seemed to be happening. Interestingly, Robertson et al. (2011) likewise found that they had to use this checklist in a loose fashion because features of SDM from theoretical and conceptual models did not appear to feature in their data.
- 5. I then examined these data 'chunks' in detail, specifically focusing on the construction of SDM. I asked myself what might be happening in the text and how speakers constructed and positioned themselves in relation to decisions being made. Consistent with the guidelines of Potter and Wetherell (1987), I focused on what was 'actually said, not some general idea that seemed to be intended' (p168). In acknowledging the challenge of maintaining awareness of my own 'presuppositions' and 'techniques of sense-making', I regularly asked myself why I might be reading the text in a particular way, or making certain interpretations.
- 6. In relation to the identified decisions, I spent time exploring key actions and features of the talk, interpretive repertoires, ideological dilemmas and particular rhetorical and discursive devices used by speakers. I focused on how these might have impacted on SDM.
- 7. I cross-referenced the construction of SDM and features of the talk both within and across the three data sets to explore whether there were any shared discursive features or strategies evident. Throughout the analysis, I was careful to look for exceptions to any commonly-occurring constructions, and consider why these might be present at that point in the talk and the associated effect.
- 8. I also explored the construction of psychosis as a discursive object at different points in the dialogue and generated some ideas about this might influence SDM.
- 9. I then spent some time exploring wider social and political issues apparent in the talk (e.g. context of mental health services). This stage of analysis emerged organically from my interaction with the data and evidence of broader systemic factors playing out in the talk of the participants at a micro-level.
- 10. I used extracts from the reflective interviews to illustrate points made in the initial analysis or where they added to the understanding of the process of decision-making and experience of different participants, or contributed to answering the research questions.

# 2.10 Reflexivity

In any qualitative research project, the researcher brings their own experiences, emotions and beliefs to all stages of the research (Willig, 2001). As such, it is important to think about how this might impact on project design, data collection, analysis and write-up and to use supervision to reflect on one's own perspective and influences.

To address this, I kept a reflective journal throughout the study, noting my rationale, decision-making and emotional responses across the design and execution of the research. I had regular meetings with my supervisors, and reflected on how my thoughts, feelings and actions during the study might have impacted on the data gathered and my approach to analysis. The following section includes some thoughts about my position in relation to the study and potential impact on the data with a view to maximising transparency and increasing the integrity and validity of the findings (Elliott, Fischer & Rennie, 1999).

Prior to clinical training I worked in a medium secure forensic hospital and witnessed how difficult it could be to involve service-users in decisions about care. Some of this was systemic; the client group was often detained in hospital for compulsory intervention and thus there was a fundamental lack of choice embedded in their situation. Service-users were often also involved with the criminal justice system, which imposed other involuntary conditions and parameters. There were also organisational issues. For example service-users were only permitted to attend ward rounds at the end for 'feedback' once all the decisions had been made. I always found this uncomfortable, because of the implication that the service-user was a passive recipient of interventions decided by others in the team. Other contributing factors related to service-user apparent desire or willingness to be involved in decisions. It seemed service-users were used to being told what to do by a system that disempowered them. People often had other experience of contact with other services (e.g. social services, criminal justice system) that might have related to them in a similarly authoritarian way, which seemed to contribute to familiarity with a paternalistic approach to care.

As a team, we often faced a shared dilemma about how much to express an opinion or sense of what might be helpful (e.g. taking medication, attending groups, engaging with therapy) and how much to be led by the service-user. There always seemed to be a wider question about how much the system allowed that to happen, or what the consequences might be of people making certain choices. For example,

someone saying they did not want to go to the gardening group was often conceptualised as disengagement, lack of motivation, or enduring negative symptoms of 'schizophrenia'. This again always made me feel uncomfortable, and I became increasingly interested in the way that service-users are meaningfully included in decisions about their care, particularly when mental health diagnoses of 'schizophrenia' or 'schizoaffective disorder' seem to provide a framework for pathologising all behaviour. I have wondered at times whether I am guilty of being idealistic, or unrealistic about what is achievable, particularly in settings where there are significant risk issues. I did sometimes find myself thinking that risk was often used as a justification, in that constructing decisions about enforced intervention as related to risk warranted and legitimised them, rather than seeing these as further experiences of disempowerment. For example, I remember times when a service-user would be told they could not have leave because they did not wish to engage with psychological therapy, thus their lack of insight and unwillingness made them too risky. In conducting this study, I was aware that my experiences might make me vigilant to examples of disempowerment or lack of SDM and zoom in on times when it seems service-users are positioned outside decision-making, or interpret utterances in this way.

I am aware it is important to acknowledge the complexity of these issues, and the multiple ideological dilemmas that make it difficult to provide consistent and responsive care in practice. I am keen to emphasise that in conducting this project, I do not wish to criticise individuals in a system, but rather to think about SDM in the context of mental health services in order to offer some ideas about ways to facilitate this in practice. I am aware however that some of my experiences have the potential to impact on my interpretation of the data, and judgments about what is happening in the talk. I was particularly mindful of any critical responses I had to the data, and interrogated my cognitive and emotional responses and any conclusions I made at these times. I also made sure I took examples to supervision to check out my interpretations with my supervisors and explore possible alternative understandings.

# 2.11 Quality checks

In light of the above influences on my approach to the data, I took a number of steps to mitigate my influence and allow the reader to evaluate my assertions. Before constructing the analysis chapter, I read the guidelines by Elliott et al. (1999) and ensured the following:

- Owning my own perspective as above, I have included explicit reflections on
  my position and how this might impact on the execution of the project across
  all stages.
- *Situating the sample* I have provided contextual information about the sample including a pen portrait of the participants in each data set to allow the reader to judge the wider applicability of the findings.
- *Grounding in examples* I have provided examples throughout the results chapter to illustrate the key features of the talk and particularly salient examples of any discursive strategies or rhetorical devices that contribute to the process of shared decision-making.
- Providing quality checks I met regularly with supervisors during the analysis
  process to discuss and reflect on my thinking in relation to the data. Although
  short transcript extracts are included in the report for readability, longer
  sections of text were shared with supervisors during the process of initial
  analysis to enable them to see the context from which my conclusions were
  drawn and to allow different understandings of the data to be discussed.

# 2.12 Write-up and transcription conventions

For ease of presentation and to make the passages clearer to read, utterances that involved brief interjections from another speaker have been presented as follows:

Speaker 1: This is speaker 1 talking [speaker 2: yes] and this is still speaker 1 talking.

Other conventions:

[nodding] Non-verbal information

[...] Indicates gap in the transcript to facilitate ease of reading

[???] Section of speech that was inaudible

... Indicates short pause

<u>Underlining</u> to indicate emphasis

Data from the reflective interviews is presented in boxes to distinguish it from the initial meetings.

# **Chapter 3: Results and Analysis**

I start this chapter with pen portraits of the data sets including a summary of the main discursive features in each meeting. Here, I comment on what was at 'stake' for each of the participants and how this seemed to impact on the talk, both in terms of the primary recordings and the reflective interviews. This is consistent with the assertion in DP that all speakers have a 'stake' in social interactions, such that their language is used to manage this 'stake', and to pursue certain aims or objectives (Willig, 2001; p102). There is also a table summarising the decisions being discussed in the meetings. I then provide a brief commentary and exploration of the construction of psychosis across the data sets to provide a context for how these understandings might shape SDM. I present the key features of the talk, with examples of how these manifest across the different groups and some ideas about possible functions and the impact on SDM. Transcript extracts are included throughout the chapter to exemplify particular discursive actions or rhetorical devices. Supplementary data from the reflective interviews is also included to facilitate a richer exploration of the data. Whilst these reflective interviews are intended to add to the analysis of the initial meetings, it is important to note that a DA approach treats all forms of talk as constructive. As such, whilst this data can offer some insight into the experience of participants, it will still be analysed from a functional and active position, rather than treating it as a representation of true subjective experience.

# 3.1 Sample

The process of recruiting and gathering data for this project was labour-intensive. To promote the study, I attended meetings both with senior clinicians and wider CMHT staff (MDTs, formulation meetings, referral meetings), approached staff in person at the team offices, put up posters (see Appendix 3) and sent emails via nominated contacts. The tables below provide an overview of the process of recruitment and final sample. Largely it was care co-ordinators who approached potential service-user participants. I was told those who declined said they did not wish to participate; no further reasons were given. Those who declined later often said they had changed their minds, and for two participants changes to mental health experiences precluded participation.

Clinical meetings attended	Clinicians contacted	Service- users approached	Declined immediately	Declined later	Consented (final sample)
9	26	15	7	5	3

Table 2 - Recruitment information

	Data Set 1	Data Set 2	Data Set 3
Service User	Adam Natalie (his wife)	Arthur	Lydia
Staff (in meetings)	Kirsty (Care co-ordinator)  John (Psychiatrist)	Martin (Care co- ordinator)	Sally (Care co- ordinator) Barbara (Support Worker)
Staff (discussed but not present at the meeting)	N/A	Stuart (external support worker) Elizabeth (social worker) Sheryl (CMHT support worker)	N/A

Table 3 - Final Sample with Pseudonyms

# 3.2 Pen portraits

### 3.2.1 Data Set 1: Adam, Natalie, John and Kirsty

Adam was in the process of discharge from intensive community day services (ICS) to a local CMHT. Adam said that for a number of years, he heard angry and critical voices that told him he was worthless and that other people were against him. He said the voices were usually louder and more upsetting at times when he was experiencing negative thoughts, or feeling worthless, anxious or frustrated. At times of increased stress, Adam coped with his experiences by taking drugs, and described ongoing problems with gambling. There were also some identified risks both to Adam and others in the context of more acute experiences of psychosis; he had previously been admitted to an inpatient hospital setting after locking himself in a room with a weapon.

The meeting we chose to record was his discharge Care Programme Approach (CPA) review, because there were a number of decisions to be made about the ongoing care plan. Adam's wife Natalie came to the meeting with him. His care co-

ordinator from the CMHT also attended (Kirsty), and the meeting was led by one of the Psychiatrists from ICS (John). This was the second time John had met Adam, whilst Kirsty had an established relationship with him, having held the role of care coordinator a number of times during periods of involvement with mental health services. Both John and Kirsty had worked in the service for a number of years.

In the meeting, John and Kirsty managed their 'stake' as mental health professionals, which included attempts to encourage Adam to engage with a number of different interventions. They drew from a biopsychosocial model of psychosis to persuade Adam that interventions which target social activities (e.g. joining a fishing group) and issues of self-esteem would be more helpful for his mental health than purely pharmacological options. Discursively, we see them offer opinions based on their experience working with other service-users, and make suggestions about what might be useful for Adam and how he might access it (e.g. looking through a list of vocational options and choosing one to start with). Managing this stake seems fragile, in that they do not want to be too prescriptive or commanding, and are aware that this might make Adam more likely to disengage. As such, we see a level of tentativeness in their discourse, and a recurring ideological dilemma in the competing discourses of 'clinicians as responsible for care' vs. 'service-users as autonomous and empowered'.

By contrast, Adam seems to construct his position as a recipient of medical intervention, drawing on the discourse of psychosis as illness to explain his behaviour (e.g. gambling). His aim as a 'patient' is to be 'treated' by the clinicians in the meeting, and he attempts to manage this stake through the use of passive agreement, limited initiation of ideas and minimal response to suggestions. These contrasting stakes make SDM challenging because it limits development of a shared understanding of the problems and precludes a process of deliberation.

With reference to the reflective interviews, the stakes were different. For John and Kirsty, their aim was to comment on and explain their behaviour in the meeting to another clinician (me). A number of times in the interview, John provided an indication of how his manner might have been different (e.g. suggesting he could have been more forceful or prescriptive with his recommendations). In doing so he provided a rationale for his way of interacting with Adam, thereby justifying his approach and implying it was more helpful and also more likely to secure meaningful engagement.

Adam seemed to use the interview to explain why he was not more involved in the meeting. He constructed himself as overwhelmed by the discussion, and used feelings of embarrassment and a preference for paternalism to legitimise his lack of input. Again, his construction of himself as a 'patient' and John and Kirsty as 'experts' allowed him to argue that they should have been more prescriptive, and explain why he maintains a somewhat passive position during the meeting. This helped highlight how the contrasting stakes being managed by the service-user and clinicians in this data set contributed to a 'stalemate' position in terms of decision-making because Adam's talk was organised with the aim of eliciting a response that John was working hard not to give.

Across the reflective interviews, my aim as a researcher was to elicit a commentary on the internal experience of participants that might not have been apparent during the initial meeting. In terms of the interview with Adam, I was aware that he described a sense of not being heard by services, feeling stupid and like he did not have a voice. At these times, I was aware my stake shifted somewhat in that I aimed to listen and empathise with Adam's experience, which was evident in my use of validating statements summarising or reflecting back my sense of what he was describing. At these times, I was trying to achieve something that was probably more akin to other parts of my clinical work, and noticed this overlap between my identity as an NHS clinician, but primarily a researcher in this context.

### 3.2.2 Data Set 2: Arthur and Martin

Arthur had recently been discharged from hospital following a short admission. He had a long history of contact with mental health services and an established relationship with the CMHT. Arthur described unusual experiences across much of his life, including hearing voices and significant shifts in mood. He described a mixed relationship with different aspects of his experience, enjoying the ideas and creativity that accompany periods of 'elation', but recognising professionals worry about his safety at these times.

Arthur identified Martin as someone involved in decisions about his care, and with whom he would feel comfortable recording a meeting. Arthur and Martin have known each other for over five years. Martin is currently Arthur's care co-ordinator, and was closely involved with developing the care plan that formed part of the preparation for Arthur's recent discharge. The meeting recorded was a standard review as part of post-discharge follow-up. When I first met with Arthur, he suggested 'all the big decisions had been made' whilst he was in hospital, but identified what he called 'small d decisions' around input from additional services (e.g. Age UK), ongoing management of medication and negotiating frequency of visits from the various people involved.

As with John and Kirsty, Martin occupies the role of a mental health professional in this meeting, and thus his aim is to secure Arthur's long-term mental health stability. Martin manages this stake by focusing on issues outlined in Arthur's discharge plan, and by using discursive strategies to redirect Arthur if he seemed to be deviating from this agenda. Arthur's most recent admission to hospital was the first for a number of years, and as such there seemed to be a sense that his mental health might now be more fragile or precarious. In accordance with the construction of psychosis as an undesirable illness, Martin's aim for the meeting focused on developing a care plan that will keep Arthur 'well'. This was evident the way Martin drew heavily from the discourse of psychosis as dangerous in a bid to persuade Arthur that these experiences are risky and should be avoided (e.g. through compliance with medication and identification of the most suitable accommodation). This seemed to be in part in response to Arthur's description of his lived experience of psychosis as an 'exciting' and 'creative' time, and thus something that was not exclusively negative for him.

Consistent with the experience of psychosis, Arthur spoke of his experience of confusion, 'jumbled thoughts' and an on-going struggle to see things 'objectively'. Arthur thus seemed keen to involve Martin in decisions, aiming to draw him into an exploration or reflection on a number of issues pertinent to his life. Martin is willing to do this in relation to certain decisions (e.g. housing options), which is evident in the way he presents options and asks questions, which seems consistent with a process of SDM. This contrasts with another decision in which Arthur constructs Martin's opinion as particularly important and influential. Martin seems to object to this position, not wanting to be responsible for influencing Arthur's decision. Martin manages this stake by deferring to the opinion of others (namely a social worker) and by overtly reassigning responsibility to Arthur, emphasising that the choice lies exclusively with him. There is further exploration of this example below, including transcript extracts.

In terms of the reflective interviews, again it seemed Martin's aim was to explain and justify some of his behaviour during the meeting. This was especially apparent at times when he noticed something in the recording that he did not like. For example, he identified that he had persisted in asking Arthur questions about a particular subject despite his obvious discomfort in front of the camera. At these times, I was aware of how I managed my stake in the conversation. I noted my competing aims of reflecting on the meeting in relation to SDM, whilst also being drawn into a sort of supervisory process, helping Martin reflect on what might have been said or done differently. I also noticed a pull at times to offer reassurance or challenge Martin's harsh evaluation of his practice. I was aware this extended beyond the specific

parameters of the project, which at times made me feel uncertain. Discursively, I managed this through the action of redirecting the conversation back to the recording.

Of all the participants, Arthur was the most challenging to interview in terms of maintaining a focus on the recording. It seemed Arthur's aim for our meeting was to talk about his life and experiences with mental health services more broadly. I became increasingly aware of how this contrasted with my stake in terms of trying to elicit some of his reflections on the meeting by watching the video. Whenever the tape was paused, Arthur seemed to talk about memories or experiences prompted by the recording, or his life more broadly. I was aware of my implementation of rhetorical devices (e.g. more direct questions), which seemed to relate to some frustration and anxiety about getting the data I had hoped for. I also noticed my experience of critical thoughts (both at the time and afterwards), which related to how congruent I might have been with the principles of SDM at different times.

### 3.2.3 Data Set 3: Lydia, Sally and Barbara

Lydia was experiencing a second episode of psychosis in the context of stress at work. A previous period of psychosis seemed to have been precipitated by a court case where Lydia acted as a character witness for a colleague. The case involved other staff from work, and the events and details seemed to reawaken traumatic memories from the past that had previously not been attended to. Lydia's subsequent return to work was seemingly managed with little consideration of the circumstances; she was asked to work long hours with people involved in the proceedings and spoke of significant politics and interpersonal difficulties in this context. Lydia described how this culminated in a further period of distress, which was subjectively and objectively more extreme than the first. Her experiences during these times included concerns about being controlled by external forces, difficulty thinking clearly and strong shifts in mood. She received support from the local day hospital and CMHT and described rapid improvements in her well-being having taken time off work.

Sally is Lydia's care co-ordinator from the CMHT, and Barbara is a support worker from the day hospital. They spoke very fondly of Lydia, describing her as warm and affectionate. They also said she spends a lot of time ruminating about events from the past, and conversations with clinicians tend to mirror this process, which makes it hard to discuss other things or problem-solve. This seemed to relate to underlying difficulties with low mood and low self-esteem. Lydia had been keen to return to her previous workplace despite emerging evidence this might not be helpful for her mental health, something which both clinicians described finding puzzling and somewhat

frustrating. The meeting we chose to record was a joint review in preparation for stopping input from ICS.

Sally's aim in the meeting was persuade Lydia not to return to her previous employer, and to accept a referral to a workplace support organisation to pursue other occupation options. In seeking to achieve this, Sally positioned herself as an advocate for Lydia, using emotive language to imply the previous employer was unreasonable. This constructed her role as a protector and defender of Lydia, thereby legitimising her desire for Lydia not to succumb to the employer's demands. Sally draws from the construction of psychosis as a response to stress alongside the medical discourse of psychosis to imply that Lydia needs to avoid the stress of work in order to prevent relapse.

By contrast, Lydia seems keen to use the meeting to explore some of her experiences, and to elicit validation from Sally and Barbara by going into detail about her previous experience of poor treatment in the workplace. Lydia aims to construct a 'friendly' dialogue with Sally and Barbara, which was evident in her language and behaviour even before the recording even started, referring to them as 'my love' and making them tea and cake. These contrasting stakes again interact to make SDM difficult to achieve. As with Martin, Sally seemed to have an internalised agenda, which we see in the action of directing and redirecting conversation. Specifically, Sally used discursive strategies to bring Lydia back to a solution-focused intervention rather than spending more time exploring her thoughts and feelings or discussing events from the past.

In terms of the reflective interviews, Sally used her experience as a mental health professional to explain and justify her behaviour in the meeting (and with service-users more broadly), and to imply that Lydia would be wise to heed her advice. To do this, Sally constructed Lydia's focus on the previous workplace as peculiar and unhealthy, which justifies her moving the conversation on to other things, and also justifies her pursuit of other occupation options. Sally also spoke of her sense that wider caseload pressures meant she was keen to cover the list of topics she knew she was expected to discuss (e.g. mental health, family, medication), which she again used to explain some of her feelings and behaviours in the meeting (e.g. feeling frustrated, tapping her pen, saying 'I need to move this on now'). In terms of my stake in the interview, I was especially interested in exploring Sally's approach, because my interpretation had been that this was the more prescriptive and possibly the least representative of SDM. In seeking to access some of her thoughts and feelings about her and Lydia's behaviour in the video, I likely influenced the way Sally spoke about

her sense of herself as a clinician. I deliberately tried to keep the questions open (e.g. what was going on for you at that point?), but I imagine my curiosity about her approach likely impacted on the ways she used language to explain and justify.

Barbara seemed more curious about Lydia's 'fixation' on work in her reflective interview. Barbara's contribution to the meeting was limited, and thus in her reflective interview, her aim seemed to be to hypothesise, or to share some of her thoughts with me, along with sharing how some of Lydia's behaviour affected her emotionally. The video seemed to provide Barbara with a space to question what might be going on for Lydia. In this way, she used her language to generate some possibilities, and said it was the first time she had really thought about this.

As with Arthur, it was difficult to focus the reflective interview with Lydia, and much of her talk focused on anecdotal experiences from the past. It thus seemed that Lydia's stake (i.e. discussing memories from the past, possibly to elicit validation or empathy) contrasted with what I was trying to achieve (i.e. reflect on the recording as part of a research project). I was aware that this perhaps mirrored Sally's experience and highlighted the way contrasting stakes can generate anxiety or frustration. Again, I noted that I implemented my own discursive devices (e.g. more closed questions) to try and manage my stake and encourage Lydia to talk about her experience of the meeting.

### 3.3 Decisions in the data

The table below provides an overview of the decisions being discussed in the meetings recorded:

	Decision	Description	Outcome
Data Set 1: Adam, Natalie, John and Kirsty	Occupational activity	Following discharge from hospital and in the context of on-going sickness absence from work, it seemed Adam's activity level was low. The meeting included a discussion about whether there would be value in Adam getting involved in vocational pursuits.	Postponed
	Medication Reduction	Adam had been prescribed diazepam since his discharge from hospital. John suggested it would not be feasible to continue taking this long-term, and thus the group discussed options for reduction and termination.	Made
	Referral to Gambling	Adam has on-going difficulties with gambling and drug use. During the meeting,	Postponed

	c ·	T 1	
	Services	John suggested support from addictions services might be helpful in understanding this repeating pattern of behaviour.	
Data Set 2: Arthur and Martin	Housing Options	Arthur and Martin told me there were ongoing conversations about Arthur's current residence, and whether an independent flat leaves him socially isolated. The meeting involved a discussion about alternative accommodation options and locations.	Postponed
	Support Worker	Arthur pays for additional support from someone external to the CMHT and has done for some time. It seems this person charges quite a lot, but Arthur values the relationship and it provides him with greater social contact and community engagement than he would have otherwise. During the meeting, Martin revisits Arthur's thoughts about input from this person.	Postponed
	Clothing/ Gender Services	Prior to the most recent hospital admission, Arthur bought a number of expensive women's clothes. This meeting included an on-going discussion about whether Arthur would like to return these for a refund, and likewise if he wants any support from Gender Identity Services.	Postponed
Data Set 3: Lydia, Sally and Barbara	Return to work	Lydia's current employer had seemingly been inflexible about her return to work after a previous episode of sickness; she was working long hours again and not getting many full days off, which seemed to contribute to the current psychotic episode. Sally and Barbara discussed whether she was ready to go back to work this time, whether it would be better to go to a different employer and whether to pursue a referral to an employment support organisation.	Postponed

Table 4 - Decisions in the data

# 3.4 Constructions of psychosis

# 3.4.1 Psychosis as dangerous and damaging

A notable construction of psychosis in the talk in data sets 2 and 3 draws from an interpretive repertoire of dangerousness. In the talk between Arthur and Martin, psychosis is consistently constructed as something unpredictable, scary and

threatening. This can be seen in the extract below where Arthur and Martin discuss some of his mental health experiences:

Arthur: That was the ... the psychosis about to go bang or already in the process

of going bang [Martin: yeah. Yeah. Okay] just a thing...

Martin: I think this is the thing, you know the danger signs. We know the

danger signs [...] I suppose from my point of view...is when you're unwell: you're poorly, you're ill. And I suppose it's not just that, but it's

the risks that you expose yourself to. You make yourself quite vulnerable and that is obviously a great concern [...] [Arthur: no

response]

Arthur's use of the word 'bang' depicts psychosis as something sudden and extreme. Externalisation of 'the psychosis' positions Arthur outside of the experience and constructs it as something that happens outside of his control, implying the 'bang' is unpredictable. Martin uses words like 'risk' and 'danger signs', which again speak to a repertoire of dangerousness and allow the construction of psychosis as threatening. The word 'vulnerable' arguably constructs Arthur as defenceless and allows Martin to position himself in the role of protector. This repertoire of risk justifies the argument for Arthur to accept treatment to suppress these experiences, even though Arthur says he finds them pleasurable to a certain extent. This favours the dominant way of understanding these experiences as dangerous and unwanted, and perpetuates the prevailing understanding of these in the wider context of services and society.

In terms of SDM, this seemed to particularly impact on the dialogue between Martin and Arthur in relation to housing options. The talk is organised such that housing is constructed as being strongly linked to Arthur's on-going mental health and stability, so it becomes essential to find the right place for him to live to protect against this 'risk' of him becoming 'unwell'.

### 3.4.2 Psychosis as illness

Alongside the repertoire of danger and threat, Martin draws from the medical discourse in the extract above by saying to Arthur 'for me when you're unwell, you're poorly, you're ill'. Jefferson (1990) suggested a three –part list can generate an implication of representativeness or completeness. This use of a list of synonyms (unwell, poorly, ill) emphasises the understanding of Arthur's experiences in this framework, and supports the notion that psychosis is something to be treated, as these experiences are indicative of something wrong or someone in poor health.

We also see the construction of psychosis as illness in data set 1, but the way this is used differs between speakers. Natalie and Adam draw on the medical discourse of psychosis, using words like 'ill' and 'relapse' to describe Adam's experience. They

also use this to explain some of his gambling behaviour, as captured in the extract below:

John: Would it be an unusual thing, could you say this has been happening

over recent weeks? [...]

Natalie: yeah over the last couple of weeks and then previously... it was about

May, that he last did that, and he was ill in May, he had that relapse in

May

Adam: [...] It's usually been when I've been ill [Natalie: yeah] and I go on and

spend money

Here Natalie depicts Adam's gambling as something that only happens at times when he is 'ill'. I wondered if it feels less painful to conceptualise Adam's behaviour in these terms. Natalie is in a relationship with someone whose behaviour is having significant financial and social consequences. Understanding this as illness externalises the problem, and positions Adam as a victim of disease, rather than as someone with choice or responsibility in terms of these behaviours. Holding onto this explanation also means she does not have to feel angry or disappointed with him. Likewise for Adam, using a medical discourse to explain his experiences perhaps reduces his own distress because he can make sense of these behaviours as out of his control, rather than something he knowingly does despite the impact on his family. This seems to impact on SDM such that Adam and Natalie are more able to engage in parts of the conversation related to decisions about medication, presumably because this is consistent with their understanding of the causes of these experiences, whereas there is less active participation when John and Kirsty try to discuss engagement with vocational pursuits (this is explored further below).

### Reflective Interview Data

In his reflections, John spoke about the impact of Adam and Natalie's understanding on the perpetuation of his difficulties:

John: Over the years, he and his partner, they-they've [...] held quite a

biological sense of his problems. And there's been a sense that when things go wrong it's because he's ill: and he goes to hospital and he takes medication and things get better [...] but I think part of the reason why it goes round in circles like that [...] because there's such a focus

on the biological, the other things get neglected.

Here John links the repeating cycle of hospital admission to Adam and Natalie's formulation. This seems complex, because one imagines their understanding has not developed in a vacuum, but is likely influenced by the systems that have been involved in responding to Adam's distress. Indeed during the meeting, the speakers discussed changing formulations of Adam's difficulties over time, and the lack of consistency

from professionals. By suggesting the focus on 'the biological' means 'other things get neglected', John constructs his own understanding of psychosis as multifaceted, and implies he would see a purely biological understanding as reductionist.

In contrast, John and Kirsty construct Adam's experiences and on-going difficulties in a biopsychosocial framework and relate these to low self-esteem, rumination and negative thoughts. In the extract below, John puts forward one formulation of Adam's experiences:

John:

you could take one extreme and say that this is an illness, and you need to stay drug free and take an antipsychotic, and if you do that the voices won't come back, and things will be OK...I'm not convinced that's accurate because I think there are other issues, perhaps around your self-esteem, and erm how you deal with stress and worries and situations like this...you will gamble, or like in the past you've used drugs

In terms of SDM, one can already see there could be a barrier in terms of developing a shared understanding of Adam's problems, because the speakers draw from different explanatory narratives. Here, we see John's understanding legitimises subsequent discussion of interventions aside from medication (e.g. occupational activity, addiction services), because he relates these to potential improvements in low self-esteem and ways of managing stress, which contribute to Adam's overall mental health.

#### 3.4.3 Psychosis as a response to stress

We see a third construction of psychosis in data set 3 in terms of a link to external stress:

Sally:

And always if people go back too soon you might start to relapse again **[Lydia: yeah. Mm]** and that's the big worry, isn't it **[Lydia: yeah]** that's a big worry

Here, Sally implies Lydia's experience of psychosis was a response to stresses specific to her job. This legitimises Sally's expression of concern about Lydia going back to that employer, and validates her suggestions of alternative options and input from employment support. Sally uses repetition of the phrase 'big worry' to emphasise her concern, and the gravity of the situation (Potter, 1996).

Here, Sally also draws from the interpretive repertoire of risk and danger by suggesting the prospect of these experiences returning is worrying, and thus something to be avoided. Use of the word 'relapse' links to the medical discourse of

psychosis, and has connotations of setback. This adds to the construction of work as stressful, in particular too stressful for Lydia, and likely to precipitate mental health deterioration.

### 3.5 Features of talk

The following section includes examples of the most prominent features of talk across the data sets and reflection on how these impact on SDM.

#### 3.5.1 The 3 Is model

The 3 Is model (Stacey et al, 2015) was initially presented in the introduction as the only SDM model specifically developed in mental health services with consideration of capacity and power. This made the paper particularly relevant as a pre-cursor to the current study. I completed the initial analysis without reference to the 3 Is model, largely because I did not want this to unduly influence my approach to the data or interpretation of the talk. As the analysis proceeded however, it became apparent this might offer a helpful framework for commenting on the nature of sharing and collaboration across decisions. Indeed, a question I posed in the introduction was about what the model might look like in practice, and what discursive strategies or discursive features of talk might be used to position a speaker as Informed, Involved or Influential. In the analysis that follows, where relevant I have commented on how the model might manifest in the talk between participants, but I am keen to emphasise that these reflections came after my initial interaction with the recordings and transcripts.

A reminder of the model and definitions is presented below. Stacey et al (2015) proposed that for SDM to occur, all parties in a given exchange must be Informed, Involved and Influential.

Informed	Ensuring everyone knows what is up for consideration. The model suggests people with mental health problems have 'insight into the distress that such problems cause and impact on sense of self, identity and relationships; what it feels like to live with a diagnosis'. Professionals have expertise in different treatment options, the structure of services. The action of informing thus means valuing all information contributed by different parties.
Involved	Being willing to 'adapt decisions in light of the information shared and respond to expertise of others'. This could include 'how service-users involve professionals, rather than the other way around'. It also means professionals having the opportunity to contribute their views. Those in positions of perceived control should be open to the views of others.

Influential	Being considerate and respectful of others views, even if the majority does
	not share these. This may challenge professionals to support service users
	choices that are perceived as bad. This means all parties holding power and
	accountability for decisions.

Table 5 - Summary of 3 Is Model (taken from Stacey et al, 2015)

### 3.5.2 Sharing an opinion

One feature of the talk is how clinicians and service-users present and share their opinions, what function this might serve (i.e. to explain, persuade, convince, validate) and the subsequent impact on SDM. This action arguably enabled speakers to be 'Informed' and 'Involved' (Stacey et al., 2015) although there were also times speakers seemingly used their views to Influence others.

### Adam, Natalie, John and Kirsty

In the extract below, John and Kirsty have asked Adam how he would like to go about re-establishing some sort of vocational routine following his discharge from hospital. The clinicians suggested various organised groups (e.g. fishing) and other general possible pursuits (e.g. swimming, voluntary work). Asking this question represents an example of 'making the evidence speak for itself' (Gilbert & Mulkay. 1984) in that it implies it is a foregone conclusion that Adam would want to do this in the first place.

Adam: I suppose [...] even when I'm well [...] I kind of keep myself to myself

really and, err, I do find it hard to err, go and join in and stuff like that

John: ...I guess, it's not because we're insensitive, but we'll still push you

because we kind of see that **[Adam: yeah]**, we see lots of people who feel similarly to you find the different groups [...] quite a positive experience instead of a stressful experience, but there's this, just this first bit of getting started which is often the hardest, but it's a really

important step...

Adam makes an intervention here by saying 'even when I'm well I try to, I kind of keep myself to myself really and err, I do find it hard to err, go and join in and stuff like that'. This utterance implies his lack of participation in activity is not linked to problems with mental health, but rather a stable and typical behaviour for him. Adam uses this trait of 'keeping to myself' to legitimise and normalise his behaviour. Saying this is something he 'finds hard' provides further explanation and justification about his lack of confidence socially, and in doing so identifies a barrier to heeding their suggestions. This represents an example of Adam 'Informing' others of his lived experience.

In response, John uses his experience of working with other people who 'feel similarly' to Adam to persuade him to engage with an activity. John's provision of information about others experience is also consistent with the SDM concept of 'Informing', in that John is sharing his professional knowledge with Adam. Use of this strategy adds legitimacy and serves as collateral evidence for his argument; people who found these groups useful have 'similar' feelings to Adam, and thus their experience is relevant. John uses a disclaimer (Hewitt & Stokes, 1975) to pre-empt the possibility of Adam interpreting him as 'insensitive' for continuing to 'push' him, despite the fact that he finds this 'hard'. There is an implication here that others have benefitted from being 'pushed', which normalises and legitimises John behaving in this way, despite Adam's position of reluctance. This perhaps also creates some pressure for Adam to follow his suggestion; if these things have been consistently helpful for other people, it makes sense for him to also participate. Whilst the first part of this exchange seems consistent with SDM, after the extract above, Adam does not respond to John's utterance, which means that the process cannot continue and the decision is left unresolved.

### Reflective Interview Data:

In the reflective interview, I asked John about his approach to the discussion about occupational activity:

John:

with this particular person, if you were to be too prescriptive, it wouldn't happen. So if you were to say, 'I think you should do this or I want you to do this or go and do this', it definitely wouldn't happen! [...] So there's something about drawing him into [...] making some choices, some decisions about what he would like to do.

I was interested here in John's use of the phrase 'draw him in'. This implies use of a conscious and deliberate strategy and puts John in a position of power in terms of active attempts to elicit a certain response from Adam. There's a dilemma here, because on the one hand, John wants to be collaborative and involve Adam in the decision-making, but it also implies reluctance on Adam's part and an suggestion that John must employ coercive strategies to do this. It also points to John's powerlessness; he cannot force Adam to engage and must therefore rely on covert strategies of persuasion.

We see a different approach to the discursive action of 'sharing an opinion' in relation to the decision about medication. This seems consistent with the DP literature, and the suggestion that speakers are rarely consistent in their 'attitudes' or 'thoughts' throughout a particular exchange, but rather make use of different strategies

depending on current social aims (Potter & Wetherell, 1987). In this extract, John and Adam begin to talk about the prospect of reducing his current prescription of diazepam, and John has already stated that this should happen 'sooner rather than later' because of potential problems with dependence:

Adam: I don't know you see, because I've just got a, err, a month's supply

[John: right] and it, like I say they, it comes in the dosset box, so yeah...

John: right, OK, erm, we could, I suppose we've got two options really, we

could ask them to take it back and refill it and change it all, or we could

wait for a month [Adam: yeah], erm..

Adam: I think I'd rather wait...I think I still need to use it

Adam makes an intervention by saying 'I don't know you see, because I've just got a, err, a month's supply'. This rhetoric device of 'making evidence speak for itself' (Gilbert & Mulkay, 1984) allows Adam to present a barrier to the proposed changes and justify maintaining the status quo. This distances Adam from the decision by implying it is circumstantial rather than his choice.

In response, John presents two options. This was the first (and only) time in the meeting John offered explicit choices. I argue this enables Adam to express a preference clearly - also the only time he does this in the meeting. I wondered if this was a good example of both parties being 'Influential' in that John begins with the options available based on his knowledge about medication side effects, and Adam is then able to choose between these. That said, Adam's influence is limited in that the overall decision (whether to stop the medication at all) has already been made. Whichever scenario Adam chooses here, the medication will stop eventually. As such, John secures his preferred outcome, whilst Adam can feel that he has contributed. It could thus be argued this exchange exhibits limited SDM because the power ultimately lies with John.

#### Reflective Interview Data

After watching this part of the data, John reflected on the impact of Adam directly expressing an opinion:

John:

[...] there's something about him committing to saying I think I would, I'd like to leave it as it is. And he doesn't commit to much but he does commit to say actually, I would like to. But it's not in a really assertive or aggressive way. Again, you know he-he's always open to, if I was to tell him and be really bolshie, 'No, no, you can't take the medication,' he'd accept it. But I think there is, it's a fairly clear communication: this is what I think I can manage....so we kind of go, 'Actually that's okay'...

Here John uses the rhetorical device of active voicing (Wooffitt, 1992) ('No, no, you can't take the medication'). Use of direct quote adds salience, and allows John to present his alternative choice of behaviour as favourable. The suggestion is that Adam's 'clear communication' makes it more likely the clinicians will agree to his request. John implies here that Adam sharing his preference facilitates a collaborative decision being made.

Throughout the meeting, John seems to be deliberately avoiding being too prescriptive because of his sense that this would increase the likelihood of Adam refusing, whilst Adam's interview suggests that he is seeking this direction from professionals:

Adam:

[...] what I found with mental health service is-is that they kind of will suggest summat then ask you [...] what do you think. And I know it-it's kind of good in ways [...] but I'd rather be just told, 'Look, this is what you gotta do. This is what we're gonna do and that's that' and I'll be like, 'Yeah-yeah, fair enough, take control of the situation' rather than have them, you know leave it up to me. Cause I don't know. I'm not a mental health professional. I just, I know that I get poorly and-and that's it...

Adam's talk here speaks to a paternalistic model of mental health care, in that he feels frustrated about being given a choice when he does not want one. Adam uses category entitlement (Potter, 1996) to suggest you must be a mental health professional to know what might help manage distress. This constructs Adam's contribution as redundant, and is perhaps a way of explaining or justifying his lack of active participation in the meeting.

As above, John has indicated he thinks being prescriptive would mean things 'wouldn't happen', but Adam here suggests he wants to be told what to do. Adam does not wish to be 'Involved' or 'Influential' in decision-making, but John thinks Adam will disengage if he is too forceful. Although a decision is ultimately made in relation to medication, these contrasting positions seem to contribute to an impasse in other decisions in this data set; John is aware of his position of power, and does not wish to use this to direct or 'Influence', whilst Adam does not want to increase his 'Involvement' and wants a decision to be made for him. These different positions and aims make it hard to engage in a collaborative process of decision-making and so bring SDM to a halt.

#### Arthur and Martin

The action of expressing opinions looks different when it comes to the decision about whether Arthur wants to continue paying for additional input from external support worker, Stuart. In the extract below, Martin has initiated a discussion about this:

Martin: Have you had any more thoughts about Stuart [Arthur: well...] 'Cause

I know you weren't that keen to sort of see him anymore

Arthur: I, I was very interested in your comments last time [Martin: Right.

> Okay] Cause you-y-y-you spoke up quite well for him [Martin: As long as he's all, you know legit ...] That's made a lot of difference [Martin; **above board; pays his taxes and that sort of thing]** That's made a lot of difference to me, Martin. [Martin: Right mm-huh, okay] Your opinion on my opinion. [Martin: yeah] Cause, cause I, I tend to see people subjectively that's why [Martin: right, ah-hah] I'm not very

good at being objective

Martin: I suppose I'm kind of, you know thinking about what [social worker]

said about Stuart and his involvement. She wasn't that keen. I know she wasn't that keen because of the amount that he charges you. She felt that maybe it was a bit much [Arthur: I thought she spoke..] to me, I'll leave you that choice as to what you want to, you know see him or not um, you know you've got [CMHT support worker]. She is not going to charge you anything um, but [she] can't take you out to places that Stuart can take you. So again it's very much up to you. Um, people will have their opinions and able to express them as long as he's not, there's nothing devious or wrong going on then, you know it really is up to you

Arthur initially acknowledges his own fallibility, and uses this to explain why he might sometimes refer to others' opinions to shape his own. Martin responds by deferring to the view of the social worker, perhaps with a view to constructing himself as neutral. Use of the rhetorical device of category entitlement (Potter, 1996), implies the status of the social worker means her opinion should be taken seriously. Drawing another professional into the dialogue may also be a way for Martin to add weight to this argument without having to own the opinion directly. Martin says 'it's up to you' three times in this utterance, perhaps to emphasise Arthur's autonomy. The 3 Is model stresses that all parties must share their views and opinions in order to facilitate SDM. Here, Martin creates a barrier to sharing by emphasising that the decision belongs to Arthur alone. In this way, he seeks to avoid being 'Involved' or 'Influential' and is wary about sharing his personal view.

#### Reflective Interview Data

In his reflective interview, Martin talked at length about how uncomfortable he was when Arthur said he had been swayed by his (Martin's) opinion. Martin's

objection seemed to centre on a sense that Arthur had misunderstood or misrepresented him by suggesting he had spoken favourably about Stuart.

Martin: Yeah, I wasn't happy with him with this [...] Arthur has kind of latched

onto my opinion [Interviewer: yeah] and said 'oh no, you said....' [...] I'm, I'm not happy with him about that really [Interviewer: Okay] yeah I feel a bit uncomfortable with that really, because it's, to me, it's

his decision, as long as he's legit [...]

Interviewer: yeah, yeah so it sounds like you're saying you didn't like he was

implying you'd said...

Martin: well he quoted me "[Martin] says it's fine"...and it's 'well no, I haven't

said that Arthur [...] I suppose because if he was dodgy, then maybe [Arthur] is going to blame me, and say 'well, you said Stuart is alright'[...] [Interviewer: Would you have preferred to have said something else there? Looking back now?] Yeah, I think now, I would have liked to have said something else, and said to go with what [social worker] is saying, you know, no, I think you should dump him, not have him, he's bad [Interviewer: Okay] But then if I say that, to Arthur, should I then be doing something about that, [...] maybe I've been a bit too airy fairy with it, I don't know... too fluffy [Interviewer: Well...] That's probably deliberate, I'm thinking 'I'll be a bit airy fairy, a bit fluffy with this and give the onus to [Arthur]', but then [Arthur]

turned it around and has thrown it back at me

Martin used emotive language during this part of the interview, and I was aware that his tone of voice and body language (sitting up in his chair, more animated) also communicated a strong emotional response. Martin uses the rhetorical device of active voicing a number of times in this extract (Wooffitt, 1992). Wooffitt (1992) emphasises we should not assume a speaker who uses quotes is presenting the actual speech of another. It seems here Martin uses active voicing to explain and justify his objection to Arthur's assertions by presenting the implied meaning of the things Arthur has said (e.g. 'well, Martin says it's fine').

There was evidence of an interpretive repertoire of responsibility in this part of the interview. Martin suggests Arthur would 'blame' him if Stuart turned out to be 'dodgy'. It seems this concern about culpability pulls Martin to be more abrupt and direct with his point of view, which can be seen in the use of the words 'dump him, he's bad'. Here Martin constructs his previous approach as weak by using the phrase 'airy fairy, fluffy'. Martin's use of the phrase 'thrown it back at me' constructs Arthur's action in the meeting as deliberate, suggesting he has intentionally misrepresented him. Again, I got the sense here that Martin was speaking from an emotional state of anxiety and anger at being put in a position of responsibility for Arthur's decision, a position he does not wish to be in. This is interesting in terms of the 3 Is, because the model suggests all parties should be 'Involved' and 'Influential', which allows for

professionals to contribute their views to decisions as long as this is shared with other parties. Perhaps Martin's frustration comes from the insinuation that Arthur is basing his view entirely on Martin's opinion, rather than as part of a collaborative process. These extracts capture some of the challenges of SDM. Arthur puts Martin in a position where he could make a decision for him, which would go against the principles of SDM. However, Martin's seeming discomfort with this then draws him into a position of neutrality, which also reduces the opportunity for SDM.

I also wondered how my presence both at the initial meeting and then in the interview might have influenced Martin's behaviour in relation to this. I wondered if he objected more because of a sense of having to defend or explain his behaviour to another clinician, and whether his embarrassment or irritation at being 'exposed' by Arthur contributed to the reaction we see here. This exchange between Martin and Arthur gives us a helpful insight into these processes in mental health teams where staff are working in high stress environments and managing challenging situations related to risk (in this case, exploitation). I wondered if Martin here responds to his discomfort in the reflective interview by favouring a position of increased direction. Does this suggest clinicians might be more forceful with their opinions if they worry that by not being explicit, they may be responsible for any adverse outcomes? Understandably, this is a difficult balance to strike, particularly at a time when empowerment and client-centred care are prominent in current service values and policy. This seems to link to an ideological dilemma (explored further below) in terms of offering a professional opinion, and supporting service-users but also being aware of the importance of self-determination.

#### Lydia, Sally and Barbara

Compared to the other clinicians in the sample, Sally seemed more willing to be direct in expressing an opinion. In the extract below, Lydia, Sally and Barbara discuss the hours that Lydia was working prior to the most recent experience of psychosis. Lydia's use of the rhetorical device of detail builds a more vivid picture of the narrative, and presents her account as 'reliable' and 'accurate' (Potter, 1996).

Lydia:

so the hours they give me was a Monday, 11 while 5; Tuesday, 2 while 6 **[Sally: mm-huh]** Wednesday, 9 while 5; Thursday, I have off **[Sally: okay]** Friday, 10.30 till 7 **[Sally: Good lord!]** and Saturday, 11 while 8 **[Sally: Good lord!]** and then alternate Saturday's, 9 while 6. So 2 alternate Saturdays there **[Sally: that's too much]** umm, so because I was finishing on the 7pm and 8pm **[Sally: mm]** I was really vulnerable because I didn't want to go into city centre late at night waiting for a bus **[Sally: yeah. And winter-time it's dark as well, isn't it]** I just didn't like that idea **[Sally: yeah]** so I didn't say anything. I accepted the

hours **[Sally: okay]** umm, but what [care worker] did, he put in place er, taxis er, through finance [...] **[Sally: to get you home safely]** [...]

Sally:

[...] how do you feel about the hours as a whole? Cause I'd look at that and think, that's a lot [Barbara: it is a lot] [Lydia: it is. It is] that's more hours than me and Barbara nearly put together, d'you know what I mean? That's a lot of hours [Lydia: yeah] and a lot of hours can equal a bit more stress or a bit too much stress [Lydia: yeah] and that's, that's what we're trying to keep to a minimum, isn't it?

Sally makes use of emotive language during this exchange. Repetition of 'Good Lord!' communicates shock and implies the current hours are excessive, seemingly to indicate this timetable is untenable. Sally uses statements to add to the narrative ('it's dark as well isn't it; to get you home safely'), which contribute to the on-going construction of Sally as understanding and positioned alongside Lydia. I argue this means that when Sally then makes a comment about the situation (e.g. in the second utterance when the phrase 'a lot' is used repeatedly in reference to the hours), she is able to do so from a position of advocacy. Sally uses her and Barbara's experience to emphasise the unreasonableness of Lydia's work schedule ('that's more hours than me and Barbara put together'), which normalises Lydia's struggle to maintain this. This is interesting because the total constitutes standard full time hours, but here Sally constructs this as excessive. Sally implies going back to work could make Lydia 'unwell' by drawing on the construction of psychosis as linked to stress. This seems to be used as a threat or warning, used to persuade Lydia that reinstating her previous hours would be risky.

#### **Reflective Interview Data**

Sally spoke about her approach to sharing opinions in the reflective interview:

Sally:

I think it's about being honest, I think it's giving it back to people, isn't it? And saying, 'Okay, here are the facts, stress, makes you unwell' [Interviewer: yeah] the stress seems to be triggered off by your work. This has happened several times now since I've known you and probably before then. What are you gonna do? What are you gonna do? These are the options that you've got. So what are you gonna do? [...] I think it's about being very open and honest with people and saying, you know, 'I've done this a long time. I see what happens when people with your illness go back to work too soon. You put that pressure on yourself. You're going back to full time hours and . . . ' you know that's crazy...

Sally here uses the rhetorical device of 'making evidence speak for itself' (Gilbert & Mulkay, 1984) by saying 'here are the facts'. This allows her to minimise her role in identifying a link between stress and 'illness', presenting this argument as self-

evident. Although questions often represent a way of seeking to involve someone in a conversation, in this case I interpreted these as challenging, with an associated implication that Lydia should heed Sally's advice. Sally uses her experience ('I've done this a long time') working with others ('I see what happens when people with your illness go back to work too soon') to validate her perspective and legitimise her opinion, although again I would argue this also has the quality of a threat or warning: If you do not follow my advice, something bad will happen.

There is little acknowledgment here that it might be helpful to validate or understand the function of Lydia's desire to go back to work, rather it is constructed as incomprehensible and 'crazy'. In terms of SDM, this brings the process of deliberation to a halt because Lydia's actions are defined as invalid. Further, the fact that Sally's views are constructed as valuable due to her experience allows her to occupy a position of 'Influence' that is not available to Lydia. Although Sally says 'its about giving it back' to Lydia, the rest of this utterance constructs her as expert and knowledgeable, which contradicts this assertion. Again, I wondered about the impact of my presence and the research context here; it could be that Sally is emphasising her experience to explain and justify her approach to me as another clinician.

# 3.5.3 Responsibility and autonomy

Another notable feature of the talk across the data was the action of allocating responsibility for decision-making. It seems that clinicians are caught between competing aims of wanting to empower service-users to take charge of their own lives, whilst also holding a sense of responsibility to offer support and direction. This also arguably reflects the wider legal framework in that clinicians (especially those in the role of Responsible Clinician) are held accountable if something goes wrong. This leads to an ideological dilemma, which is illustrated in clinicians talk through the competing actions of offering guidance vs. encouraging independent volition.

#### Adam, Natalie, John and Kirsty

The extract below relates to the decision about occupational activity, and captures the movement between these two positions. The rhetorical device of pronoun switching illustrates how responsibility is allocated at different points in the dialogue:

John: Like I say, we can show you what's there...but there's something...

Adam: It's up to me at the end of the day

John: Yeah it is...not in a, in a 'it's all down to you loads of pressure way' but

in a, somehow, you've got to, there is something really important in finding a way of test-, you know, allowing yourself to test it out, giving

something a bit of a try...often it snowballs [Adam: Yeah (pause)] [...] But perhaps if we give you the list of all the options and you have a think about it? [Adam: yeah] And maybe one of the things to over the next few weeks is to set a really clear aim of right this is, I'm going to go here, this is the place I'm going to start, I'm going to try and make that one work, first, and then take it from there [Adam: yeah, OK]

John's use of a disclaimer (Hewitt & Stokes, 1975) pre-empts Adam's interpretation of the previous utterance as 'pressurising' and exemplifies the alternative construction of encouraging Adam whilst also giving him power and promoting self-efficacy. There is evidence here of John being 'Informed', 'Involved' and 'Influential'; he again expresses his view that an activity would benefit Adam and speaks in the first person to model how Adam might approach this. Although Adam agrees with an affirmative 'yeah' a number of times, he does not expand. This means the conversation reaches an impasse. As outlined in previous reflective extracts, John is wary of being too prescriptive, and we see this constructed through his tentativeness in the use of qualifies such as 'perhaps; a bit; maybe'. Without moving into use of command or instruction, there is nothing further John can do to facilitate SDM.

# Reflective Interview Data

In his interview, John talked at length about the dilemma he faces in terms of giving Adam choice and autonomy whilst also offering support and fulfilling his role and responsibilities as a mental health professional:

John:

It's a bit of a tight rope actually; and that [...] 'It's all down to me' I remember feeling anxious with that because [...] it's one of the big complaints about mental health services [...] often people walk out feeling um, dismissed or rejected, saying [...] 'This is, this is down to you. You've got to fix it. You've got to sort it out'. Cause that isn't, that isn't really what we're saying. But it's a strange one cause [...] we can't do it without him. He hasn't got to do it on his own. So [...] there's got to be something that comes from him. But not, 'It's all down to you'

John's use of the 'tight rope' metaphor constructs this balance between support and autonomy as delicate and precarious. John uses active voicing (Wooffitt, 1992) and a hypothesised quote from those who might feel 'dismissed or rejected' by services to explain his anxiety when Adam says 'it's all down to me'. This implies John understands his role as a position of care and responsibility, such that he notices an emotional response when this is questioned or threatened. John's acknowledgment of wider context demonstrates how other factors are likely to impact on the talk between

professionals and service-users. I reflected here that John seems to capture the central tenet of the 3 Is model; both parties in an exchange have to be 'Involved' and 'Influential' in order for decision-making to be collaboratively enacted. In a context where there is little input from one party, the opportunities for effective sharing are limited.

# Lydia, Sally and Barbara

In my reflections, I noted that Sally's talk perhaps seems more directive compared to other clinicians in the sample. I wondered if this acts as a barrier to sharing in a different way, because it makes her more comfortable being instructive, and less inclined to take steps to maximise Lydia's involvement and influence in the process. The extract below comes towards the end of the meeting, when the group discuss Lydia's next move in terms of her employer:

Sally: [...] When does your sick note run out Lydia? [Lydia: 13th of March]

[...] Okay. Have a think over the next two weeks. Don't rush into anything [...] [Lydia: mm] They're calling all the shots at the moment, and they've done a very terrible job of supporting ya as I can see over the last few years [Lydia: yeah] So if you're going to have to go back it's going to have to work this time cause this is really last chance saloon isn't it [Lydia: mm] for them [Lydia: yeah] yeah. Finances aside, realistically this is your health, no job is worth that [Lydia: I know. I know] is it? [...] So for the next two weeks have a think. If at the end of the two weeks on the 13th you don't feel ready, then we get

another sick note for another month

Lydia: I said that to [Barbara] that's what I intended to do

Sally: [...] but before you go back, promise me that you and [care worker] will

have an occupational health meeting with your manager [Lydia: mm] and sit down and say this is what we propose [Lydia: yeah] and I want

it setting up before you even step back [Lydia: mm]

Barbara: Before you even think about it [Sally: absolutely Barbara, you're

right. Yeah. Definitely] [Lydia: yeah]

In this extract, Sally's talk has the quality of demand at times with a number of statements and instructions (e.g. 'Think about what you want from them; 'promise me'; 'I want it setting up before you even step back'). This arguably represents an example of Sally being 'Influential' in that she explicitly uses her opinion to try and affect Lydia's behaviour. By contrast, Lydia's contributions are minimal, and thus the level of sharing is limited.

This extract also draws on a battle repertoire, which allows Sally and Barbara to be positioned as fighting for Lydia on her behalf. So far the employer has been 'calling all the shots' and Sally seeks to re-align power with Lydia and the team.

Constructing the employer as unsupportive by saying 'they've done a very terrible job' also legitimises the decision to challenge them. Use of pronoun 'we' positions Sally and Barbara alongside Lydia, united against the employer. Sally constructs this decision as important by using the phrase 'last chance saloon'. This implies the situation is serious and has connotations of finality, which are perhaps used to persuade Lydia to follow previous instructions (i.e. not to be pressured back into work, to make a list, to be firm with the employers). Sally twice uses the 'confirmation-expecting tag-question 'isn't it?' (Antaki, Young & Finlay, 2002) to elicit Lydia's agreement with her point of view. Sally also uses Lydia's health as another way of warning her by flagging up what the consequences might be if she does not do as they had previously agreed. In terms of SDM, it seems that Sally and Barbara use rhetorical devices to influence Lydia. Their use of instructions allows a concrete plan to emerge, thereby arguably facilitating decision-making, although I was uncertain whether this could be considered 'shared'.

# Reflective Interview Data

Sally paused the video after this exchange and made this comment:

Sally:

cause it's like we're trying to empower people where we make decisions together [...] but then you're creating some sort of hierarchy because I'm disempowering you by saying I don't think you should do this. So it's very difficult getting those dynamics right [...] You don't spend three years training, then studying, then doing god-knows what, nearly 15 years of nursing without being able to say to people: I can tell you this won't work..I can tell you, you do this, this will happen [Interviewer: yeah] and that's not me disempowering you. That's telling you through my experience [...]

Sally again draws on her experience here, citing the length of time she has been practicing as a nurse to justify and legitimise her approach in telling people what she thinks they should or should not do. A three-part list (Jefferson, 1990) including the phrase 'god knows what' adds to the scope of Sally's experience, implying this is extensive. There seems to be a broader question here about whether categorically saying 'I don't think you should do this' is disempowering. I would argue that Sally's talk is organised in such a way to construct her use of instructions or directions as supportive and validating and allow her to position herself alongside Lydia. However, I also wonder if Sally's confidence and certainty here makes it difficult for Lydia to disagree, or shuts down different understandings, which therefore makes it difficult for a shared decision to be made.

Having said that, it seems important to consider this independent of the construction of SDM as something that is always positive and desirable for service-

users. After watching this part of the recording in the reflective interview with Lydia, she commented on her experience of Sally's approach as helpful:

Lydia: That were helpful because [...] I'd have done what I did last year: just go

back to work again[...] that-that's what I would've done umm, because I

had no option..

Interviewer: [...]so what do they [CMHT staff] bring do you think?

Lydia: er, more options. More...more paths to go down, you know it's not just

straight there and you've got to get back into this workplace; you've got

to be doing this, you've got to be doing that

Earlier in the interview, Lydia had spoken at length about how financial pressure meant she went back to work quickly after her last contact with mental health services. Here we see that Sally's strong view perhaps gives Lydia a voice to express her needs in a way she is unable to do herself. Interestingly, whilst this manner does not epitomise the philosophy of SDM, it seems it allowed Lydia to feel like she had more choice.

The meeting ends with Sally explaining what she will do following the meeting:

Sally: what I'll do, I'll fill in the referral form for [employment support]

[Lydia: yeah] and then as soon as you give me the green light, I'll pop it in the post then [Lydia: yeah] cause [...] I'm very aware that teams get a bit full and I don't want it to get to the point where, 'Oh crikey, they need ya and they're not accepting referrals for another month' [Lydia: yeah] so I'll just do it [Lydia: yeah] as soon as you give me the nod

[Lydia: yeah] in the post it goes [Lydia: right]

Although there is some evidence of Sally seeking to involve Lydia here, we still see Sally occupying a position of 'Influence' through use of statements of intent, which I argue make it hard for Lydia to disagree, or for true sharing to occur. Sally uses information about the capacity of the organisation to try and persuade Lydia to give her the 'green light' quickly. This again has the quality of warning; if we do not do this soon the opportunity might disappear.

One of my main reflections on the exchanges in this data set was that Sally seems keen to construct herself as an advocate for Lydia. We see that throughout the extracts in terms of her expressed shock and outrage on her behalf and use of compliments and use of instructions, seemingly aimed to protect Lydia's best interests and to give her confidence in asserting her needs. However, in terms of SDM, this also seems to have the effect of limiting some of the opportunities for meaningful sharing. By constructing her role as an advocate or crusader for Lydia, it seems Sally justifies

her use of instruction and command, which limits Lydia's opportunities for meaningful involvement or influence. Taken with Lydia's reflections, this highlights some of the ethical complexities of SDM and the need for a flexible approach to decision-making that accounts for what clinicians know about the specific needs and wishes of service-users. In this case, Sally's approach arguably encourages and allows Lydia to be assertive with her employer. However, I wondered if this also prevented Lydia contributing to a decision, even if it might have been one that Sally would have perceived as unwise.

# 3.5.4 Directing and re-directing conversation

Another key feature of the talk in relation to SDM was the action of directing or redirecting conversation.

#### **Martin and Arthur**

During the meeting between Martin and Arthur, Arthur would sometimes start talking about something seemingly unrelated to the current topic, and I often wondered how this might relate to Arthur's unusual experiences. In his reflective interview Arthur spoke of his experience of 'jumbled thoughts', and right at the start of the recorded meeting he also mentioned this pattern:

Arthur:

when you're talking to me I tend to pick up on some of what you said [Martin: ah-hah] but and then vanish off the conversation huh! [Martin right, okay] and then off the planet! I tend to do that!

Here Arthur suggests he is aware his mind can wander. The words 'off the planet' emphasise the extent of Arthur's wandering, such that he ends up completely disconnected from the other speaker in the conversation. This could represent a barrier to SDM, because it has the potential to make it difficult for both parties to retain a shared understanding of issue and to explore options, risks and benefits in a mutually coherent way.

#### Reflective Interview Data

Martin spoke about his broader use of the strategy of redirection in the reflective interview at a point in the meeting where Arthur had started to talk in detail about going to a local deli for a salad:

Martin:

Erm, yeah, so I was thinking 'I've got this visit to do, I've got that visit to do, so that's always in the back of my mind, with every visit [Interviewer: yeah, yeah] There's 'where am I going next?' or 'I'm

going home from here and I've got my paperwork to do [...]

[Interviewer: So what do you do then, usually?] I suppose I usually

try to bring him back on track [Interviewer: yeah, yeah] And think about the question I asked originally [...] obviously if he starts talking about something related to his mental health, how he's thinking, or something directly related, well then yeah, I'll let him talk, but if he's talking about the price of fish in the local supermarket [chuckles]...

This part of the interview helps us understand the topics Martin considers important or relevant and how the wider context might influence his behaviour. Martin uses the rhetorical device 'making evidence speak for itself' (Gilbert & Mulkay, 1984) by using the word 'obviously' to imply that 'mental health' and 'how he's thinking' are important areas to let Arthur talk about. Use of the first person-pronoun in "I'll let him talk' positions Martin in control of the dialogue, which is arguably less consistent with the ideas of SDM in terms of both parties being involved in establishing what is up for discussion. This links back to idea of service expectations, which areas are considered important to discuss, what professionals feel they are expected to do and how this manifests in their talk.

An example of the action of directing the conversation comes when Martin and Arthur discuss the clothes he purchased whilst experiencing psychosis just prior to his last admission. This is introduced by Martin and comes after a discussion about Arthur's last CPA review; in the previous utterance Arthur was still talking about his view of his inpatient consultant.

Martin:

I suppose sort of one thing. I know we talked about it before and I know that this is a big thing for you as well Arthur is the clothes that you bought from back in June. My suggestion was to return them but you weren't that keen to do that. Again, I was thinking of trying to get your money back but I know it's maybe not as straightforward as that. [...] The things, the issues that we talked about, you know. Do you want me to kind of pursue that? [Arthur shaking head] You don't? You don't want me to pursue that? Is there anything you want me to do? Is there anything that you can do around that. ..[Arthur: no, I think um ... I think... I think... no um ...] I know ...

Arthur:

[looking at care plan document, mumbling] the bit about goals down here ...and enabling and optimisation the best use of his time [Martin: right. Yeah. I-I sup-that's . . .] but that's . . . [Martin:I wasn't, when I wrote that I wasn't thinking of the clothes situation] no, I . . . [Martin: it's whether you want to keep those clothes] I think . . .

Martin:

whether you want to return them. And I can understand the reasons you gave for keeping them. I can understand that. I didn't see that before. It didn't click what you said [Arthur: we're a bit across each other here] Yeah. You know the clothes that you bought. You know don't want to return them [Arthur: I'm about to go onto another subject altogether! [chuckles, looks directly at camera]] It's all right. I know it's, yeah. It's okay. If you don't want to talk about it now [Arthur] that's fine. Shall we leave it? [Arthur: It, it, it's a very deep

subject] It is. And this is why I want to make sure that if you want help with that that you're seeing the right people. I'm not sure if I'm the right person. It's not my, it's not something I deal with on a regular basis. So that alone I'd want you to get the right help from the right service. Which the Trust does have, does have that service, you know that type of service [...] [Arthur: it's a very deep subject] It is. It is. [Arthur: it goes back 72 years] I imagine, yes [Arthur: it's been ongoing for 72 years]. Yeah. Again, I want to stress that you've got, you know the choice there, the option. So if you want to talk about it with me again. If you want to talk to Sheryl about it [[...] Arthur: it's a difficult one. Umm] Well you know something to think about isn't it? Something to think about. As you say it's been around for a long time so it's not going to go away, is it?! Like that. So..

In response to Martin introducing the 'issue' of the clothes and whether Arthur might want to return these, he shakes his head, smirking slightly. I wondered if it was difficult for Martin to know exactly what this was communicating, which prompted a number of clarifying questions. Arthur seemingly attempts to redirect the conversation to stop Martin asking him questions about this. For example, Arthur looks at the care plan document he's holding and tries a number of times to continue talking about what is written there. This creates a barrier to SDM because a shared understanding of the issue is not reached. Martin initially seems persistent in coming back to the topic of the clothes, even when Arthur is trying to use his talk to change the subject, before eventually responding to Arthur's cues.

At this point in the meeting, Arthur is looking at the floor and I noticed myself feeling uncomfortable and having thoughts like 'I don't think I should be here for this'. Arthur glanced at the camera during this exchange, which represented the only time he does so during the meeting, and I wondered if this was reflective of his discomfort. Arthur stops making eye contact with Martin and his voice is soft and quiet. This is in contrast with other parts of the recording, where Arthur seems more jovial and upbeat, making consistent eye contact with Martin, chuckling and smiling frequently. Martin responds to this by also softening his voice. When he says 'it's alright, I know, it's OK' he constructs himself as understanding, and uses this utterance to reassure and comfort Arthur. Again, Martin and Arthur's established relationship plays a role here; this is something they have discussed previously, and as such Martin knows it might be difficult for Arthur to talk about, or precipitate feelings of shame and sadness. Arthur's use of the word 'deep' constructs this issue as something serious and hidden, and perhaps suggests behaviour of dressing in women's clothes is something he finds embarrassing.

Martin then moves away from the emotional discomfort back into the practicalities and logistics of the situation, saying he wants to make sure Arthur has access to the best support. I wondered if this reflected Martin's awareness of Arthur's discomfort in front of the camera, and a desire to relieve him of this. I also wondered if Martin here seeks to justify his previous insistence on continuing with this topic of conversation using phrases like 'this is why...'.

In the end, Martin uses the phrase 'it's not going to go away is it?' and this is said in a lighter tone of voice. This arguably represents another example of the action of 'directing' the conversation, but seems to be used here to acknowledge this is something they can come back to another time. Martin seems to be responsive to Arthur's body language and communication of current emotion, recognising it is a difficult subject and thus giving them permission to move on. It is not possible to achieve a shared decision here, but arguably the choice to bring the topic into conversation initially was not shared, and Arthur's embarrassment combined with my presence perhaps prevent him being Involved in the same way Martin can be. However, Arthur arguably shares some of his experience non-verbally through body language and the acknowledgment this is a deep and complex issue for him.

#### Reflective interview Data

In the subsequent interview, Martin reflected on this part of the meeting:

Martin:

[...] Yeah I didn't want to embarrass him, I was just very aware of the camera[...] Now that's something I'm wishing I hadn't have brought up **[Interviewer: ok, ok]** but, you know, it came up the week before, so you know, it's going to, it's not going to go away, **[Interviewer: okay]** [...] maybe it was wrong of me to sort of, bring it up, but, you know it, because it wouldn't have come up if I hadn't sort of, mentioned it

Here Martin recognised that this part of the conversation precipitated feelings of discomfort for Arthur, and acknowledged that he was largely responsible for directing the dialogue towards this subject. Martin uses the fact that this 'came up the week before' to explain and justify his decision to raise it with Arthur. This highlights the importance of consistency in clinical relationships in the pursuit of SDM; as we see here, this is a subject that has come up before, and will likely be discussed again. The consistency between clinician and service-user seems important in allowing these issues to be revisited in a way that allows the decision-making process to progress, particularly if these topics are difficult or create feelings of shame and embarrassment for the service-user. It also highlights the importance of being considerate of these feelings, and allowing service-users to have some choice and

control in terms of when and how these are raised. Indeed it is interesting here that Arthur had no say in terms of whether the issue was addressed in the first place, particularly thinking about the research context and my presence.

# Lydia, Sally and Barbara

In relation to the talk between Sally, Lydia and Barbara, we also see this action of directing or steering conversation. In the extract below, Lydia is telling Sally and Barbara about an incident at work that happened several years ago.

Lydia:

[...] and me manager, huh! I'll never forget this. I said, 'Oh, I've found out what were wrong with me on Saturday.' I said, 'I'd had a miscarriage.' He said, 'Oh, I thought it was something like that.' Now what a thing to say to me **[Sally: mm]** 'I thought it were something like that.' In't that awful? **[Sally: yeah]** and that's what I say, it's so real, you know the feelings that I had are so real. They still hurt **[Sally: mm, of course they do]** and err...

Sally:

but that's great that you suddenly decided that was something you needed to work through [Lydia: mmm] and then because carrying that around is no good for any of us, is it? [Lydia: no, that's what I say] [...] but that's positive stuff. There's so many things that you do to try and keep yourself well, you know Mrs! [Lydia: mm. do you think so?] God, yeah! Get you a new job! [Lydia: a new job would be great! Yeah, that'd be great. I love to help people]. [...] well you so wanted to do that counselling, didn't you [Lydia: I did] let's see if we can find a way into that somehow [...] where's there's a will there's a way. I'm a massive firm believer of that, do you know what I mean? [Lydia: yeah] it might not be, it might take us time [Lydia: yeah] but I reckon the more people we get on board with this, the more we'll find a way in . . . [Lydia: yeah]

Lydia uses the rhetorical device of active voicing (Woofitt, 1992) by quoting her previous manager directly to enhance the vividness of the description of the event. We then see Sally trying to pull Lydia away from the distressing memory of this incident. During the meeting, Lydia described her mood as low, and this seems to make it hard for her to move beyond depressive rumination. Being off work seems to exacerbate this in that Lydia spends lots of time at home going over the past. In the extract above, Lydia repeats the quote from her manager 'I thought it were something like that' using repetition to emphasise how 'awful' this was and constructing the manager as malicious and Lydia as mistreated. A confirmation-expecting tag question (Antaki, Young & Finlay, 2002) ('in't that awful?) is used to elicit agreement and from Sally and Barbara, to extract their shared outrage and validate Lydia's position as the wronged party. Sally responds by validating Lydia's emotional response, but then seems to try and reframe the scenario as something Lydia did that was positive. Sally's utterance 'carrying that around is no good for any of us is it?' had the quality of a

rhetorical question (even though Lydia does reply) and implies it is self-evident that one should not hold onto difficult or painful experiences. This justifies Sally moving the conversation on to a different topic.

Sally uses maximisation for emphasis, saying there are 'so many things you do to try and keep yourself well'. She seems to be using this strategy to buoy Lydia up in response to feelings of being 'hurt' and invalidated by the manager in the story she's just told. Use of the moniker 'Mrs' is jovial and affectionate, which suggests familiarity between Sally and Lydia. Sally draws on the rhetorical device of 'boosters' (e.g. 'God, yeah'). This device is often used in an argument when a speaker's views might conflict with another person (Talbot, 2010), and seems to be used here to counteract Lydia's self-doubt. Taken together, these discursive devices seem to represent a strategy to diffuse Lydia's rumination and to allow Sally to redirect the conversation towards a concrete goal: getting Lydia a new job. I found this quite hard to think about in terms of SDM. In some ways, Sally occupies a greater position of 'Influence' in this exchange in terms of the flow of the conversation. However, redirecting the conversation away from rumination about past events seems to enable Lydia to identify a different type of job that she might like to do. Arguably, this allows her to be 'Informed' and 'Involved' by discussing this with Sally and Barbara, which would be consistent with SDM.

In my reflections, I noted several points in this meeting where I wondered if Lydia was seeking an opportunity to explore her thoughts and feelings, or attempting to elicit sympathy or understanding, but the clinicians often redirected her towards tangible plans or outcomes. In the extract above, I was very aware that Lydia had just talked about her experience of a miscarriage, and within moments Sally is joking. Sally also uses a number of clichés here (where there's a will there's a way; I'm a firm believer in that'), which I experienced as a bit superficial. The way Sally says 'Get you a new job' implies this is simple and constructs this as the solution to Lydia's problem, which arguably does not account for the complexity associated with her sense of self, experiences of work and other people over time, which Lydia is trying to share with them. I wondered if this might be experienced as dismissive, even if Lydia's actions in terms of recounting work-related anecdotes and seeking validation also inhibit a process of SDM.

#### Reflective Interview Data

In the subsequent interview, Sally spoke of Lydia's apparent focus on events from the past related to work:

Sally: this is the thing, it's this pre-occupation with it. She's so

absorbed in it. [...] but what-what's feeding that? [Interviewer: yeah] what is feeding – why do you need to know all that [...]

It's very peculiar [Interviewer: yeah] very peculiar

Interviewer: and what's that like when you're in a situation like this or in a

meeting like this?

Sally: Frustrating! [Interviewer: yeah] because you've only so much

time and there's so much stuff you need to cover [...] I need to talk about medication; I need to know she's safe; I need to know she's getting on with her family and that's all okay. Work is just a small slice. A small bite of what I've got to cover in my head with her whilst I'm there. So when you've got somebody who's very hell-bent on just keeping it all in one, in one camp, it's

really difficult [...]

This part of Sally's interview reminded me of Martin's reflections above. Sally uses three-part list (Jefferson, 1990) as a way to explain her frustration with Lydia, because her focus on work means there is less time for these other things. Here Sally also 'makes the evidence speak for itself' (Gilbert & Mulkay, 1984) implying it is obvious these other areas must be covered in the meeting. This again shows how clinicians' sense of their agenda, time-pressure and other caseload commitments might impact on their feelings in meetings, and how this might lead to redirection of conversation, or pushing a certain topic more forcefully. The use of first-person pronouns positions Sally in control of the dialogue, and precludes SDM because it constructs the agenda as being dictated by the things Sally needs to cover, rather than what Lydia chooses.

Here Sally again describes Lydia's focus on the past as 'peculiar', which has connotations of oddness and implies it is neither logical nor understandable. Again this justifies and explains her frustration, because it is not something she can understand. This seemingly priorities Sally's conceptualisation of the focus on past events as strange, rather than it being something that makes sense to Lydia, but that Sally has not yet understood. It also justifies her attempts to change the conversation, because it suggests there is no benefit to exploring this further: it's incomprehensible. The phrase 'hell-bent' implies determination, suggesting Lydia works hard to keep the conversation focused on previous negative experiences, to the exasperation of Sally. Arguably, this disconnect between Lydia's apparent fixation on this topic and Sally's lack of understanding of the function of this precludes development of a shared understanding and co-operation. Sally went on to reflect more on her behaviour in the meeting:

Sally: I can see from my body language I'm getting frustrated as well.

I'm playing with my pen and I'm, you know . . . I'm restless. It's like I need this to move on now [...]I'm very aware of time [...] you can't just keep going round on this wheel. It's really

unhealthy for her

Interviewer: so what do you think that makes you more likely to do or say?

Sally: I suppose it's trying to find a way of moving it on again [...] I

always like to have something to be doing [...] Do you know

what I mean? I always have a bit of a plan

In terms of SDM, Sally's awareness of time pressure and proclivity for having a 'bit of a plan' means she implements strategies to facilitate this in the conversation. Again, first-person pronouns construct the meeting as being driven by Sally's needs; the implication is that Lydia is obstructive for not allowing these 'plans' to be made by talking about other things. Sally suggests 'going round on this wheel' is 'unhealthy' for Lydia, again using this to justify her attempts to stop Lydia talking about work. This implies Sally is doing this for Lydia's benefit, but we do not know how Lydia experiences this. I would argue this means the process of SDM gets stuck because Sally feels under pressure to address certain topics, and Lydia seems to seek to use the meetings to seek validation or an empathic response, which again halts or interrupts decision-making.

# 3.5.5 Agreement and disagreement

Another feature of the talk across data sets is the action of agreeing or disagreeing, either explicitly or through the use of other rhetorical devices. This seemed to be more prominent in the talk of service-user participants.

# **3.5.5.1 Agreement**

# Adam, Natalie, John and Kirsty

The extract below comes during the discussion about Adam getting support in relation to gambling and addiction. Here John uses the strategy of 'drawing on other's experience' to persuade Adam to engage with such a service, with a suggestion of dire consequences if he chooses not to.

John:

[...] for someone to make that choice ....they're, they're taking a risk with the people around them...the risk is something really quite destructive, you're risking, you know, I know it sounds...but you're risking conflict in relationships, and you know you see people even in relationship breakdowns in the end because of these kind of patterns... I'm not saying that's what's happen-, that't where you're-, but I see...I can see the danger...and you see it repeating ...

Adam: yeah, yeah I know where you're coming from..[long pause]

Adam seemingly agrees with John a number of times during this extract, saying 'yeah' and making affirmative sounds. The utterance 'I know where you're coming from' is a statement, rather than expression of intention, and the subsequent pause draws John into talking more, into further trying to convince or persuade Adam (John's subsequent utterance was another lengthy one with further rationale for involving addiction services). Adam makes a single statement during this to say 'yeah, I'll think about it'. This seems to have the effect of postponing the decision because John does not want to dictate or be prescriptive and Adam is not forthcoming with a subsequent expression of intention or commitment; he is able to refuse without being explicit. This could arguably represent an example of Adam influencing the outcome because it prevents the conversation progressing any further and means a decision is not made. This is different to the conversation about medication, where Adam expressing a preference seems to facilitate the decision-making process. This also enables Adam to maintain some power in relation to postponing; by agreeing with John, he constructs himself as 'engaged', but lack of any further expression of volition or intent means that a concrete decision is not made which contributes to a position of passive resistance. As such, this passive agreement acts as a barrier to SDM.

In his reflective interview, Adam commented on his tendency to agree and related this to an eagerness to please, to come across to John and Kirsty as motivated. This was not my experience of Adam in the meeting; rather I was struck by his flat tone of voice, and one of my reflections was that some of his statements felt a bit empty; I got the impression he would not be 'thinking about it', and I wondered if Adam was just saying what he thought he should say to 'get through' the meeting. My interpretation of the data was then influenced by the reflective interview.

# Reflective Interview Data

Here Adam talked about his use of agreement in meetings with clinicians in terms of impression management:

Adam:

they talk to me about this before and it's summat I won't do at all and I just, like I say, I just agree with 'em [...] [Interviewer: okay] y-eah, yeah, just cause [...] I want to sound as though not-not just sound but I want to try to come across as though you know I'm.. I want to do whatever it take to get me well.

Adam's interview helps us understand why there was a difficulty reaching decisions about occupational activity and gambling services in the meeting. Adam's sense of what will help him is different to John and Kirsty's, and in addition Adam is keen to present himself as motivated even though he is aware this will not translate into action. In the extract below, John talks about his desire for the content of the meeting, and things that are agreed to reflect genuine intent on Adam's part:

John:

I think I am conscious that anything that's too prescriptive, I think he just won't do it or he'll just be agreeing with me and leave[...] and he'll write it down and we've got a plan and it's sorted, but actually it's not. So to try and get away from that [...]it's strange I'd rather they left with nothing, if they're not, if it's not a real commitment to anything. I'd rather we end, 'Well actually we haven't got to where we need to get to yet.' That's okay.

This shows awareness on John's part of the strategies that Adam might employ (i.e. agreeing in the moment but not following through later, being passively compliant). John acknowledges the importance of Adam sharing his views with the team (i.e. being Involved and Influential); without this, there are limits to a meaningful shared decision being made. It is not the action of agreeing on a decision that is important, rather the intent to follow through later.

In his reflective interview, Adam also said his lack of input was not related to avoidance, but rather embarrassment. These comments came after the discussion about occupational activities, although I got the sense that Adam was speaking of his experience of formal meetings more broadly. Consistent with DA, it was important to think about this in terms of the active and constructive nature of talk. I wondered if this could be seen as a discursive strategy, in that Adam used feelings of embarrassment and fear of coming across as stupid to explain and justify his lack of input in the meeting.

Adam: I-I find sometimes it a bit over-whelming, you know the meeting and

stuff like that, yeah . . . especially when they start, when-when he starts going on about all these medical terms and using all these big words

and stuff like that...

Interviewer: and how do you think that impacts on what you might say?

Adam: I think I don't, I don't say as much cause I... feel sometimes a bit

embarrassed to say things cause I might sound a bit stupid, if you know

what I mean

Ultimately, this again represents a barrier to SDM; Adam cannot be Informed, Involved or Influential because he is unable to share his thoughts, feelings and

experience with the team and responds to his discomfort by retreating and taking a passively compliant or ambivalent position. In my reflections, I noted John did speak a lot in the meeting, and his utterances tended to be long. As with all talk, this seemed to be a dyadic phenomenon in that Adam's lack of responses appeared to draw John into talking more. Whilst I did not notice particularly long words or jargon, I did wonder whether Adam's current cognitive capacity in the context of his experience of psychosis and psychiatric medication might have made it difficult for him to follow at times. As we see here, he then interprets this as evidence of his own stupidity.

## Lydia, Sally and Barbara

In the extract below, Lydia likewise uses agreement in response to Sally's proposition that it might be helpful to refer her to a workplace support organisation.

Sally:

that could open a whole world of stuff for you there [Lydia: mm, yeah-yeah]...what do you think? [Lydia: yeah-yeah. I'll try ought] I don't think we have too many people involved [Lydia: no, no, no] rather too many than not enough [Lydia: that's right. Yeah]

As we saw with Adam, Lydia uses affirmations, thereby implying she is on board with Sally's suggestion. She also uses repetition, which constructs her agreement as more emphatic. As with data set 1, my interpretation of this part of the data was influenced by the subsequent reflective interview with support worker, Barbara.

#### Reflective Interview Data

During the interview with Barbara, she stopped the tape at this point and talked about her experience of working with Lydia, and sense that Lydia often uses this strategy, but that it does not always indicate true intent:

Barbara: she is just agreeing, isn't she? 'Yeah, we'll do that'...but then.. [...] Sally

will have another meeting with her... it'll be the same again

Interviewer: [...] so what that [...] like to work with?

Barbara: I suppose it's quite hard. It's quite frustrating in some ways when

you're . . . you're wanting to support someone and you can see the answer in a way [...] you know cause this is what you could do, you know... but Lydia's just not getting it, is she? She's just not . . . she's

agreeing but she's not taking it in...

As with John's interview, the discussion with Barbara highlights that SDM relies on truthful sharing of opinions and intentions, and how violation of this can lead to frustration for clinicians. As such, passive or non-meaningful agreement can get in the way of an SDM process because it prevents an accurate shared understanding being developed. As with Adam, Lydia presumably uses agreement because she is keen to

construct herself as engaged with intervention suggestions, but Barbara predicts that this agreement will not have translated into action the next time Lydia meets with the team. This also speaks to some of the broader moral and ethical challenges for clinicians in navigating situations where it seems service-users are making choices that they might perceive as unwise. In this scenario, Barbara was speaking in relation to Lydia's commitment to return to the same employer, despite the distress associated with that job.

## 3.5.5.2 Disagreement

#### **Arthur and Martin**

In the talk between Arthur and Martin, we see how the strategy of disagreement plays out in the talk about housing, and the consequent impact on SDM. The extract below comes at a point when Martin is outlining some potential advantages of moving to a different location:

Martin: [...] you'd be nearer to [unit1] and you'll also be nearer to

[organisation] okay, the homecare provider

Arthur: I don't particularly want to live in [area] but

Martin: oh no, there's choices, there's options. This is it. It doesn't have to be

[area] no, it doesn't have to be ...

Here, Arthur's disagreement allows other options to be considered and explored, unlike in the previous scenario with Adam, where (passive) agreement prevents the conversation developing. Martin goes on to say 'there's choices, there's options'. Here he steps back in order to avoid making the decision for Arthur, or having undue influence. Repetition of 'it doesn't have to be' emphasises this denouncement of the previous suggestion and constructs Martin as open and responsive, positioning him alongside Arthur in terms of this decision. This seems to represent a good example of both parties being 'Informed', 'Involved' and 'Influential'. Martin makes a suggestion (Informed), Arthur disagrees (Involved) and Martin adapts his approach (Involved) according to this (Influential). There were other examples of Arthur disagreeing with Martin in the meeting, which likewise allowed options to be discounted (e.g. residential care). Overall, this seemed to facilitate SDM. By contrast, although Adam spoke of his disagreement with some of the views or suggestions of John and Kirsty in the reflective interview, difficult emotions prevented him from actively disagreeing in the meeting in a way that might have opened up an opportunity for discussion of other ideas. This points to the broader issue of service-users being able to disagree with

clinicians, and highlights how this is perhaps an important part of SDM. Potential barriers to disagreement including issues of power and education are implicated in the findings here, and will be addressed further in the discussion.

# 3.6 Summary

The meetings recorded as part of the study involved decisions relating to issues such as work, housing, medication and vocational pursuits. The analysis highlighted a number of service-user and clinician discursive actions, which impacted on the process and outcome of SDM in different ways. Ultimately, only the decision about medication between Adam, Natalie, John and Kirsty had a concrete shared outcome. All the other decisions were left with an understanding that more discussion would be required at a later date.

There were differences in the way service-users and staff expressed opinions, which seemed to relate to a broader ideological dilemma about how staff can offer knowledge based on their experience, whilst also encouraging independent choice. For John, this was evident in utterances that distanced him from a direct opinion or recommendation, whilst Martin actively retreated from an opinion at times when Arthur disagreed with him, or implied that he had especially influenced him. For Martin and Arthur, particularly in relation to the decision about housing, this seemed to result in exploration of a number of different options, and Martin's frequent use of questions combined with Arthur's expression of his point of view contributed to the enactment of SDM by allowing them both to be 'Informed', 'Involved' and 'Influential'. Conversely, Adam's passive agreement in relation to the decisions about vocational pursuits and addiction services acted as a barrier to SDM by preventing the conversation moving on from discussion to planning or commitment to a course of action.

In contrast to other clinicians, Sally used more statements and instructions, drawing from her experience as a nurse to justify this when reflecting on the recording in the subsequent interview. This put her in a position of increased 'Influence', and limited the amount of meaningful sharing in the data, because it constructed her opinion as valuable, and implied Lydia should follow her recommendations.

Rhetorical Devices associated with the action of directing and redirecting conversation allowed staff members in particular to keep the conversations focused on topics deemed most relevant to the context of the meeting. Again, this also often put them in a position of 'Influence' and control in relation to the unfolding dialogue, such

that even when decisions themselves were more consistent with the philosophy of SDM, clinicians largely dictated the content of the conversation. The following chapter moves into exploration of issues raised by the analysis of this data, and how the findings from this study fit in the wider context of existing literature.

# **Chapter 4: Discussion**

In this chapter, I will discuss the findings of this project in the context of wider SDM and other relevant literature. I will consider both the strengths and limitations of the study, and end with some thoughts about the potential clinical implications and directions for future research. Additional extracts from the meetings and reflective interviews are included in this chapter where they help illustrate the points made. As before, excerpts of the reflective interviews are presented in boxes to distinguish them from the primary data.

# 4.1 How much sharing was there?

Given that the focus of this research was how decisions are made collaboratively in clinical practice between clinicians and service-users with experience of psychosis, it seemed relevant to start the discussion with an exploration of the evidence of sharing across the data, using existing models of SDM to situate the findings from the current study. In general, the process of sharing was shaped by micro-level linguistic devices (e.g. how opinions were expressed), but also by broader systemic influences (e.g. the current service context). It seemed consistently hard to conclude discussions with a decision, and this was often affected by both service-user and clinician actions.

#### Data Set 1: John, Kirsty, Adam and Natalie

In the talk here, a collaborative process was affected by Adam's limited participation. According to the reflective interview, Adam underestimated the value of his contribution and expressed an expectation of paternalism because of his experience in other health service settings. Combined with John and Kirsty's desire to avoid a prescriptive or paternalistic approach, this made SDM difficult to achieve. Adam's passive agreement meant his view was often not heard, which limited the 'two-way exchange of information' considered essential for sharing to occur (Charles et al., 1999) and prevented him fully 'Informing' John and Kirsty about his experience of psychosis or his sharing views about some of their suggestions. It also seemed to prevent a deliberation process (Charles et al., 1999; Elwyn et al., 2012) and limited opportunities for him to be 'Involved' or 'Influential' (Stacey et al., 2015). However, the findings indicated this was different across decisions. In terms of medication, there was a clearer process of deliberation, and evidence of choice and option talk (Elwyn et

al., 2012) between the speakers. John presented possibilities for stopping the medication now or later, and spoke of the potential risks of dependence associated with on-going use. This was more consistent with the process of SDM outlined in the literature. However, as discussed in the results chapter, this choice was made in the context of the overall decision to stop this medication, which had already been determined by John.

#### Data Set 2: Arthur and Martin

In talk between Arthur and Martin, there were also examples of SDM consistent with existing models. I argued these largely manifest in the discursive actions of sharing opinions, Arthur's use of disagreement and Martin's strategy of re-directing conversation. Consistent with the findings from data set 1, SDM between Arthur and Martin was also seemingly dynamic, in that the dialogue was constructed differently across decisions in the meeting. For example, the discussion about housing options included two-way sharing of information, and discussion of different options including the pros and cons of particular locations. An example of this can be seen in the dialogue below:

Arthur: [area] is what I call tidy...but rough

Martin: I suppose like any, any sort of city, you know [area], has its good points

or has its bad points; but . . .

Arthur: let's just say that round here's the opposite

Martin: yeah, it's more affluent round here isn't it? And I suppose it's what you

feel comfortable with, Arthur...

The talk about the external support worker was different. In this instance, Martin constructed his position as neutral, which arguably reduced the level of SDM in relation to this decision. This part of the talk is more consistent with an 'informed' model of decision-making (Charles et al., 1999) in that Arthur was expected to make the final choice independently. Martin offered some input in terms of deliberation, (e.g. acknowledging that Arthur has known Stuart a long time, acknowledging that the CMHT support worker cannot take Arthur to the certain places), but repeated use of the phrase 'I'll leave that choice up to you' ultimately constructed the decision as belonging to Arthur and as a decision that Martin either cannot or will not buy into.

Charles et al. (1999) suggested a need for clinician movement between approaches depending on the needs of a particular service-user or clinical situation. The findings here highlight that this might not always be solely influenced by service-user needs, but that ideological dilemmas and clinician factors will impact on fluctuations in level of involvement and influence. Martin's reflective interview

suggested objection to being misrepresented and concern about being responsible for any negative outcomes influenced his talk in this part of the meeting. This points to the importance of clinicians being aware of strong responses to particular decision-making conversations, in order to reflect on how such emotions might impact on willingness to offer input.

# Data Set 3: Sally, Barbara and Lydia

Data set three again looked different in terms of the SDM. The actions of sharing an opinion and directing and redirecting conversation allowed Sally to occupy a position of Influence throughout the meeting. Lydia's tendency to talk at length about difficult work experiences precipitated more of this redirection from Sally, in line with her sense of her professional role and particular topics to cover. Whilst there was some evidence of two-way information exchange in that Lydia also shared some of her experiences, there was little consistent opportunity for her to articulate her values or preferences to the team. Sally's construction of a return to work as untenable and emphasis on the link between stress and psychosis meant Lydia was often put in a position of compliance, which limited an opportunity to put all the options on the table and collaboratively weigh up the pros and cons of each. Sally's reflective interview supported this, in that she spoke of her sense that her role and experience afforded her an expert position from which she can say 'I know what happens when people with your illness go back to work too soon'. This position of 'knowledgeable and expert other' is arguably more consistent with a paternalistic model, and acts as a barrier to option talk, or a process of deliberation.

# **4.1.1 Summary**

Existing SDM models can be used to situate the findings from this research and to support the argument for the presence or absence of SDM in the data. The findings from this study go beyond these models in highlighting the complexity of talk in mental health services and the inconsistency in SDM across decisions. The data here also captures the discursive manifestation of the dilemmas faced by clinicians in terms of enacting these principles within a legal framework that allocates responsibility for risk outcomes to them. Theoretical models are helpful in offering an indication of the different composite stages of SDM and directions for training and implementation. However, there is also a potential to oversimplify the SDM process. This study allowed us to see more explicitly what the concepts of deliberation, option talk, information exchange, influence, involvement might actually look like in practice including the way participants use their talk and the impact it has on SDM. In addition to this, the study makes a unique contribution to the literature by offering some reflection on the

challenges of implementing these principles in complex clinical consultations, along with some potential ways of 'doing' SDM in such settings (e.g. through considered sharing of opinions, awareness of issues of power and maintaining flexibility in terms of strategy implementation depending on service-user needs and experiences). It also highlights the impact of cognitive and affective processes of service-users and clinicians, and how participants' sense of their roles contributes to position and action.

# 4.2 Do all decisions qualify for 'sharing?'

One of the questions raised by the data was whether all decisions are available for 'sharing'. Existing research in mental health services has found that clinicians see certain decisions as more suitable for 'sharing' than others (Seale et al., 2006; Hamann et al., 2009; Las Cuevas et al., 2012; Shepherd et al., 2014). This is apparent in the results of this study, in that 'sharing' in relation to medication is constructed differently to other decision topics. For example, in data set two the discursive strategies used by Martin did not provide opportunity for Arthur to be involved in the way he was during other parts of the meeting. When medication is discussed, Martin says:

Martin:

I can't stress enough Arthur, for you to keep on top of your tablets. Yeah? That's kind of one of the most important things I can say to you, is keep taking your tablets.

Charles et al. (1999) said that 'for a shared model to work, both physicians and patients have to perceive that there are treatment choices. Otherwise, there is nothing to decide' (p656). It seems there is nothing to negotiate or review here; this utterance arguably represents an instruction for Arthur to comply with his prescription. This contrasts with other parts of the meeting, where Martin's talk creates more obvious opportunities for Arthur to be Involved and Influential (Stacey et al., 2015). It also contrasts with the way Martin uses utterances like 'there's choices, there's options' in relation to housing options, the support worker and gender services. This again highlights that SDM practice is not static, and varies within individuals depending on their sense of their role in relation to particular decisions. Here for example, it seems the way Martin constructs his role as a mental health professional means he is more directive in relation to medication compared to other topics. This difference also likely affects the way service-users make sense of their contributions to decision-making and times when they may experience their opinion as more or less valued.

This builds on the findings from a large questionnaire study by Hamann et al. (2009). In a sample of 352 psychiatrists, respondents considered certain decisions appropriate for 'sharing' (including work, housing, psychotherapy) whereas prescription of medication was seen as solely the clinicians' domain. We saw this in the current study in relation to John's talk about medication during his reflective interview:

# Reflective Interview Data:

John: All prescribing decisions have to be made by the doctors[...] there is a

responsibility to deal with that aspect of that care, manage it. Err, so it is part of our role [...] you-other people, we could all talk about occupational routines [...] but the part of my role is to sort out

medication.

Consistent with data set 2, the way John talks here contrasts with the rest of the reflective interview, where he talks about the need to avoid being prescriptive and draw Adam into making some decisions for himself. John uses the rhetorical device of making the evidence speak for itself (Gilbert & Mulkay, 1984) by presenting his role in 'managing' medication as self-evident and unquestionable. This speaks to the implication that service-users can be more influential in decisions about ways of living life, but not medication. Indeed, although there is evidence of SDM in terms of the decision about medication between John and Adam, this happens in the context of an assumption that the overarching decision (that it has to be stopped in the first place) has already been made by John. There was further evidence of this when Adam spoke about his experience in hospital, attributing all the decision-making about his medication doses to the clinicians:

Adam: It was down to 10 when I went in, when I was admitted, then they put it up to 15, then they put it up to 20..so [nodding].

This seems to relate to the broader medical discourses around mental health, which enable clinicians to be more direct when discussing medication and maintains the view that these decisions are outside the realm of collaboration (Morrison, Hutton, Shiers & Turkington, 2012).

# 4.3 Are there differences between mental health and physical health SDM?

One of my most consistent reflections whilst undertaking this project related to the apparent differences in SDM across physical and mental health settings (Austin, Mohottige, Sudore, Smith & Hanson, 2015).

#### 4.3.1 Medical vs. life decisions

Curtis et al. (2010) said: "Decisions in a mental health context are frequently complex, reoccurring, and embedded in day-to-day lifestyle choices rather than one-time crossroads decisions" (p18). This makes it difficult to transfer ideas from physical health (e.g. linear models, decision-aids) to mental health services, because decisions here are likely to be nuanced and related to idiosyncratic values-based outcomes. This was apparent in the types of decisions in this study. We saw Arthur and Martin consider options for the best place for Arthur to live and ongoing issues relating to gender identity. Sally, Lydia and Barbara thought about when and how Lydia might go back to work, and John, Kirsty, Adam and Natalie discussed how Adam might helpfully reconnect with an occupational routine following loss of his job and experience of loss of role within the family.

This is in contrast to the medical decisions that feature in SDM research from physical health settings. These often include choices about surgical options in relation to cancer treatment or obstetrics, medication for management of conditions across cardiology, endocrinology and urology. Drawing from a physical health model, 'option talk' involves clinicians listing all the available options and describing risks and benefits (Elwyn et al., 2012). For medical decisions, a range of tangible options is available, and the clinician can present the evidence-base for different treatments and potential outcomes and side effects, which allows for a dialogue about values, preferences and impact on quality of life. Although the decision may be difficult, and the effect on an individual's life might be extensive, the process itself seems relatively simple.

This is different from the decisions in this data, in that outcomes figures are not available for the complex life decisions in mental health services. This makes the existing models, particularly those developed in physical health settings, difficult to apply. For example, Elwyn et al. (2012) suggested it is important for clinicians to be clear with service-users about potential risks and benefits of all potential interventions. For many physical health interventions, the outcomes can be clearly measured (e.g. cancer being in remission, change in size of tumour). By contrast, in

mental health settings the process is again more complex. For example, Martin cannot give Arthur concrete statistics about the likely potential physical or psychological health outcomes of the decision to live in a particular location. Furthermore, service-users and clinicians might have different ideas about the outcomes that are important, and it could be harder to measure these for certain life decisions (e.g. clinicians may focus on symptom reduction whilst service-users might prioritise social engagement).

# 4.3.2 Different discourses of psychosis

Another difference is the impact of different ways of understanding psychosis on SDM. Coulter and Collins (2011) emphasised that SDM involves a shared understanding of a problem between service-users and clinicians. Arguably, it is easier to reach a shared understanding for a physical health diagnosis; whilst different people might hold competing ideas about why they might be experiencing a physical health condition (e.g. bad luck, fate, penance), the understanding of the physical cause is easier to delineate (e.g. cancer cells can be identified by scan). Conversely, there continue to be competing explanatory frameworks for the experience of psychosis, which we saw in different constructions across the data. Despite a number of theories about biological contributions, there remains no marker for psychosis, such that the organic manifestation of this 'disease' cannot be identified or seen in the same way as a tumour, or a blood test highlighting problematic glucose level. Alternative conceptualisations are beginning to accumulate more interest and evidence (e.g. spiritual crisis; experience of trauma), but understandings can differ between serviceusers and professionals. This was evident in data set 1 for example, where Adam and Natalie drew from a biological explanatory model to understand Adam's difficulties with gambling and lack of motivation, whilst John and Kirsty formulated this using a psychosocial framework.

These different discourses of psychosis might also influence how clinicians see their role in terms of collaborating with service users about certain decisions (e.g. as above; medication vs. life decisions). For example, the discourse of 'psychosis as illness' might mean that wider social decisions are not seen as the remit of clinical staff in the same way as medication decisions. This was apparent in John's willingness to leave Adam and Kirsty to think independently about occupational pursuits and gambling services, whilst the decision about medication needed a tangible outcome. On the other hand, the narrative of 'psychosis as a response to stress' means staff can be involved across all decisions, because these lifestyle choices are linked to the chance of 'relapse'. Another example is the way Sally constructs her role and influence in relation to Lydia's decision about going back to work. The discourse of psychosis as dangerous

or risky and associated legal responsibility puts further emphasis on the role of the clinician influencing all decisions constructed as likely to contribute to the perpetuation of psychosis.

Again, this is different to physical health settings, where clinicians and service-users can be clearer about their roles. It is unlikely one would expect their GP to discuss housing options in the context of a consultation about diabetes, for example, and we do not see the same competing explanatory frameworks for physical health conditions. Ultimately, these differences make existing models and conceptualisations of SDM difficult to apply in mental health settings, and different decisions might require different rules and principles.

# 4.3.3 Experience of psychosis

As outlined at length in the introduction, Chan and Mak (2006) wrote about the metacognitive and verbal capacities needed for SDM, which can be compromised for those with experience of psychosis (Covington et al., 2005). Consistent with this, Arthur made reference to his experience of 'jumbled thoughts' and how this impacted on his ability to engage with the initial meeting without 'vanishing off the conversation [...] and then off the planet'. Arthur spoke more about this experience in the reflective interview.

# **Reflective Interview Data:**

Arthur: I'm finding it a bit difficult to concentrate [...] I tend to drift off a

bit![...]although the um, the screen is in front of me, somehow I'm

shutting off

Indeed, the various stages of the Elwyn et al. (2012) model all relate to different forms of talk (option, deliberation, decision), but difficulties with expressive language might make it harder for those with experience of psychosis to engage in two-way sharing of information or a process of deliberation. Other difficulties for those with experiences of psychosis include changes to attention processes, executive functioning and working memory (Lee & Park, 2005; Reichenberg & Harvey, 2007). Causation remains unknown and the debate rages on as to whether psychosis can be related to the experience of trauma, medication side effects, anxiety, or all of the above. This again makes it difficult to apply SDM models developed in physical health settings where there is an assumption that service-users will have the cognitive skill to engage in this process. The meeting with Arthur and the reflective interview shows this is a struggle for him. Sally also described challenges associated with verbal interaction with Lydia, and the difficulty interrupting when she was heavily focused on a particular anecdote. In her reflective interview, Lydia likewise commented on her

'tendency to ramble on and lose me-self'. This posed a challenge to SDM because it made it difficult to follow a conversation through to a conclusion without deviating to other stories or memories. Whilst the 3 Is model was developed specifically for mental health service settings, it does not account for how the experiences associated with psychosis might impact on how people can be Informed, Involved and Influential. Intrusive thoughts, experience of voices, suspiciousness and difficulties with volition and motivation might make it hard for people to share their experience or perspective. Whilst all these experiences were not evident in the data here, Hamann et al. (2006) found 'negative symptoms' were often a significant barrier to SDM, and one could argue this might have contributed to the passivity that we saw from Adam.

In terms of how clinicians might navigate these issues in clinical practice, it seems important to account for verbal and cognitive capacity across consultations. Indeed, Adam spoke of his experience of John's speech as overwhelming at times, and it seems there is something important about clinicians being mindful of their use of language in a way that maximises the opportunity for understanding and engagement. This is consistent with the literature I read at the start of the study which pointed to the importance of limiting the length of interviews with people with experience of psychosis, speaking in a concise way and being willing to repeat or rephrase statements to facilitate communication (McCann & Clark, 2005; Cowan et al., 2012). It also seem particularly relevant given that the findings here indicate that service-users might find it difficult to express disagreement or identify times they do not understand something due to feelings of stupidity or embarrassment.

# 4.4 How does power impact on SDM?

It would be difficult to explore collaboration and service-user involvement in decision-making without noticing how the continuing imbalance of power between service users and mental health staff across Western models of service provision affect SDM (Kaminskiy, 2015; Chamberlin, 2005; Murtagh, 2009). One can think of this in terms of structural and organisational components (e.g. MHA) and enduring powerful discourses (e.g. psychosis as illness; 'doctor knows best'). This holds importance in light of the ongoing developing literature base, which has consistently found that service-users involved with mental health services value opportunities for self-determination (Adams & Drake, 2006; Deegan & Drake, 2006; 2008; Drake, Deegan & Rapp, 2010;) and that this has been found to be key in service-user narratives around recovery (Deegan & Drake, 2006).

We see these broader issues enacted at a micro-level in some of the data captured in this study. For example, despite John's efforts to construct his talk as non-prescriptive, Adam later described his sense of feeling pushed or pressured to do certain things. Adam used feelings of embarrassment to explain his lack of input in the meeting, and identified this emotional experience as a barrier to increased contribution. Even though John spoke about trying to involve Adam, it might be that there are some systemic factors and discourses that make this challenging.

## **Reflective Interview Data:**

Adam: I feel um ... ahh, what's the word I'm looking for? You know I'm-I'm-I'm

kind of like, I'm not very educated, if you know what I mean  $[\ldots]$  so I feel sometimes a bit embarrassed to say things cause I might sound a bit

stupid, if you know what I mean

Here Adam implies his level of education is related to the importance of his contributions. He also implies that this lack of education is likely to mean his contributions could 'sound a bit stupid'. This highlights the importance of clinicians attending to these power imbalances across clinical consultations. This might be especially important in relation to what cannot be said. Even though the data highlighted a number of strategies John used to involve Adam and to increase his influence, to avoid being too prescriptive, these internal factors (Adam's embarrassment) and power and status of clinicians affect his silence and lack of confidence in contributing to the conversation.

Woltmann and Whitely (2010) similarly found that when service-users disagreed with case managers' opinions, they deferred to them because of a belief that the professionals' views would be better. We see this in the extract below from Adam's reflective interview:

#### Reflective Interview Data:

Adam: [...] It's kind of like I feel it-it's the same as when the um . . . [tuts] when

 $\dots$  the  $\dots$  the tablets. Every tablet I take, the less I feel more myself  $[\dots]$  and-and the more stuff that they try to push onto me, th-the less I feel

in control of my-my own life kind of

Interviewer: right. Gosh that sounds really hard [Adam: yeah. Yeah!] I mean do

you feel you're able to say anything like that or ...

Adam: no, not really. I just kind of [...]because I . . . the-they're trying to help

and I'm trying to . . . motivate myself to do stuff that they want me to do; cause obviously, you know it must, you know they're the

professionals, it must so I, I take their word for it, you know and ...

Here Adam uses category entitlement (Potter, 1996) to validate John and Kirsty's view by virtue of their status as 'professionals'. It is as if Adam is unable to

legitimise his own thoughts and feelings (i.e. feeling less like himself, less in control), because the status of professionals trumps this: they must know best and thus he should ignore his own response and 'do as they say'. This remains true even though it is 'stuff they want me to do', rather than what Adam wants to do.

This part of the findings suggests demographic imbalances might impact on what different speakers contribute to decision-making. This is consistent with other research which found perceptions of power imbalance and differences in socioeconomic status affected how service-users behaved in clinical consultations (Protheroe, Brooke, Chew-Graham, Gardner & Rogers, 2013; Joseph-Williams et al., 2014). For example, we know that service-users with less education and from poorer backgrounds typically opt for more passive roles in decision-making (Murray et al., 2007; Say et al., 2006). It is interesting to apply these findings to the data here. Martin told me Arthur is highly educated and from an affluent background, and we see him most actively involved in the decision-making process. By contrast, Adam's social circumstances were quite different, and his involvement was less active, and he also reflected on a preference for paternalism in the reflective interview (see extract in results chapter, p66).

Having said that, I recognise that in the analysis chapter, I proposed that Adam's use of the discursive action of agreement sometimes created an impasse in terms of the decision-making process, which potentially gives him some power. Kaminskiy (2015) refers to this as 'false compliance' and suggests the experience of being treated under the MHA without consent encourages greater passivity. She suggests it prevents the construction of decision-making as a shared endeavour, and engenders thoughtless agreement because service-users do not perceive they have power to meaningfully contribute or change an outcome. We arguably see this with Adam. Whilst one could say that some of his talk prevents decisions being made and therefore represents a form of power, it seems important to think about the dyadic nature. This power occurs in a group where the clinician (John) seeks to avoid occupying a paternalistic position. Had the other speaker in this scenario been more commanding or paternalistic, one imagines the passivity would have become compliance. This implies a need for clinicians to be mindful of how their behaviour and status influences decision-making, even in more subtle or hidden ways. It seems important for clinicians to consider whether there is evidence of passive agreement in discussions with service-users, and seek to actively explore or clarify values and preferences at these times. This relates to the findings from data sets 1 and 3, where there was a sense that service-user agreement would be unlikely to translate into

action. It is also relevant when considered alongside clinicians reflections on the 'checklist' of items they carry in their heads to cover in any given encounter; one can see the potential appeal of passive agreement because it might allow them to move onto the next item on the list.

Ultimately, previous research has acknowledged the impact of power on SDM in terms of clinicians' expert position and the impact of social factors like education and social class. The findings here add a further dimension, by highlighting that even when clinicians try to address these issues and allow service-users to be Involved and Influential, invisible power imbalances can make it challenging for service-users' to value their input and see their voice as important. This is surely compounded by the earlier discussion of powerful discourses in relation to service-users with experience of psychosis, in that the constructions of risk, illness and irrationality allow and indeed encourage clinicians to be more influential and in control. This highlights a need for clinicians to pay particular attention to the potential for the framework of meetings and status of clinicians to elicit feelings of embarrassment or inadequacy, and to actively encourage service-user participation at these times.

#### 4.4.1 Who controls the content?

Masterson and Owen (2006) explored Lukes' (1986) work on power in relation to service-user empowerment in mental health services. Lukes proposed three dimensions or 'faces' of power. The first 'face' relates to power that is enacted overtly, which might be apparent in political agenda or policy. The second and third 'faces' relate to more covert or hidden ways that power is exercised. In relation to mental health, this might include things like clinician control over items included on an agenda, which then determines what topics are constructed as relevant. We saw this in the current study in that clinicians were largely responsible for introducing discussion topics, and all spoke of an internal 'checklist' of areas to cover. John is explicit about this with Adam in the initial meeting, saying: "We kind of have a checklist in our heads of things that are important"

This constructs the clinicians as 'expert', and legitimises the action of directing and redirecting the conversation to maintain focus on topics they deem important. This was apparent in Martin's reflective interview (see results chapter, p73), where he implied that areas outside Arthur's mental health or thought processes may not be labelled as 'directly related' and thus such conversation would be halted. This limits service-user opportunities to be Influential in the dialogue, because the clinician uses

their understanding of important topics to determine whether to permit the serviceuser to speak. Sally also spoke of this:

# **Reflective Interview Data**

Sally: You know I go and, right, I need to talk about medication; I need to

know she's safe; I need to know she's getting on with her family and that's all okay. Work is just a small slice. A small bite of what I've got to

cover in my head with her whilst I'm there.

As in data set 2, use of first-person pronouns positions the clinician in control of the topics, such that the agenda is about what Sally needs to cover, rather than what Lydia chooses to talk about. This part of the data highlights another difference between physical and mental health SDM in terms of the legal framework and clinicians' responsibility for managing risk. Ultimately, if service-users led on topics of conversation, there might be areas that are not discussed. Whilst this might be more congruent with their personal values, it could mean some topics that clinicians are legally accountable for do not get covered.

The literature around differences in staff and service-user perspectives on priorities for care planning seemed useful in understanding this further. Studies have found differences in areas identified as most important: professionals and service providers focus on symptom reduction, whereas service-users prioritise social, housing and financial issues (Shepherd, 1995; Crane-Ross, Roth & Lauber, 2000; Fischer, Shumway & Owen, 2002; Klein et al., 2007; Byrne, Davies & Morrison, 2010; Moritz, Berna, Jaeger, Westermann & Nagel, 2016). Interestingly, the findings in this study suggest that these areas can sometimes be understood as closely linked. For example, social and housing issues were constructed as important for maintaining remission of unusual experiences (i.e. symptom reduction). Examples from the results section include Arthur's query about whether 'another stay of time here will throw me back in hospital' and Sally's assertion that 'if you go back to work too soon, you might start to relapse'. This justifies clinicians' interest and influence in these decisions, because of the implication that these life choices relate to the chance of a service-user becoming 'unwell' again.

#### 4.5 External influences on SDM

Another issue that emerged from the results was the impact of current service pressures across all aspects of service provision. Previous research has highlighted that time-constraints are the most frequently cited barrier to SDM (Legare et al., 2008), and Sally spoke about this in her reflective interview (see results chapter, p79). The

following quote comes later in the reflective interview, but both speak to external pressures that might influence SDM:

# **Reflective Interview Data**

Sally: we haven't got time in this game. As soon as I've finished working with

her I've got a hundred people waiting to come onto my caseload. So I

have to keep moving [...]

A qualitative study by Bee, Brooks, Fraser & Lovell (2015) looked at mental health staff perspectives on collaboration in care planning. They found the focus on risk management, crisis situations, increasing workload pressures and target-driven paperwork requirements made it difficult to establish the sort of relationship required for meaningful service-user involvement.

Bee, Price, Baker & Lovell (2015) conducted a synthesis of studies looking at barriers and facilitators of meaningful involvement in care planning and SDM and found differences between staff and service-user conceptualisations. Staff saw SDM as a linear process with a number of tangible outcomes, whereas service-users focused on the relational aspects of the exchange, in particular being listened to and heard. Grundy et al., (2016) likewise found that service-users perceived that their involvement could only happen within a relationship where there was trust and communication. This discrepancy between staff and service-users is consistent with the reflections of Sally above, and perhaps helps us understand why she leans towards conceptualising Lydia's focus on the past and work as 'peculiar', because it allows her to justify moving on to other things:

#### Reflective Interview Data

Sally: I feel it's part of the illness, because she gets such a bee in her bonnet

and it's so, it's like she can't think outside of anything else...it's all about  $% \left\{ 1,2,...,2,...\right\}$ 

that [...] it's really unhealthy for her.

As such, the findings from this study suggest that external factors can have a significant impact on the SDM process. This seems important to consider in terms of the changing landscape of service provision, cuts to funding for mental health services and increases in caseload numbers which add pressure to the clinical encounter and provide less opportunity for service-users to have space to explore views, and develop a closer alliance with clinician. One recommendation emerging from the findings of this study would therefore be for clinicians to notice when a meeting might be more likely to involve decision-making, and to plan this into their diaries with enough time to allow for a process of deliberation. For example, it might be useful not to allocate this for a day when there's a particularly high number of other visits, or when other demands are imminent (e.g. particular paperwork being due).

# 4.6 Strengths and limitations

# 4.6.1 Recruitment procedure and sampling

As with all research, the choices I made at each stage of the study design will have influenced what was found, and how this can be applied to other settings and populations. Consistent with ethical approval, I was reliant on staff from the CMHT to identify service-users who might be willing to participate in the study, which likely influenced those who were approached. It might have been that staff gave the study information to people who were considered more stable in presentation, or with whom they had better relationships. Having said that, a number of service-users with more intense experiences of psychosis were also approached, and a couple initially showed some interest in the study before either explicitly informing me of their decision to withdraw, or not attending at the time agreed for recording.

Some staff were more interested in the study than others, and I suspect those who were reluctant to participate, or wary of having their practice recorded might not have introduced the study to service-users. I am aware that the staff that participated in the study are likely to be those who did not have concerns about their ability to enact SDM with service-users. There may also have been some reinforcing elements in that service-users typically nominated the staff that introduced the study to them.

The service I was recruiting from also went through a significant period of restructure and transformation during the time I was conducting the project. Discussions with the clinical leads highlighted how this might have impacted on research endeavours across the service, with staff being unsettled and under increased pressure, which reduced appetite for additional demands (e.g. participating in research).

I am also aware that some of the experiences that contribute to the challenges with implementing SDM in this population (e.g. unusual beliefs, suspiciousness and paranoia) could also have precluded participation. There was no evidence of suspiciousness of me or the nature of the project during data collection, and I did not see any evidence of this in the meetings recorded. Whilst this facilitated the process, I was also aware this somewhat limits application of the findings across a broader spectrum of psychosis experience because these characteristics are often such central features of this presentation, and also something that is likely to impact on SDM.

Ultimately, the sample of participants in this study was fairly small. Whilst qualitative research does not aim to produce findings that are widely generalisable to

other populations and settings, I am aware this study offers the experience of only 3 service-users and members of their clinical team from two CMHTs in one particular geographical location. The characteristics of the sample makes it difficult to generalise broadly to other populations. For example, the community-based nature of the sample makes the findings less applicable to acute presentations or inpatient settings.

Time constraints in terms of finishing the project also impacted on the recruitment, and the amount of analysis I was able to do with all the data. I'm aware Brown (2014) encountered similar difficulties given how much data was generated by interviewing all parties involved in the interactions. As such, the bulk of the interaction was with the primary meetings, and I was not able to work with the reflective interview data as comprehensively as I would have liked. I also focused the analysis on times in the meetings when there seemed to be a tangible decision related to on-going care, looking at collaboration and negotiation at these points. In doing so, I was aware that there would be other points in the meeting (e.g. the opening, ending, deciding when next to meet, that were not included). This was again to prevent the amount of data under analysis becoming unwieldy and increased the focus of the analysis, but means other parts of the meeting that might have influenced SDM could have been missed.

### 4.6.2 Video-recording

The use of video recording also represented a relative strength. I believe my interaction with the data was considerably enhanced by watching back video-recordings, considering the impact of embodied actions such as posture, facial expressions and incorporating these into the analysis. The video-recordings were also really helpful in the reflective interviews in bringing the experience to life and allowing participants to remember and reflect on the meeting.

Having said that, the presence of a researcher and video-recording equipment likely impacted on talk in a number of ways, including how service users and staff interacted. This was most obvious in data set one, when Arthur glanced at the camera at a point when it seemed he was feeling embarrassed or uncomfortable. In the reflective interviews, people also commented at times on the peculiarity of the experience of watching themselves on tape. This was something I noted in the first interview, so took more time to discuss with participants in subsequent interviews in terms of how they anticipated they might feel or react, emphasising the option to stop the recording or terminate the interview at any point.

### 4.6.3 Reflective interviews

The inclusion of reflective interviews in the design is also a strength. This was informed by a previous DClinPsy thesis, which looked at opportunities for self-determination in a sample of staff and service users with learning disability and similarly included follow-up interview data (Brown, 2014). This design provides an additional layer of understanding to the primary data, whilst also facilitating further meaningful service-user participation and insight into the experiences of these service-users and staff.

Staff seemed to find it much easier to engage with the process of the reflective interview than service-users. Arthur and Lydia found it difficult to focus on the recording, and moved into discussion of other things, rather than on what was happening in the meeting and their thoughts and feelings about it. I found it hard at times to know how much to try and prompt or intervene, which arguably paralleled the challenges staff identified in the meetings in terms of how and when to redirect service-users towards topics they deemed important. I had read the literature on conducting interviews with service-users with experience of psychosis and remained mindful of considerations in terms of length and the need for more direct questions to support this aspect of the study (Cowan et al., 2012; McCann & Clark, 2005). I was also aware of the fact that the study was looking at SDM and collaboration, and as such I did not want to be too imposing or directive. On reflection, it seems I was perhaps caught in a similar ideological dilemma to the clinicians in the study in balancing my role as a researcher and personal need to access service-user perspectives on the recording with a desire to promote service-user empowerment.

### 4.6.4 Discourse analysis method

As far as I can tell, this is the first study to use a discourse analysis approach to explore SDM in a population of people with experience of psychosis. Employing a DP approach allowed me to look beyond the content of the talk to the discursive features and rhetorical devices used by speakers, and to think about the active purpose of these utterances. It allowed me to think about how service-users and professionals talk in these conversations, and ask questions about what SDM might look like in practice, and the ways participants' talk impacts on this process. For example, I was able to explore how different ways of sharing opinions, expressing agreement or disagreement and actively directing the conversation impacted on decision outcomes. I was also able to then think about the broader social political context and identify some of the powerful discourses apparent in these micro day-to-day interactions. Specifically, this showed how dominant discourses of psychosis manifest in the talk

between clinicians and service-users, and how power imbalances allocate control to different speakers either overtly or implicitly.

Whilst the novelty of the study was considered a strength in some ways, there are also important limitations given that this was the first study of its kind. For example, there was little precedent in terms of how to approach this data. One of the difficulties I had related to the challenge of commenting on SDM across data in relation to existing models and understandings, which often seemed subjective and nuanced. The definitions offered by Stacey et al. (2015) in terms of the 3 Is are broad, and speak to a number of different interpersonal qualities. It was often difficult to know if an utterance was more consistent with a speaker being Involved or Influential, for example.

### 4.7 Reflexivity

It is also important to acknowledge my influence on the project at all stages of design, data collection and analysis. The analysis offered here represents one interpretation of the data, approached through the principles of DP and situated in the context of my life experiences and circumstances and wider social and historical context. In seeking to explore and acknowledge my impact, I made use of regular supervision and kept a reflective journal throughout, which allowed me to note any strong emotional responses I had to the data and think about how these might affect my interpretations (Elliott et al., 1999; Antaki, Billig, Edwards & Potter, 2003). I regularly revisited the methodological principles of DA and moved between the original recordings, transcripts and conclusions to refine, check out my ideas and increase validity.

### 4.8 Future Research

### 4.8.1 Alternative methods

SDM with service-users who experience psychosis in mental health settings remains an area where the research base is still developing. There has been exploration of views and attitudes of different parties, barriers and facilitators and consistent finding that levels of SDM are low. Whilst there have been some larger scale studies in physical health services, (see chapter 1), there remains a need for more research looking at levels of SDM, implementation and impact on outcomes specific to mental health services in the UK (Duncan et al., 2010).

### 4.8.2 Exploring different service settings

Given that this is the first study to employ a DA approach with service-users with experience of psychosis using naturalistic data, there would be value the replicating the study across different locations and services. For example, it would be interesting to use this study design in an inpatient setting to see if decisions are made differently at times when issues of capacity and consent are even more challenging because of the added issue of involuntary detention. One might predict, for example, that we would see more use of instruction and command by staff. It would also be interesting to see whether the types of decisions being shared look different, given that research has found there is even more emphasis on medication in inpatient settings compared to other aspects of care (Hamann et al., 2006).

It would also be helpful to more specifically apply the 3 Is model to different mental health settings, and I have wondered if doing this would allow exploration of some of the issues identified earlier in the chapter. This was not an intended aim of the current study, but rather use of the model in the analysis came later in the process as some of the common features and actions in the talk began to emerge. It would be helpful to see if using this model with service-users and staff could highlight how the principles of 'sharing' can be achieved in situations where capacity might fluctuate. This might give service-users more confidence in, for example, offering an opinion and sharing their experiences, and seeing these as essential and valuable parts of the process. It might also help staff think about the therapeutic value of offering an opinion at different times and in relation to different decisions or when working with different service-users, and help them think about the impact of being more or less emphatic with their views or recommendations.

### 4.8.3 Exploring SDM in talk

In finding a way to make the process of analysis manageable in the context of other factors, this study focused on points in the conversation where 'decision-making' was happening. Matthias, Salyers and Frankel (2013) suggest the whole of a clinical encounter should be examined in consideration of the enactment of SDM. They suggest this is important because certain points (e.g. the opening few minutes, the demeanour of the clinician) are likely to have a significant impact on service-users' subsequent ability to express opinions about proposed interventions or disagree with the clinician, and more broadly how much they are able to participate in SDM. With this in mind, it might be helpful for future studies to look to the wider context of the whole clinical exchange to explore the potential impact on SDM. Interestingly, Matthias et al. (2013) suggest collaboration and sharing should be embedded into the process of agenda-

setting to maximise service-user involvement. This would address some of the points made earlier about how clinicians' constructions of their role impacts on the way topics introduced.

### 4.9 Clinical Implications

### 4.9.1 Awareness of service pressure and impact on SDM

Care co-ordinators particularly spoke of the current pressure associated with high caseloads, and how this made them more likely to move towards strategies of directing and redirecting conversation to 'get through' the meetings and secure outcomes they needed. This highlights the challenge of maximising service-user involvement in care planning at times of increased pressure and reduced resource. The literature on the differences in staff and service-user perspectives on goals for treatment serves to reiterate this dilemma, alongside studies that point to the importance of the therapeutic alliance in facilitating SDM (Klingaman et al., 2015; Grundy et al., 2016). This relationship is arguably something which takes time to develop, whilst non-verbal behaviour (for example Sally's observation of her playing with a pen, and this being linked to frustration) might act as a barrier to this by communicating this restlessness or desire to move on, invalidating what the service-user might be currently saying.

This feels like a crucial point in the context of significant cuts to services. The NHS trust involved in this study is expected to lose £19m from its budget in the period 2014-2018 (Norfolk & Suffolk Mental Health Crisis, 2015) and multiple conversations with frontline staff during the recruitment process for the study revealed a recurring narrative of 'doing more with less'. Ultimately it seems we can try to promote reflective staff and ways to embed ideas about empowerment and collaboration, but clinicians face huge challenges in a system that cannot support this. Small-scale studies like this serve as windows into what this might actually look like on the ground.

This project also highlights the need for refining ways of thinking about SDM, which are applicable to different clinical situations and types of decision. It seems there is an argument for adjusting approach based on needs of the individual, moving away from a 'one-size SDM for all' that is implicated in the models from physical health. Indeed, it could be that mental health services require a different set of models altogether, which is where Stacey et al. (2015) tried to target their efforts. This might help address some of the differences in the types of decisions being made in mental health services. It seems there is an argument for listening to what people want and

need at different times, and being adaptable based on current experiences. For example, offering tangible options might be useful if someone is experiencing lots of intrusions into awareness, lethargy or lack of motivation. This seemed to help Adam be more Involved in the decision about medication, and helped Lydia feel she had more choice in terms of managing her return to work.

### 4.9.2 Use of session recordings to promote reflective practice

All staff commented on the value of watching the recordings of their practice. This is consistent with findings from Brown (2014). Pressures on services can compromise opportunities for supervision and reflection, but these are important ways that we can think about encouraging professional development, which have been found to improve service-user outcomes (Paget, 2001; Gustafsson & Fagerberg, 2001; O'Donovan, 2006). This offers value in terms of increasing awareness; staff said they noticed things in the recordings they had not been aware of, or did not remember. They were sometimes surprised by an utterance, or commented that they would have liked to say something differently. For example, this allowed Sally to notice that her frustration with Lydia had been more apparent than she realised, evidenced by her lack of eye contact and tapping of her pen. Consistent with this, O'Donovan (2006) found reflective practice increased nurses' awareness of their own emotional responses to clinical work in mental health settings.

The use of video-recording seemed helpful in bringing the meeting to life, and as a memory aid for staff, which enabled them to comment on their body language and the organisation and features of their talk. This is captured by the reflection from Martin below, when he commented on the way he started the meeting by saying *'This is your care plan [...] Do you want to go through it with me?'* 

Martin: I'm offering him a question, but it's actually a statement isn't it,

I'm saying you ARE going to go through this with me now..

Interviewer: And what do you make of that?

Martin: That's bad...I didn't give him a choice really did I?

My tone of voice is that 'you are going to go through this with

me now..not saying, or giving him a choice.

Here Martin comments on the active and constructive nature of talk, recognising that the content of his utterance doesn't necessarily reflect a 'truth'. Martin identifies that the use of a question here is a strategy used to inform Arthur what they are going to do in the meeting. This highlights an important learning opportunity for staff. Whilst this typically happens as part of clinical training for clinical psychology, it is not something that is routinely considered in other professions.

Brown (2014) also found staff rarely picked up on positive aspects of their practice or the exchange, and I similarly noticed I felt pulled to validate at times when they were being self-critical. This was apparent with some staff more than others. Whilst this sort of reflective practice largely offers ways to identify areas for improvement, it also offers a way to notice positive aspects of practice, which is something I think I would have emphasised more with staff if I had not been so aware of my role in the process and how my contributions might have influenced later answers or comments. This again seems important at times when morale is low and clinicians' experience is one of ploughing through a huge caseload with little reward.

### 4.9.3 Challenging dominant discourses

Creating a truly meaningful collaborative approach to decision-making arguably requires a greater challenge to long-held assumptions about distress, types of intervention, and the role of mental health services. For example, the Open Dialogue programmes originating in Finland take a collaborative and systemic approach to mental distress, working primarily in service-users' homes and involving all those who can contribute to developing the narrative around an individual's difficulties.

Medication is used sparingly, and largely only for short-term management of acute distress, fitting more with the understanding of psychosis as a psychological response to trauma and distress rather than an illness that necessarily requires on-going treatment with medication (Seikkula & Olsen, 2003; Seikkula et al., 2006). I wondered if part of our role is in drawing attention to these powerful discourses and areas of practice that make SDM difficult in the current model of UK mental health service provision, and thinking with teams about ways to promote collaboration and respect service-users' views and choices, even if we do not agree with them.

### 4.10 Final summary

This project aimed to explore SDM in clinical consultations between service-users with experience of psychosis and mental health professionals. To do this, I recruited service-users and members of their clinical teams from two local CMHTs, and recorded routine meetings involving decisions. Using principles of Discursive Psychology to guide analysis, I found a number of prominent features of talk, which seemed to contribute to collaboration. These included different ways of sharing opinions, directing or redirecting the dialogue, expressing agreement or disagreement and the challenge for staff in terms of promoting choice whilst also fulfilling legal and clinical responsibility. There were differences across the data sets in terms of the

behaviour of staff and service-users. These included the extent to which different speakers involved themselves in a process of information-exchange and deliberation, or occupied positions of influence. The findings from this study were linked to existing models of SDM from physical and mental health literature, and I reflected on some of the differences between the types of decisions being made and how the service context and the experience of psychosis might impact on SDM in practice. Working with the construction of psychosis across the data sets, I also reflected on the enduring power of medical and biological discourses, and the way these, combined with the changing landscape of mental health services makes for a difficult environment in which to enact SDM. I ended with some suggestions about ways to promote SDM in clinical practice, acknowledging that the current socio-political context is a substantial perpetuating factor for paternalism despite policy rhetoric.

Ultimately, although the data gathered here represents a small sample, the meetings and interviews recorded as part of this study highlight some of the key challenges embedding collaborative decision-making in mental health services. I have come to think that perhaps it is not feasible to enact truly patient-centred care across the spectrum of healthcare decision-making when working service-users with complex or severe mental health needs. This is because the system allows and indeed requires professional opinion to trump service-user views across a number of scenarios. It strikes me that dominant discourses of mental distress cannot be reconciled with true service-user choice. As long as the prevailing understanding is that psychosis results in loss of capacity due to illness, there will always be a need for an 'expert' to step in and make decisions. As we saw with Adam, these discourses also make it more likely that service-users will expect a paternalistic model of intervention, which limits their ability or willingness to actively engage in the two-way dialogue that is a prerequisite for SDM.

I have wondered whether there is a need for increased transparency about the fact that there are times when we do not believe that collaboration is feasible or indeed desirable. This could perhaps reduce the dissonance felt by professionals who are trying to fit an approach to decision-making that cannot always be reconciled with the parameters of their role. As highlighted in findings here, for professionals there is a tension between the expectation that they should provide patient-centred care and a sense that they hold responsibility for securing certain specified outcomes (e.g. compliance with medication, generation of a care plan across social and occupational domains), which again makes SDM difficult to enact in practice.

Without this acknowledgment, it seems we end up perpetuating an on-going pretence whereby policy and guidance recommends patient-centred care, but the established framework of clinical practice and legislation does not allow this to happen.

### 4.11 Closing reflections

When I began this project, I had a preconception that SDM would be a fairly straightforward process. Having read the models from the physical health literature, I was surprised that more had not been written in relation to mental health aside from a focus on low levels of implementation and barriers to enacting these principles with service-users with complex difficulties. Conducting this project has drawn my attention to the complexities of SDM, both in terms of the decisions being faced by service-users of CMHTs and clinicians working with them, and in reconciling the principles of collaboration with organisational practices and enduring discourses of mental illness, capacity and risk.

This makes me wonder whether part of the challenge is in cultivating a critical approach to what we do, and encouraging other clinicians to do the same. Reflecting on my own practice, I have become much more aware of collaboration in decision-making in my work. I've often found myself asking whether my conversations with therapy clients would demonstrate 'sharing', and have tried to incorporate more of the ideas from the literature into my practice. I've often been struck by the challenges of doing this, and found myself facing the same dilemma of behaving consistently with the way I understand my role and responsibilities, whilst also being congruent with the values of SDM. I hope this has made me more empathic to the moral and ethical challenges faced by clinicians working in mental health services, which are likely even more challenging in the context of austerity and on-going service cuts.

### References

- Adams, J. R., & Drake, R. E. (2006). Shared decision-making and evidence-based practice. *Community mental health journal*, 42(1), 87-105.
- Adams, J. R., Drake, R. E., & Wolford, G. L. (2007). Shared decision-making preferences of people with severe mental illness. *Psychiatric Services*, *58*(9), 1219-1221.
- Amador, X. F., Flaum, M., Andreasen, N. C., Strauss, D. H., Yale, S. A., Clark, S. C., & Gorman, J. M. (1994). Awareness of illness in schizophrenia and schizoaffective and mood disorders. *Archives of general psychiatry*, *51*(10), 826-836.
- American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th edn.). Washington, DC: APA.
- Antaki, C. Young, N, and Finlay, M. (2002) Shaping clients' answers: departures from neutrality in carestaff interviews with people with a learning disability. *Disability and Society, 17,* 435-455.
- Antaki, C., Billig, M., Edwards, D., & Potter, J. (2003). Discourse analysis means doing analysis: A critique of six analytic shortcomings. *Discourse Analysis Online* [electronic version], 1(1).
- Austin, C. A., Mohottige, D., Sudore, R. L., Smith, A. K., & Hanson, L. C. (2015). Tools to promote shared decision making in serious illness: a systematic review. *JAMA internal medicine*, 175(7), 1213-1221.
- Beavan, V., & Read, J. (2010). Hearing voices and listening to what they say: The importance of voice content in understanding and working with distressing voices. *The Journal of nervous and mental disease*, 198(3), 201-205.
- Bee, P., Brooks, H., Fraser, C., & Lovell, K. (2015). Professional perspectives on service user and carer involvement in mental health care planning: a qualitative study. *International journal of nursing studies*, *52*(12), 1834-1845.
- Bee, P., Price, O., Baker, J., & Lovell, K. (2015). Systematic synthesis of barriers and facilitators to service user-led care planning. *The British Journal of Psychiatry*, 207(2), 104-114.
- Beitinger, R., Kissling, W., & Hamann, J. (2014). Trends and perspectives of shared decision-making in schizophrenia and related disorders. *Current opinion in psychiatry*, 27(3), 222-229
- Bentall, R. (2014). *The social determinants of psychosis*. In Presentation to the 3rd Bergen International Conference on Forensic Psychiatry: Treatment and Management of Psychosis, 17th-19th September.

- Bentall, R. P. (1993). Deconstructing the concept of 'schizophrenia'. *Journal of Mental Health*, 2(3), 223-238.
- Bentall, R. P. (2003). *Madness Explained: Psychosis and Human Nature*. London: Penguin Books Ltd
- Bentall, R. P., & Fernyhough, C. (2008). Social predictors of psychotic experiences: specificity and psychological mechanisms. *Schizophrenia Bulletin*, *34*(6), 1012-1020
- Bentall, R. P., Corcoran, R., Howard, R., Blackwood, N., & Kinderman, P. (2001). Persecutory delusions: a review and theoretical integration. *Clinical psychology review*, *21*(8), 1143-1192.
- Bentall, R. P., Jackson, H. F., & Pilgrim, D. (1988). Abandoning the concept of 'schizophrenia ': Some implications of validity arguments for psychological research into psychotic phenomena. *British journal of clinical psychology*, *27*(4), 303-324.
- Bentall, R. P., Wickham, S., Shevlin, M., & Varese, F. (2012). Do specific early-life adversities lead to specific symptoms of psychosis? A study from the 2007 the Adult Psychiatric Morbidity Survey. *Schizophrenia bulletin*, *38*(4), 734-740.
- Braddock III, C. H., Edwards, K. A., Hasenberg, N. M., Laidley, T. L., & Levinson, W. (1999). Informed decision making in outpatient practice: time to get back to basics. *Jama*, 282(24), 2313-2320.
- Braddock III, C. H., Fihn, S. D., Levinson, W., Jonsen, A. R., & Pearlman, R. A. (1997). How doctors and patients discuss routine clinical decisions: informed decision making in the outpatient setting. *Journal of general internal medicine*, *12*(6), 339-345.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.
- Brown, P. (2014) People with learning disabilities and the interpersonal construction of self-determination (Unpublished thesis)
- Burr, V. (2015). Social constructionism. Routledge.
- Byrne, R., Davies, L., & Morrison, A. P. (2010). Priorities and preferences for the outcomes of treatment of psychosis: a service user perspective. *Psychosis*, *2*(3), 210-217.
- Cairns, R., Maddock, C., Buchanan, A., David, A. S., Hayward, P., Richardson, G., ... & Hotopf, M. (2005). Prevalence and predictors of mental incapacity in psychiatric in-patients. *The British Journal of Psychiatry*, 187(4), 379-385.
- Calderhead, J. (1981). Stimulated recall: A method for research on teaching. *British journal of educational psychology*, *51*(2), 211-217.

- Carabine, J. (2001). Constituting sexuality through social policy: the case of lone motherhood 1834 and today. *Social & Legal Studies*, *10*(3), 291-314.
- Care Quality Commission. (2010). *The State of Health Care and Adult Social Care in England: Key themes and quality of services in 2009* (Vol. 343). The Stationery Office.
- Carpenter, W. T., Gold, J. M., Lahti, A. C., Queern, C. A., Conley, R. R., Bartko, J. J., ... & Appelbaum, P. S. (2000). Decisional capacity for informed consent in schizophrenia research. *Archives of general Psychiatry*, *57*(6), 533-538.
- Casey, B., & Long, A. (2003). Meanings of madness: a literature review. *Journal of Psychiatric and Mental Health Nursing*, 10(1), 89-99.
- Cashwell, C. S. (1994). Interpersonal process recall. ERIC Clearinghouse.
- Chamberlin, J. (2005). User/consumer involvement in mental health service delivery. *Epidemiologia e Psichiatria Sociale, 14*(01), 10-14.
- Chan, K. K., & Mak, W. W. (2012). Shared decision making in the recovery of people with schizophrenia: The role of metacognitive capacities in insight and pragmatic language use. *Clinical psychology review*, 32(6), 535-544.
- Chaplin, R., Lelliott, P., Quirk, A., & Seale, C. (2007). Negotiating styles adopted by consultant psychiatrists when prescribing antipsychotics. *Advances in Psychiatric Treatment*, 13(1), 43-50.
- Charles, C., & DeMaio, S. (1993). Lay participation in health care decision making: a conceptual framework. *Journal of Health Politics, Policy and Law,18*(4), 881-904.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean?(or it takes at least two to tango). *Social science & medicine*, 44(5), 681-692.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social science & medicine*, 49(5), 651-661.
- Charles, C., Gafni, A., & Whelan, T. (2004). Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. *Health Expectations*, 7(4), 338-348.
- Chong, W. W., Aslani, P., & Chen, T. F. (2013). Shared decision-making and interprofessional collaboration in mental healthcare: a qualitative study exploring perceptions of barriers and facilitators. *Journal of Interprofessional Care*, 27(5), 373-379.

- Colombo, A., Bendelow, G., Fulford, B., & Williams, S. (2003). Evaluating the influence of implicit models of mental disorder on processes of shared decision making within community-based multi-disciplinary teams. *Social science & medicine*, *56*(7), 1557-1570.
- Corstens, D., Escher, S., & Romme, M. (2008). Accepting and working with voices: The Maastricht approach. In A. Moskowitz, I. Scha¨fer, & M. J. Dorahy (Eds.), *Psychosis, trauma and dissociation: Emerging perspectives on severe psychopathology* (pp. 319–332). Oxford, England: Wiley-Blackwell.
- Coulter A (2010) Do patients want choice and does it work? *British Medical Journal 341*, 973–975.
- Coulter, A., & Collins, A. (2011). *Making shared decision-making a reality. No decision about me, without me.* The King's Fund.
- Coulter, A., Härter, M. H., Moumjid-Ferdjaoui, N., Perestelo-Perez, L., & van der Weijden, T. (2015). European experience with shared decision making. *International Journal of Person Centered Medicine*, *5*(1), 9-14.
- Covington, M. A., He, C., Brown, C., Naçi, L., McClain, J. T., Fjordbak, B. S., et al. (2005). Schizophrenia and the structure of language: The linguist's view. *Schizophrenia Research*, 77, 85–98.
- Cowen, P., Harrison, P., & Burns, T. (2012). Shorter Oxford textbook of psychiatry. Oxford University Press.
- Crane-Ross, D., Roth, D., & Lauber, B. G. (2000). Consumers' and case managers' perceptions of mental health and community support service needs. *Community Mental Health Journal*, 36(2), 161-178.
- Curtis, L. C., Wells, S. M., Penney, D. J., Ghose, S. S., Mistler, L. A., Mahone, I. H., ... & Lesko, S. (2010). Pushing the envelope: shared decision making in mental health. *Psychiatric rehabilitation journal*, *34*(1), 14 22.
- David, A. S. (1990). Insight and psychosis. The British Journal of Psychiatry, 156(6), 798-808.
- De las Cuevas, C., & Peñate, W. (2014). To what extent psychiatric patients feel involved in decision making about their mental health care? Relationships with socio-demographic, clinical, and psychological variables. *Acta neuropsychiatrica*, 26(06), 372-381.
- Deegan, P. E. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *Psychiatric rehabilitation journal*, *31*(1), 62.
- Deegan, P. E., & Drake, R. E. (2006). Shared decision making and medication management in the recovery process. *Psychiatric Services*, *57*(11), 1636-1639

- Department of Health (2012) Liberating the NHS: no decision about me, without me. Further consultation on proposals to secure shared decision-making. Department of Health, London.
- Dimsdale, J. E., Klerman, G., & Shershow, J. C. (1979). Conflict in treatment goals between patients and staff. *Social Psychiatry*, 14(1), 1-4.
- Drake, R. E., Deegan, P. E., & Rapp, C. (2010). The promise of shared decision making in mental health. *Psychiatric Rehabilitation Journal*, 34 (1), 7-13
- Duncan, E., Best, C., & Hagen, S. (2010). *Shared decision making interventions for people with mental health conditions.* The Cochrane Library.
- Dunn, L. B., & Roberts, L. W. (2005). Emerging findings in ethics of schizophrenia research. *Current opinion in psychiatry*, *18*(2), 111-119.
- Edley, N. (2001). Analysing masculinity: Interpretative repertoires, ideological dilemmas and subject positions. *Discourse as data: A guide for analysis*, 189-228.
- Edwards, A., & Elwyn, G. (2006). Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Health Expectations*, *9*(4), 307-320.
- Edwards, A., Elwyn, G., Hood, K., Robling, M., Atwell, C., Holmes-Rovner, M., ... & Russell, I. (2003). The development of COMRADE—a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. *Patient education and counseling*, 50(3), 311-322.
- Eliacin, J., Salyers, M. P., Kukla, M., & Matthias, M. S. (2014). Factors influencing patients' preferences and perceived involvement in shared decision-making in mental health care. *Journal of Mental Health*, 24(1), 24-28.
- Elliott, R., Fischer, C.T., and Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229
- Elwyn, G., Edwards, A., Kinnersley, P., & Grol, R. (2000). Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. *British Journal of General Practice*, *50*(460), 892-899.
- Elwyn, G., Edwards, A., Wensing, M., Hood, K., Atwell, C., & Grol, R. (2003). Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality and Safety in health care, 12*(2), 93-99.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of general internal medicine*, *27*(10), 1361-1367.

- Elwyn, G., Frosch, D., Volandes, A. E., Edwards, A., & Montori, V. M. (2010). Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. *Medical Decision Making*, 30(6), 701-711.
- Elwyn, G., Gwyn, R., Edwards, A., & Grol, R. (1999). Is 'shared decision-making'feasible in consultations for upper respiratory tract infections? Assessing the influence of antibiotic expectations using discourse analysis. *Health Expectations*, 2(2), 105-117.
- Elwyn, G., Hutchings, H., Edwards, A., Rapport, F., Wensing, M., Cheung, W. Y., & Grol, R. (2005). The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expectations*,8(1), 34-42.
- Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *Bmj*, *341*, c5146.
- Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: the case for a broader conceptual framework. *Patient education and counseling*, 63(3), 268-278.
- Estroff, S. (1993). Identity, disability and schizophrenia: The problem of chronicity. In S. Lindenbaum, & M. Lock (Eds.), *Power, knowledge and practice: The anthropology of medicine and everyday life.* Berkeley: University of California Press
- Fischer, E. P., Shumway, M., & Owen, R. R. (2002). Priorities of consumers, providers, and family members in the treatment of schizophrenia. *Psychiatric Services*, *53*(6), 724-729.
- Flory, J., & Emanuel, E. (2004). Interventions to improve research participants' understanding in informed consent for research: a systematic review. *Jama*, *292*(13), 1593-1601.
- Flynn, K.E., Smith, M.A., Vanness, D. (2006). A typology of preferences for participation in health care decision-making. *Social Science and Medicine*, *63* (5), 1158–69
- Fox, A., & Reeves, S. (2015). Interprofessional collaborative patient-centred care: a critical exploration of two related discourses. *Journal of interprofessional care*, 29(2), 113-118.
- Freidson, Eliot (1970). *Profession of medicine. A study of the sociology applied knowledge.* Chicago: The University of Chicago Press.
- Freud, S. (1924). Neurosis and Psychosis. S.E. IXX. Republished (1961). London: Hogarth Press.
- Frosch, D. L., May, S. G., Rendle, K. A., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians and patients' fear of being labeled 'difficult'among key obstacles to shared decision making. *Health Affairs*, 31(5), 1030-1038.
- Ganzini, L., Volicer, L., Nelson, W. A., Fox, E., & Derse, A. R. (2004). Ten myths about decision-making capacity. Journal of the American Medical Directors Association, 5(4), 263-267.

- Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. E. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological medicine*, *31*(02), 189-195.
- General Medical Council (2009). *Good Medical Practice*. London: General Medical Council. Retrieved from: www.gmc-uk.org/Static/documents/content/ GMP\_0910.pdf
- Georgaca, E., & Avdi, E. (2012). Discourse analysis. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*, 147-162.
- Georgaca, E. (2013). Social constructionist contributions to critiques of psychiatric diagnosis and classification. *Feminism & Psychology*, *23*(1), 56-62.
- Gilbert, N., and Mulkay, M. (1984). *Opening Pandora's Box: A Sociological Analysis of Scientists' Discourse*. Cambridge: Cambridge University Press
- Godolphin, W. (2009). Shared decision-making. *Healthcare Quarterly*, 12 (186-190).
- Goossensen, A., Zijlstra, P., & Koopmanschap, M. (2007). Measuring shared decision making processes in psychiatry: skills versus patient satisfaction. *Patient education and counseling*, 67(1), 50-56.
- Goss, C., Moretti, F., Mazzi, M. A., Del Piccolo, L., Rimondini, M., & Zimmermann, C. (2008). Involving patients in decisions during psychiatric consultations. *The British Journal of Psychiatry*, 193(5), 416-421.
- Gravel, K., Légaré, F., & Graham, I. D. (2006). Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implementation Science*, 1(1), 16.
- Grisso, T., & Appelbaum, P. S. (1995). The MacArthur Treatment Competence Study. III: Abilities of patients to consent to psychiatric and medical treatments. Law and human behavior, 19(2), 149.
- Grundy, A. C., Bee, P., Meade, O., Callaghan, P., Beatty, S., Olleveant, N., & Lovell, K. (2016). Bringing meaning to user involvement in mental health care planning: a qualitative exploration of service user perspectives. *Journal of psychiatric and mental health nursing*, 23(1), 12-21.
- Guadagnoli, E., & Ward, P. (1998). Patient participation in decision-making. *Social science & medicine*, 47(3), 329-339.
- Gustafsson, C., & Fagerberg, I. (2001). Reflection, the way to professional development. *Journal of Clinical Nursing*, 13, 271-280

- Hamann, J., & Heres, S. (2014). Adapting shared decision making for individuals with severe mental illness. *Psychiatric Services*, *65*, 1483–1486.
- Hamann, J., Cohen, R., Leucht, S., Busch, R., & Kissling, W. (2005). Do patients with schizophrenia wish to be involved in decisions about their medical treatment?. *American Journal of Psychiatry*, 162(12), 2382-2384.
- Hamann, J., Kohl, S., McCabe, R., Bühner, M., Mendel, R., Albus, M., & Bernd, J. (2016). What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists. *Social psychiatry and psychiatric epidemiology*, *51*(4), 617-625.
- Hamann, J., Langer, B., Winkler, V., Busch, R., Cohen, R., Leucht, S., & Kissling, W. (2006). Shared decision making for in-patients with schizophrenia. *Acta Psychiatrica Scandinavica*, 114(4), 265-273.
- Hamann, J., Leucht, S., & Kissling, W. (2003). Shared decision making in psychiatry. *Acta Psychiatrica Scandinavica*, 107(6), 403-409.
- Hamann, J., Mendel, R. T., Fink, B., Pfeiffer, H., Cohen, R., & Kissling, W. (2008). Patients' and psychiatrists' perceptions of clinical decisions during schizophrenia treatment. *The Journal of nervous and mental disease*, 196(4), 329-332.
- Hamann, J., Mendel, R., Bühner, M., Kissling, W., Cohen, R., Knipfer, E., & Eckstein, H. H. (2012). How should patients behave to facilitate shared decision making–the doctors' view. *Health Expectations*, 15(4), 360-366.
- Hamann, J., Mendel, R., Cohen, R., Heres, S., Ziegler, M., Bühner, M., & Kissling, W. (2009). Psychiatrists' use of shared decision making in the treatment of schizophrenia: patient characteristics and decision topics. *Psychiatric Services*, 60(8), 1107-1112.
- Hamann, J., Mendel, R., Meier, A., Asani, F., Pausch, E., Leucht, S., & Kissling, W. (2011). "How to speak to your psychiatrist": shared decision-making training for inpatients with schizophrenia. *Psychiatric Services*,62(10), 1218-1221.
- Harper, D. J. (2004). Delusions and discourse: Moving beyond the constraints of the modernist paradigm. *Philosophy, Psychiatry, & Psychology, 11*(1), 55-64.
- Haug, M. R., & Lavin, B. (1981). Practitioner or patient-who's in charge? *Journal of Health and Social Behavior*, 212-229
- Health and Social Care Act (2012) London: Stationery Office.
- Heim, C., Newport, D. J., Heit, S., Graham, Y. P., Wilcox, M., Bonsall, R., & Nemeroff, C. B. (2000). Pituitary-adrenal and autonomic responses to stress in women after sexual and physical abuse in childhood. *Jama*, 284, 592-597

- Hepburn, A., & Potter, J. (2006). *Discourse analytic practice*. Qualitative Research Practice: Concise Paperback Edition, 168.
- Hewitt, J.P. and Stokes, R. (1975). Disclaimers. American Sociological Review, 40, 1-11.
- Holloway, I., & Wheeler, S. (2013). *Qualitative research in nursing and healthcare*. John Wiley & Sons.
- Hutchinson, S. A., Wilson, M. E., & Wilson, H. S. (1994). Benefits of participating in research interviews. *The Journal of Nursing Scholarship*, *26*(2), 161-166.
- Iyengar, S. I., & DeVoe, S. E. (2003). Rethinking the value of choice: Considering cultural mediators of intrinsic motivation. In V. Murphy-Berman & J. J. Berman (Eds.), Nebraska Symposium on Motivation: Vol. 49. Cross-cultural differences in perspectives on the self (pp. 129-176). Lincoln, NE: University of Nebraska Press
- Jablensky, A. (2010). The diagnostic concept of schizophrenia: its history, evolution, and future prospects. *Dialogues in clinical neuroscience*, *12*(3), 271
- Janssen, I., Krabbendam, L., Bak, M., Hanssen, M., Vollebergh, W., Graaf, R. D., & Os, J. V. (2004). Childhood abuse as a risk factor for psychotic experiences. Acta *Psychiatrica Scandinavica*, 109(1), 38-45
- Jardim, L. L., Pereira, M.E.C., & de Souza Palma, C.M. (2011). Fragments of the Other: A Psychoanalytic Approach to the Ego in Schizophrenia. *International Forum of Psychoanalysis*, 20, 159-166.
- Jefferson, G. 1990. 'List construction as a task and resource', in G. Psathas (ed.) *Interaction Competence*. Washington, DC: University Press of America, 63–92.
- Jeste, D. V., Depp, C. A., & Palmer, B. W. (2005). Magnitude of impairment in decisional capacity in people with schizophrenia compared to normal subjects: an overview. *Schizophrenia Bulletin*, 32(1), 121–128.
- Jewitt, C. (2012). *An introduction to using video for research*. National Centre for Research Methods, NCRM Working Paper. Retrieved From: http://eprints.ncrm.ac.uk/2259/
- Joosten, E. A., DeFuentes-Merillas, L., De Weert, G. H., Sensky, T., Van Der Staak, C. P. F., & de Jong, C. A. (2008). Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. Psychotherapy and psychosomatics, 77(4), 219-226.
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient education and counseling*, 94(3), 291-309.

- Joseph-Williams, N., Lloyd, A., Edwards, A., Stobbart, L., Tomson, D., Macphail, S., ... & Thomson, R. (2017). Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMI*, 357, j1744.
- Kagan, N. (1980). *Influencing human interaction Eighteen years with IPR.* In A.K. Hess (Ed.), Psychotherapysupervision: Theory, research, and practice.
- Kaminskiy, E. (2015). The Elephant in the Room: A Theoretical Examination of Power for Shared Decision Making in Psychiatric Medication Management.Intersectionalities: A Global Journal of Social Work Analysis, *Research, Polity, and Practice, 4*(2), 19-38.
- Kasper J, Burish G, Geiger F, Heesen C. (2007) *Do Patients perceive the involvement we observe?* Poster at the 4th International Shared Decision Making Conference, Freiburg.
- Kasper, J., Heesen, C., Köpke, S., Fulcher, G., & Geiger, F. (2011). Patients' and observers' perceptions of involvement differ. Validation study on inter-relating measures for shared decision making. *PloS one*, 6(10), e26255.
- Kasper, J., Légaré, F., Scheibler, F., & Geiger, F. (2012). Turning signals into meaning-'Shared decision making' meets communication theory. *Health Expectations*, *15*(1), 3-11.
- Keynejad, R. (2008) Barriers to seeking help: What stops ethnic minority groups in Redbridge accessing mental health service. Redbridge CVS: NHS North East London. Retrieved from: http://www.rcmh.org.uk/documents/reports/barrierstoseekinghelp.pdf
- Klein, E., Rosenberg, J., & Rosenberg, S. (2007). Whose treatment is it anyway? The role of consumer preferences in mental health care. *American Journal of Psychiatric Rehabilitation*, 10(1), 65-80.
- Klingaman, E. A., Medoff, D. R., Park, S. G., Brown, C. H., Fang, L., Dixon, L. B., ... & Kreyenbuhl, J. A. (2015). Consumer satisfaction with psychiatric services: The role of shared decision making and the therapeutic relationship. *Psychiatric rehabilitation journal*, 38(3), 242.
- Kovandžić, M., Chew-Graham, C., Reeve, J., Edwards, S., Peters, S., Edge, D., ... & Dowrick, C. (2011). Access to primary mental health care for hard-to-reach groups: from 'silent suffering'to 'making it work'. *Social science & medicine*, 72(5), 763-772.
- Kovnick, J. A., Appelbaum, P. S., Hoge, S. K., & Leadbetter, R. A. (2003). Competence to consent to research among long-stay inpatients with chronic schizophrenia. *Psychiatric Services*, *54*(9), 1247-1252.
- Langdon, R., Coltheart, M., Ward, P. B., & Catts, S. V. (2002). Disturbed communication in schizophrenia: the role of poor pragmatics and poor mind-reading. *Psychological medicine*, *32*(07), 1273-1284.
- Larsen, J. A. (2004). Finding meaning in first episode psychosis: Experience, agency, and the cultural repertoire. *Medical anthropology quarterly*, 447-471.

- Las Cuevas, C., Rivero-Santana, A., Perestelo-Perez, L., Perez-Ramos, J., Gonzalez-Lorenzo, M., Serrano-Aguilar, P., & Sanz, E. J. (2012). Mental health professionals' attitudes to partnership in medicine taking: a validation study of the Leeds Attitude to Concordance Scale II. *Pharmacoepidemiology and drug safety, 21*(2), 123-129.
- Lee, J., & Park, S. (2005). Working memory impairments in schizophrenia: a meta-analysis. *Journal of abnormal psychology*, 114(4), 599.
- Légaré, F., Ratté, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient education and counseling*, 73(3), 526-535.
- Lerman, C. E., Brody, D. S., Caputo, G. C., Smith, D. G., Lazaro, C. G., & Wolfson, H. G. (1990). Patients' perceived involvement in care scale. *Journal of General Internal Medicine*, 5(1), 29-33.
- Lerner, J.S. and Keltner, D. (2000) Beyond valence: toward a model of emotionspecific influences on judgement and choice. *Cognition and Emotion*, *14*, 473-493
- Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making. *Journal of general internal medicine*, *20*(6), 531-535.
- Loft, N. O., & Lavender, T. (2015). Exploring compulsory admission experiences of adults with psychosis in the UK using Grounded Theory. *Journal of Mental Health*, 1-6
- Loh, A., Simon, D., Hennig, K., Hennig, B., Härter, M., & Elwyn, G. (2006). The assessment of depressive patients' involvement in decision making in audio-taped primary care consultations. *Patient education and counseling*, 63(3), 314-318.
- Longden, E., Corstens, D., Escher, S., & Romme, M. (2012). Voice hearing in a biographical context: a model for formulating the relationship between voices and life history. *Psychosis*, *4*(3), 224-234.
- Ludman, E., Katon, W., Bush, T., Rutter, C., Lin, E., Simon, G., ... & Walker, E. (2003). Behavioural factors associated with symptom outcomes in a primary care-based depression prevention intervention trial. *Psychological Medicine*, *33*(06), 1061-1070.
- Lukes, S. (1986). Power. NYU Press.
- Lyle, J. (2003). Stimulated recall: A report on its use in naturalistic research. *British educational research journal*, *29*(6), 861-878.
- Lysaker, P. H., & Dimaggio, G. (2014). Metacognitive capacities for reflection in schizophrenia: implications for developing treatments. *Schizophrenia bulletin*, *40*(3), 487-491.

- Lysaker, P. H., & Lysaker, J. T. (2001). Psychosis and the disintegration of dialogical self-structure: Problems posed by schizophrenia for the maintenance of dialogue. *The British Journal of Medical Psychology*, 74, 23–33.
- Lysaker, P. H., Olesek, K. L., Warman, D. M., Martin, J. M., Salzman, A. K., Nicolò, G., ... & Dimaggio, G. (2011). Metacognition in schizophrenia: Correlates and stability of deficits in theory of mind and self-reflectivity. *Psychiatry Research*, 190(1), 18-22.
- Machin, D., & Mayr, A. (2012). How to do critical discourse analysis: A multimodal introduction. Sage.
- Mahone, I. H., Farrell, S., Hinton, I., Johnson, R., Moody, D., Rifkin, K., ... & Barker, M. R. (2011). Shared decision making in mental health treatment: qualitative findings from stakeholder focus groups. *Archives of psychiatric nursing*, 25(6), e27-e36.
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient education and counseling*, 60(3), 301-312.
- Malm, U., Ivarsson, B., Allebeck, P., & Falloon, I. R. H. (2003). Integrated care in schizophrenia: A 2-year randomized controlled study of two community-based treatment programs. *Acta Psychiatrica Scandinavica*, 107(6), 415-423.
- Martin, L. R., & DiMatteo, M. R. (Eds.). (2013). *The Oxford handbook of health communication, behavior change, and treatment adherence*. Oxford University Press.
- Masterson, S., & Owen, S. (2006). Mental health service user's social and individual empowerment: Using theories of power to elucidate far-reaching strategies. *Journal of mental health*, 15(1), 19-34.
- Matthias, M. S., Salyers, M. P., & Frankel, R. M. (2013). Re-thinking shared decision-making: context matters. *Patient Education and Counseling*, *91*(2), 176-179.
- Mazza, M., Di Michele, V., Pollice, R., Casacchia, M., & Roncone, R. (2008). Pragmatic language and theory of mind deficits in people with schizophrenia and their relatives. *Psychopathology*, 41, 254–263.
- McCabe, R., Khanom, H., Bailey, P., & Priebe, S. (2013). Shared decision-making in ongoing outpatient psychiatric treatment. *Patient education and counseling*, *91*(3), 326-328.
- McCabe, R., Skelton, J., Heath, C., Burns, T., & Priebe, S. (2002). Engagement of patients with psychosis in the consultation: conversation analytic study Commentary: Understanding conversation. *BMJ*, 325(7373), 1148-1151.
- McCann, T. V., & Clark, E. (2005). Using unstructured interviews with participants who have schizophrenia. *Nurse researcher*, *13*(1), 7-18.

- McKinstry, B. (2000). Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BMJ*,321(7265), 867-871.
- McLelland, E. (27 June, 2015) *Schizophrenic thug who strangled partner and then set fire to pink Audi with her body jammed into the footwell is sent to secure hospital indefinitely.* Daily Mail. Retrieved from www.dailymail.co.uk
- Mental Capacity Act (2005). London: The Stationery Office.
- Mental Health Act (1983). *London: HMSO*. Retrieved from: http://www.legislation.gov.uk/ukpga/2007/12/contents
- Mikesell, L., Bromley, E., Young, A. S., Vona, P., & Zima, B. (2016). Integrating client and clinician perspectives on psychotropic medication decisions: Developing a communication-centered epistemic model of shared decision making for mental health contexts. *Health communication*, *31*(6), 707-717.
- Morant, N., Kaminskiy, E., & Ramon, S. (2015). Shared decision making for psychiatric medication management: beyond the micro-social. *Health Expectations*, *19*, 1001-1014
- Moritz, S., Berna, F., Jaeger, S., Westermann, S., & Nagel, M. (2016). The customer is always right? Subjective target symptoms and treatment preferences in patients with psychosis. *European archives of psychiatry and clinical neuroscience*, 1-5.
- Morrison, A. P., Hutton, P., Shiers, D., & Turkington, D. (2012). Antipsychotics: is it time to introduce patient choice?. *The British Journal of Psychiatry*, *201*(2), 83-84.
- Morrison, K (2012) *Knife-wielding schizophrenic woman in court after killing gran in street.* The Sun. Retrieved from www.thesun.co.uk
- Moser, D. J., Schultz, S. K., Arndt, S., Benjamin, M. L., Fleming, F. W., Brems, C. S., ... & Andreasen, N. C. (2002). Capacity to provide informed consent for participation in schizophrenia and HIV research. *American Journal of Psychiatry*, 159(7), 1201-1207.
- Moumjid, N., Gafni, A., Bremond, A., & Carrere, M. O. (2007). Shared decision making in the medical encounter: are we all talking about the same thing?. *Medical Decision Making*, 27(5), 539-546.
- Munro, K., Killoran Ross, M., & Reid, M. (2006). User involvement in mental health: time to face up to the challenges of meaningful involvement? *International Journal of Mental Health Promotion*, 8(2), 37-44.
- Murray, B. (2003). Qualitative research interviews: therapeutic benefits for the participants. *Journal of Psychiatric and Mental Health Nursing*, *10*(2), 233-236.
- Murray, E., Pollack, L., White, M., & Lo, B. (2007). Clinical decision-making: Patients' preferences and experiences. *Patient education and counseling*, 65(2), 189-196.

- Murtagh, M. J. (2009). Decision-making, power, and the doctor-patient relationship. In G. Edwards & G. Elywn (Eds.), *Shared decision-making in health care: Achieving evidence-based patient choice* (pp. 79–84). Oxford, UK: Oxford University Press.
- Nessa, J., & Malterud, K. (1998). Tell me what's wrong with me: a discourse analysis approach to the concept of patient autonomy. *Journal of Medical Ethics*, 24(6), 394-400.
- Norfolk & Suffolk Mental Health Crisis (2015). Campaign research shows mental health trusts nationwide face impossible 8% cut in budgets. Retrieved from: <a href="http://norfolksuffolkmentalhealthcrisis.org.uk/campaign-research-shows-mental-health-trusts-face-impossible-8-cut-in-budgets/">http://norfolksuffolkmentalhealthcrisis.org.uk/campaign-research-shows-mental-health-trusts-face-impossible-8-cut-in-budgets/</a>
- NICE (2011) *Psychosis and schizophrenia in adults: prevention and management.* Retrieved from: https://www.nice.org.uk/guidance/cg178
- NICE (2014). Psychosis and schizophrenia in adults: treatment and management (update). Retrieved from <a href="http://www.nice.org.uk/guidance/cg178/evidence">http://www.nice.org.uk/guidance/cg178/evidence</a>
- NICE. (2016) .Shared Decision Making Collaborative. A consensus statement. Retrieved from: <a href="https://www.nice.org.uk/Media/Default/About/what-we-do/SDM-consensus-statement.pdf">https://www.nice.org.uk/Media/Default/About/what-we-do/SDM-consensus-statement.pdf</a>
- NICE. (2016) Shared Decision Making Collaborative. An action plan. Retrieved from: <a href="https://www.nice.org.uk/Media/Default/About/what-we-do/shared-decision-making-collaborative-action-plan.pdf">https://www.nice.org.uk/Media/Default/About/what-we-do/shared-decision-making-collaborative-action-plan.pdf</a>
- O'Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Col, N. F., Eden, K. B., ... & Rovner, D. (2009). Decision aids for people facing health treatment or screening decisions. The Cochrane Library.
- O'Donovan, M. (2006). Implementing reflection: Insights from pre-registration mental health students. *Nurse Education Today*, 27,610-616.
- Owen, G. S., David, A. S., Richardson, G., Szmukler, G., Hayward, P., & Hotopf, M. (2009). Mental capacity, diagnosis and insight in psychiatric in-patients: a cross-sectional study. *Psychological medicine*, *39*(8), 1389-1398.
- Owen, G. S., Richardson, G., David, A. S., Szmukler, G., Hayward, P., & Hotopf, M. (2008). Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study. *BMJ*, 337, a448.
- Paget, T. (2001). Reflective practice and clinical outcomes: practitioners' views on how reflective practice has influenced their clinical practice. *Journal of clinical nursing*, 10(2), 204-214.

- Parker, I. (1990). Discourse: Definitions and contradictions. *Philosophical psychology*, 3(2-3), 187-204.
- Patel, S. R., Bakken, S., & Ruland, C. (2008). Recent advances in shared decision making for mental health. *Current opinion in psychiatry*, 21(6), 606.
- Perestelo-Perez, L., Gonzalez-Lorenzo, M., Perez-Ramos, J., Rivero-Santana, A., & Serrano-Aguilar, P. (2011). Patient involvement and shared decision-making in mental health care. *Current clinical pharmacology*, 6(2), 83-90.
- Pitt, L., Kilbride, M., Welford, M., Nothard, S., & Morrison, A. P. (2009). Impact of a diagnosis of psychosis: user-led qualitative study. *The Psychiatrist*, 33(11), 419-423.
- Pollard, S., Bansback, N., & Bryan, S. (2015). Physician attitudes toward shared decision making: a systematic review. *Patient education and counseling*, *98*(9), 1046-1057.
- Potter, J. (2002). Two kinds of natural. Discourse Studies, 4(4), 539-542.
- Potter, J. (2010). Contemporary discursive psychology: Issues, prospects, and Corcoran's awkward ontology. *British Journal of Social Psychology*, 49(4), 657-678.
- Potter, J. (1996). Representing Reality. London: Sage.
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. Sage.
- Protheroe, J., Brooks, H., Chew-Graham, C., Gardner, C., & Rogers, A. (2013). 'Permission to participate?' A qualitative study of participation in patients from differing socio-economic backgrounds. *Journal of health psychology*, 18(8), 1046-1055.
- Quirk, A., Chaplin, R., Lelliott, P., & Seale, C. (2012). How pressure is applied in shared decisions about antipsychotic medication: a conversation analytic study of psychiatric outpatient consultations. *Sociology of health & illness,34*(1), 95-113.
- Radley, A., & Billig, M. (1996). Accounts of health and illness: Dilemmas and representations. *Sociology of Health & Illness*, 18(2), 220-240.
- Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiologia e psichiatria sociale*, 18(04), 299-310.
- Read, J., Fosse, R., Moskowitz, A., & Perry, B. (2014). The traumagenic neurodevelopmental model of psychosis revisited. *Neuropsychiatry*, *4*(1), 65-79.

- Read, J., Os, J. V., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112(5), 330-350.
- Reddy, M.S (2015). Insight and Psychosis. *Indian journal of psychological medicine*, 37(3):257-60
- Reichenberg, A., & Harvey, P. D. (2007). Neuropsychological impairments in schizophrenia: Integration of performance-based and brain imaging findings. *Psychological bulletin*, 133(5), 833.
- Right Care Shared Decision Making Programme, 2013. *NHS England*. Retrieved from: <a href="https://www.england.nhs.uk/ourwork/pe/sdm/rightcare4/">https://www.england.nhs.uk/ourwork/pe/sdm/rightcare4/</a>
- Roberts, C., & Sarangi, S. (2005). Theme-oriented discourse analysis of medical encounters. *Medical education*, *39*(6), 632-640.
- Roberts, L. W., Warner, T. D., & Brody, J. L. (2000). Perspectives of patients with schizophrenia and psychiatrists regarding ethically important aspects of research participation. *American Journal of Psychiatry*, 157(1), 67-74.
- Robertson, M., Moir, J., Skelton, J., Dowell, J., & Cowan, S. (2011). When the business of sharing treatment decisions is not the same as shared decision making: a discourse analysis of decision sharing in general practice. *Health:*,15(1), 78-95
- Rogers, A., & Pilgrim, D. (2014). A sociology of mental health and illness. McGraw-Hill Education (UK).
- Royal College of General Practitioners. (2014). *An inquiry into patient-centred care in the 21st Century*. Retrieved from: <a href="mailto:file:///users/pca07ah/Downloads/RCGP-Inquiry-into-Patient-Centred-Care-in-the-21st-Century.pdf">file:///users/pca07ah/Downloads/RCGP-Inquiry-into-Patient-Centred-Care-in-the-21st-Century.pdf</a>
- Salmon P, Hall GM (2003) Patient Empowerment and Control: A Psychological Discourse in the Service of Medicine. *Social Science & Medicine* 57(10): 1969–1980
- Salyers, M. P., Matthias, M. S., Fukui, S., Holter, M. C., Collins, L., Rose, N., ... & Torrey, W. C. (2012). A coding system to measure elements of shared decision making during psychiatric visits. *Psychiatric Services*, *63*(8), 779-784.
- Say, R., Murtagh, M., & Thomson, R. (2006). Patients' preference for involvement in medical decision making: a narrative review. *Patient education and counseling*, 60(2), 102-114.
- Schauer, C., Everett, A., del Vecchio, P., & Anderson, L. (2007). Promoting the value and practice of shared decision-making in mental health care. *Psychiatric Rehabilitation Journal*, 31(1), 54.

- Scholl, I., Koelewijn-van Loon, M., Sepucha, K., Elwyn, G., Légaré, F., Härter, M., & Dirmaier, J. (2011). Measurement of shared decision making–a review of instruments. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 105*(4), 313-324.
- Schwartz, B., Ward, A., Monterosso, J., Lyubomirsky, S., White, K. and Lehman, D.R. (2002) Maximizing versus satisficing: happiness is a matter of choice. *Journal of Personality and Social Psychology*, 83, 1178-1197.
- Scull, A. (2015). *Madness in civilization: A cultural history of insanity, from the Bible to Freud, from the madhouse to modern medicine.* Princeton University Press.
- Seale, C., Chaplin, R., Lelliott, P., & Quirk, A. (2006). Sharing decisions in consultations involving anti-psychotic medication: a qualitative study of psychiatrists' experiences. *Social science & medicine*, *62*(11), 2861-2873.
- Seikkula, J., & Olson, M. E. (2003). The open dialogue approach to acute psychosis: Its poetics and micropolitics. *Family process*, 42(3), 403-418.
- Seikkula, J., Aaltonen, J., Alakare, B., Haarakangas, K., Keränen, J., & Lehtinen, K. (2006). Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. *Psychotherapy research*, 16(02), 214-228.
- Seikkula, J., Alakare, B. & Aaltonen, J. (2011). The comprehensive open-dialogue approach in western Lapland: II. Long term stability of acute psychosis outcomes in advanced community care. *Psychosis*, *3*(3), 192-204
- Shad, M. U., & Keshavan, M. S. (2015). Neurobiology of insight deficits in schizophrenia: An fMRI study. *Schizophrenia research*, 165(2), 220-226.
- Shay, L. A., & Lafata, J. E. (2015). Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making*, 35(1), 114-131.
- Shepherd, A., Shorthouse, O., & Gask, L. (2014). Consultant psychiatrists' experiences of and attitudes towards shared decision making in antipsychotic prescribing, a qualitative study. *BMC psychiatry*, 14(1), 127.
- Shepherd, G. (1995). Perspectives on schizophrenia: a survey of user, family carer and professional views regarding effective care. *Journal of Mental Health*, *4*(4), 403-422.
- Simon, D., Wills, C. E., & Harter, M. (2009). Shared decision-making in mental health. *Shared decision-making in health care: Achieving evidence based patient choice*, 269-272.
- Slade, M. (2017). Implementing shared decision making in routine mental health care. *World Psychiatry*, 16(2), 146-153.

- Slovic, P., Finucane, M. L., Peters, E., & MacGregor, D. G. (2004). Risk as analysis and risk as feelings: Some thoughts about affect, reason, risk, and rationality. *Risk analysis*, 24(2), 311-322.
- Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (eds), *Qualitative health psychology* (pp. 218–240). London: Sage
- Speed, E. (2006). Patients, consumers and survivors: A case study of mental health service user discourses. *Social science & medicine*, *62*(1), 28-38.
- Stacey, D., Bennett, C. L., Barry, M. J., Col, N. F., Eden, K. B., Holmes-Rovner, M., ... & Thomson, R. (2011). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev, 10*(10).
- Stacey, G., Felton, A., Hui, A., Stickley, T., Houghton, P., Diamond, B., ... & Willis, M. (2015). Informed, involved and influential: three Is of shared decision making: Gemma Stacey and colleagues describe how service users can improve their levels of freedom through close collaboration with mental health professionals. *Mental Health Practice*, 19(4), 31-35.
- Stroup, S., & Appelbaum, P. (2003). The subject advocate: protecting the interests of participants with fluctuating decisionmaking capacity. *Irb*, 9-11.
- Szasz, T. S., & Hollender, M. H. (1956). A contribution to the philosophy of medicine: the basic models of the doctor-patient relationship. *AMA Archives of Internal Medicine*, *97*(5), 585-592.
- Tajfel, H. (1974). Social identity and intergroup behaviour. *Information (International Social Science Council)*, 13(2), 65-93.
- Talbot, M (2010) Language and Gender: An Introduction. Cambridge, UK: Polity Press
- Thomson, R. G., Eccles, M. P., Steen, I. N., Greenaway, J., Stobbart, L., Murtagh, M. J., & May, C. R. (2007). A patient decision aid to support shared decision-making on anti-thrombotic treatment of patients with atrial fibrillation: randomised controlled trial. *Quality and safety in Health Care*, 16(3), 216-223.
- Thornhill, H., Clare, L., & May, R. (2004). Escape, enlightenment and endurance: Narratives of recovery from psychosis. *Anthropology & Medicine*, *11*(2), 181-199.
- Torrey, W. C., & Drake, R. E. (2010). Practicing shared decision making in the outpatient psychiatric care of adults with severe mental illnesses: Redesigning care for the future. *Community Mental Health Journal*, 46(5), 433-440.
- Towle, A. (1997) Physician and patient communication skills: competencies for informed shared decision-making. *Informed Shared Decision Making Project: internal report.* Vancouver: University of British Columbia

- Towle, A., & Godolphin, W. (1999). Framework for teaching and learning informed shared decision making. *BMJ*, 319(7212), 766.
- Towle, A., Godolphin, W., Grams, G., & LaMarre, A. (2006). Putting informed and shared decision making into practice. *Health Expectations*, *9*(4), 321-332.
- Tusaie, K. R., & Fitzpatrick, J. J. (2012). *Advanced practice psychiatric nursing: Integrating psychotherapy, psychopharmacology, and complementary and alternative approaches.*Springer Publishing Company
- Van Dijk, T. A. (2006). Ideology and discourse analysis. *Journal of political ideologies, 11*(2), 115-140.
- Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., ... & Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective-and cross-sectional cohort studies. *Schizophrenia bulletin*, 38(4), 661-671.
- Wehmeyer, M. L. (2006). Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations. *Research and Practice in Severe Disabilities,* 30, 113–120.
- Wensing, M., Elwyn, G., Edwards, A., Vingerhoets, E., & Grol, R. (2002). Deconstructing patient centred communication and uncovering shared decision making: an observational study. *BMC medical informatics and decision making*, 2(1), 2.
- Wetherell, M. (1998). Positioning and interpretative repertoires: Conversation analysis and post-structuralism in dialogue. *Discourse & Society*, *9*(3), 387-412.
- Wiggins, S., & Potter, J. (2008). Discursive psychology. *The Sage handbook of qualitative research in psychology*, 73-90.
- Willig, C. (2001). *Introducing qualitative research in psychology Adventures in theory and method.* Maidenhead: McGraw-Hill Open University Press.
- Wills, C. E., & Holmes-Rovner, M. (2006). Integrating decision making and mental health interventions research: research directions. *Clinical Psychology: Science and Practice*, 13(1), 9-25.
- Wilson, A., & Beresford, P. (2002). Madness, distress and postmodernity: Putting the record straight. *Disability/postmodernity: Embodying disability theory*, 143-158.
- Wilson, D. K., Kaplan, R. M., & Schneiderman, L. J. (1987). Framing of decisions and selections of alternatives in health care. *Social Behaviour*, *2*(1), 51-59.

- Wirshing, D. A., Wirshing, W. C., Marder, S. R., Liberman, R. P., & Mintz, J. (1998). Informed consent: assessment of comprehension. *American Journal of Psychiatry*, 155(11), 1508-1511.
- Woltmann, E. M., & Whitley, R. (2010). Shared decision making in public mental health care: perspectives from consumers living with severe mental illness. *Psychiatric rehabilitation journal*, 34(1), 29.
- Woltmann, E. M., Wilkniss, S. M., Teachout, A., McHugo, G. J., & Drake, R. E. (2011). Trial of an electronic decision support system to facilitate shared decision making in community mental health. *Psychiatric Services*, *62*(1), 54-60.
- Wooffitt, R. (2005). Conversation analysis and discourse analysis: A comparative and critical introduction. Sage.
- Wooffitt, R. (1992). *Telling Tales of the Unexpected: the Organisation of Factual Discourse*. Hemel Hempstead: Harvester Wheatsheaf
- World Health Organization. (1992). The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. Geneva: World Health Organization.
- Younas, M., Bradley, E., Holmes, N., Sud, D., & Maidment, I. D. (2016). Mental health pharmacists views on shared decision-making for antipsychotics in serious mental illness. *International Journal of Clinical Pharmacy*, 38(5), 1191-1199.
- Young, H. N., Bell, R. A., Epstein, R. M., Feldman, M. D., & Kravitz, R. L. (2008). Physicians' shared decision-making behaviors in depression care. *Archives of internal medicine*, 168(13), 1404-1408.
- Zola, I. K. (1972). Medicine as an institution of social control\*. *The Sociological Review, 20*(4), 487-504.

# Health Research Authority

Yorkshire & The Humber - Leeds East Research Ethics Committee

Tyne and Wear NE32 3DT Jamow Business Centre Rolling Mil Road

Telephone: 0207 1048081

you to start your study at NHS sites in England until you favourable opinion of the REC only and does not allow Please note: This is the receive HRA Approval

20 June 2016

Leeds Teaching Hospitals NHS Trust Room 2.07, Charles Thackrah Building rainee Clinical Psychologist 101 Clarendon Road Mrs Alice Staniford

Leeds LS2 9LJ

Dear Mrs Staniford

Shared decision-making between people with sperience of psychosis and mental health professionals: A discourse analysis. 16/YH/0189 Study title:

IRAS project ID: REC reference:

June 2016. Thank you for attending to discuss the application.

The Research Ethics Committee reviewed the above application at the meeting held on 07

We plan to publish your research summary wording for the above study on the HRA website together with your contact details. Publication will be no earlier than three months from the please contact the REC Manager Katy Cassidy, mescommittee yorkandhumber-leedseast@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, date of this favourable opinion letter. The expectation is that this information will be publication of the study.

### **Appendices**

### **Appendix 1: REC & HRA Approvals**

# Conditions of the favourable opinion

The members of the Committee present gave a favourable ethical opinion of the above

Ethical opinion

research on the basis described in the application form, protocol and supporting

documentation, subject to the conditions specified below.

The REC favourable opinion is subject to the following conditions being met prior to the start of the study. The Committee requested reassurance that staff would be clearly told that they could refuse to participate.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at <u>www.hra.nhs.uk</u> or at

participants to research sites ("participant identification centre"), guidance should be sough Where a NHS organisation's role in the study is limited to identifying and referring potential from the R&D office on the Information it requires to give permission for this activity. For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host

## Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant. There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory. If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact the studyregistration/gibris.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

# Ethical review of research sites

### NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

# Summary of discussion at the meeting

The Committee welcomed you to the meeting as Chief Investigator, alongside Academic Supervisor Dr Anjula Gupta.

# Social or scientific value; scientific design and conduct of the study

The sample for the study was very small, potentially consisting of only four dyads. The Committee expressed a concern that comments made during the reflection meeting may make participants identifiable.

# Recruitment arrangements and access to health information, and fair participant selection

Question A-31 of the IRAS form stated that an e-mail was sent to inform the nominated staff member that service users wanted to involve them. This was followed-up by another e-mail two weeks later, and then a telephone call after a further two weeks. The Service Manager may be involved if the researcher has difficulty in contacting staff members. The Committee queried whether this was too coercive.

You noted this and stated that you would reconsider the approach

# Informed consent process and the adequacy and completeness of participant information

The researchers aimed to recruit four to five dyads comprised of a service user with a diagnosis of psychosis and a staff member. An interview between the service user and staff member was recorded and transcribed, and then played back to the dyad. The interview was then discussed and reflected on. Following the interview, participants were given five days to withdraw consent. The Committee queried whether you could allow for withdrawal at a later date. Good practice is that a period of time for withdrawal is allowed for before analysis begins.

You advised that participants could take part in the interview stage but not the reflection stage, if they chose to. Data from the first stage could be retained and used. The Committee queried how many days participants were given to withdraw following the reflection stage.

You advised that this was also five days.

The Committee suggested the inclusion of a timeline for participants, describing at which point data can be withdrawn. The Committee also recommended that participants were given two weeks to withdraw.

The service user identified the member of staff who would form the other half of the dyad. The staff member needed to give consent. The Committee queried what happened if the staff member the service user identified did not agree to participate, and whether this would potentially impact on their chinisal relationship. You explained that this had been a key question when designing the study. You wanted to capture something that was not orchestrated and to minimise the impact of the researcher observing the interaction. The research team hoped that the conversations held with the service users and staff prior to the project starting would allay any concerns.

Dr Gupta added that staff had already been spoken to. They were relying on the Mutti-Disciplinary Team and Care Co-ordinators to promote the study among staff. Service Management also reassured the staff. Miss Staniford had also spoken to both of the teams that may be involved in the project, it was hoped that the service users would select staff from these teams. You explained that you planned to meet with the Care Co-ordinators who would identify the service user participants. Staff were asked to let you know if they did not wish to take part in the study and consequently their patients would not be approached.

The Committee were satisfied with the responses given.

## Other general comments

The Committee commended the Public and Patient Involvement that had been carried out when designing the study.

You advised the Committee that you were able to store the study data, including the interview recordings, on a more secure drive.

The Committee raised no objection to this.

You were advised that other issues may be raised in correspondence

The research team were thanked for attending and left the meeting.

# Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants [Recruitment Poster (service-user)]		18 April 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]		18 April 2016
Interview schedules or topic guides for participants [Prompt Sheet - Reflective Conversation]	_	18 April 2016
IRAS Application Form [IRAS_Form_22042016]		22 April 2016
IRAS Application Form XML file [IRAS_Form_22042016]		22 April 2016
IRAS Checklist XML [Checklist_28042016]		28 April 2016

Letter from sponsor [Sponsor Letter]	1	18 April 2016
Letters of invitation to participant [Recruitment Flyer (service-user)]	1	18 April 2016
Other [Additional Information about Clinical Psychology Doctorate]	1	18 April 2016
Participant consent form (Staff Consent Form)	1	18 April 2016
Participant consent form [Service-User Consent Form]	-	18 April 2016
Participant information sheet (PIS) [Service-User PIS]	,	18 April 2016
Participant information sheet (PIS) [Staff PIS]	,	18 April 2016
Research protocol or project proposal [Research Protocol Version 1]	,	18 April 2016
Summary CV for Chief Investigator (CI) [Alice Stanford CV]	,	18 April 2016
Summary CV for supervisor (student research) [Carol Martin CV (Supervisor)]		18 April 2016
Summary CV for supervisor (student research) [CV for supervisor (Anjula Gupta)]	1	18 April 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart]	1	18 April 2016

# Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and compiles fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
  - Adding new sites and investigators
- Notification of serious breaches of the protocol
  - Progress and safety reports

  - Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-thehra/governance/quality-assurance/

### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days - see details at http://www.hra.nhs.uk/hra-training/

Please quote this number on all correspondence

16/YH/0189

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Rhona Bratt Chair

E-mail: nrescommittee.yorkandhumber-leedseast@nhs.net

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers" (SL-AR2 for other

Ms Sinead Audsley, Leeds and York Partnership Foundation Trust

Faculty Research Ethics and Governance Administrator, University of

Copy to:



# Health Research Authority

Mrs Alice Staniford

Leeds Teaching Hospitals NHS Trust Trainee Clinical Psychologist

Room 2.07, Charles Thackrah Building

101 Clarendon Road

Leeds

LS2 9LJ

15 July 2016

Dear Mrs Staniford

## Letter of HRA Approva

Shared decision-making between people with experience of

Study title:

psychosis and mental health professionals: A discourse

analysis.

195173

University of Leeds 16/YH/0189 IRAS project ID: REC reference: Sponsor

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter

# Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

England for arranging and confirming capacity and capability. Please read Appendix B carefully, in Appendix B provides important information for sponsors and participating NHS organisations in Participating NHS organisations in England – this clarifies the types of participating particular the following sections:

- organisations in the study and whether or not all organisations will be undertaking the same activities
- Confirmation of capacity and capability this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
  - Altocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID 195173

### User Feedback

Email: hra.approval@nhs.net

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra approvat@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is 195173. Please quote this on all correspondence

Yours sincerely

Alison Thorpe

Senior Assessor

Email: hra.approval@nhs.net

Faculty Research Ethics and Governance Administrator, University of Leeds, Copy to:

Sponsor Contact

Ms Sinead Audsley, Leeds and York Partnership Foundation Trust, Lead NHS R&D Contact

### Audsley Sinead (LEEDS AND YORK PARTNERSHIP NHS FOUNDATION TRUST) <sinead.audsley@nhs.net> @

To: Alice Staniford (umahd@leeds.ac.uk) <umahd@leeds.ac.uk>
Cc: --, Gupta Anjula (LEEDS AND YORK PARTNERSHIP NHS FOUNDATION TRUST) <anjula.gupta@nhs.net>
IRAS 195173 Confirmation of Capacity and Capability at Leeds and York Partnership NHS Foundation Trust

25 July 2016 12:26 Hide Details Inbox - leeds.ac.uk

2 Attachments, 105 KB Save ▼ Quick Look

### Dear Alice

This email confirms that Leeds and York Partnership NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.

The proposed start date for participant identification is 1 August 2016.

If you wish to discuss further, please do not hesitate to contact me.

Sinead Audsley



### Research and Development

Leeds and York Partnership NHS Foundation Trust St Mary's House St Mary's Road Leeds LS7 3JX

Tel: 0113 85 52387 Fax: 0113 85 54466

### Appendix 2: Participant Information Sheets and Consent Forms



# UNIVERSITY OF LEEDS

# Shared decision-making between people with experience of psychosis and mental health professionals: A discourse analysis.

## Service User Information Sheet

My name is Alice Staniford and I am a Trainee Clinical Psychologist at the University of Leeds. You are being invited to take part in some research that I am doing as part of my training. Before you decide whether to take part, please read the information below. This will tell you exactly what the research is about and what your participation would involve.

## What is the research about?

I want to find out more about how decisions are made about your care and treatment. The government is really keen for service-users to share the decision-making process with clinicians. However, even though this features in lots of policy documents, it is largely unknown what this 'sharing' might look like in practice. It is important that we explore this further in order to identify ways that service-users and staff can make conversations about treatment decisions more collaborative.

## What will the research involve?

I would like to record a conversation between you and members of your care team where there is a decision being made. I want you to help me choose a relevant conversation for us to record. This could be with anyone who is involved with your care and treatment (e.g. Psychiatrist, Social Worker, OT, Psychologist, Care aga, acdinator). I will then watch the tape back and think about how you and clinicians talk to each other. I will also ask you to watch the tape back with me and talk about your thoughts and feelings during the conversation. I will also ask staff to watch the tape back separately to get their point of view too.

# Why am I being asked to take part?

I am asking service-users with experiences of psychosis that use this CMHT if they would be interested in taking part. This is because there is less research into decision-making in mental health services than in other areas of the NHS. I will also being asking members of staff to take part because they will be part of the conversations that I am recording. I will be asking you to help decide which members of staff you would like to be recorded having a conversation with.

### Do I have to take part?

No. It is entirely up to you whether you take part or not. If you decide not to take part, this will not have any effect on your treatment.

### Can I withdraw later?

You can withdraw from the research at any time during the conversation or up until 5 days after we record. This is because at this point, the videos will have been transcribed

# Will my information be kept confidential?

The University of Leeds has a procedure for managing data. I will be following these guidelines, which means that all information will be stored securely in a locked cabinet or on a secure computer data drive. Once the conversations have been recorded, they will be transcribed anonymously. Your name and any other tecogability information will be removed so that you can't be identified from the scriot.

The only exception to this would be if anything was said that involved risk to self or others. In these circumstances, I would share this information with the relevant clinical staff and my supervisors.

# What happens to the results of the research?

After I've looked at all the conversations and watched them back with the participants, I will be writing a report on the findings. This will be assessed as part of my training. I will make reference to the conversations in the report and there may be some extracts included too. This will all be anonymous and I will use pseudonyms to protect the identity of those who take part.

I'm hoping this project will show how service-users can actively take part in decisions about their care. I'm hoping that the project will help us think about how staff can best support their service-users in participating in treatment decisions.

Once the report is complete, you are welcome to request a summary. I will be submitting the report as part of my training and there may be an opportunity to write up articles for publication in peer-reviewed journals.

### What happens next?

If you are interested in taking part, I will ask you to identify an upcoming conversation with a member of staff where a decision will be made. I will ask your permission to contact this staff member to see if they would like to participate. If not, I will ask you to think of another member of your team for us to ask. I will then arrange to meet with you again to check that you still want to take part and ask you

to sign another consent form. I will then speak with you and the staff member to arrange a time and place to record the conversation. At this meeting, I will arrange a time with each of you when we can watch the tape back together. I will then go away and apaixe, all the data. We can then arrange to meet a few months later to discuss the findings, if you would like to.

If you would like more information, please contact me at one of the addresses below:

Alice Staniford
Programme of Clinical Psychology
Charles Thackigh Building
101 Clarendon Road
Leeds
LS2 91
umahd@leeds.ac.uk

# If you have a concern, compliment or complaint please contact:

Carol Martin C.Martin@leeds.ac.uk Aniula Gupta (Clinical Supervisor; Consultant Clinical Psychologist)
Anjula\_gupta@nhs.net

Consent to take part in: Shared decision-making between people with experience of psychosis and mental health professionals: A discourse analysis.	Add your initials next to the statement if you agree
I have read and understand the information sheet dated [Insert date] explaining the above research project.  I have had the opportunity to ask questions about the project.	
I give permission for the researcher to contact a named member of my clinical team to discuss their participation in the study.	
I understand that my participation is voluntary  I understand that I am free to withdraw at any time during the recording (both initial and reflective discussion) and until 5 days post-recording without giving any reason and without any negative consequences.	
(07XXXXXXX) if you wish to withdraw from the study.  I give permission for the agreed conversation to be video-recorded and then	
analysed.  I give permission for the reflective discussion to be recorded and analysed.	
I understand that the data gathered during the project will be stored securely.	
I understand that I will not be identified or identifiable in any of the materials or reports that result from the research.	
I give permission for the research team to see extracts of anonymised responses.	
I understand that my responses will be kept strictly confidential.	
I understand that the only time that confidentiality would be broken would be if the Researcher became worried about my safety or the safety of someone else.	
I agree for the Lead Research to contact me by telephone (please provide contact number) or by email (please provide email address) during the project (e.g. to arrange visit to watch back the video).	
I understand that I can contact the Lead Researcher on (07XXXXXXX) if I have any questions about or concerns during the study.	
I understand that I will have the opportunity to request a summary of the	
final report, and to meet with the Lead Researcher to discuss findings, should I choose to.	

Lagree to take part in the above research project and will tell the lead researcher should my contact details change.



SDM between people with psychosis and mental health staff, gt.



Leeds Institute of Health Sciences Faculty of Medicine and Health

# UNIVERSITY OF LEEDS

# Shared decision-making between people with experience of psychosis and mental hared decision-making health professionals: A discourse analysis.

### Staff Information Sheet

My name is Alice Staniford and I am a Trainee Clinical Psychologist at the University of Leeds. You are being invited to take part in some research that I am doing as part of my training. Before you decide whether to take part, please read the information below. This will tell you exactly what the research is about and what your participation would involve.

## What is the research about?

'Shared Decision Making' has become prominent in government and NHS policy and guidance in recent years with an emphasis on collaboration with service-users in making decisions about care and treatment. However, research has shown that we still don't really know how this happens in practice. I want to find out more about how decision-making happens and what the experience is like for service-users and clinicians.

## What will the research involve?

I want to record a conversation between you and a service-user that involves a decision being made about some aspect of care and treatment. Service-users have been asked to help identify a relevant conversation to record. Afterwards, I'll ask you to watch the videos back with me individually and talk about what you might have been thinking and/or feeling at different points during the conversation. There are no right or wrong answers. I'll be asking service-users who participate to do the same.

# Why am I being asked to take part?

Collaborative decision-making is likely to be particularly challenging when service users have mental health difficulties, especially those associated with a diagnosis of psychosis. I'm keen to draw on the experience and expertise of mental health staff to provide some insight into how they navigate decision-making conversations with service-users.

I asked service-users to choose a member of staff who is important to them and with whom decisions about their care and treatment are made. I asked service-users to

Staff Information Sheet

think about someone in their care team who they would be interested in recording a conversation with. A service-user that you work with has identified you as this person.

### Do I have to take part?

You do not have to take part in the project. Your decision to participate is entirely voluntary. If you do not wish to take part, an alternative member of staff will be asked to participate. Deciding not to participate will not have any effect on your job.

# If I decide to participate, can I withdraw from the study later?

If you do decide to take part, you will be asked to sign a consent form. You can still decide to withdraw from the study at any point during the recording or up to 5 days afterwards. After this time, the conversations will have been transcribed and data will therefore be used in the analysis.

# Will what I say be kept confidential?

The University of Leeds has a procedure for managing data. I will be following these guidellogs, which means that all information will be stored securely in a locked cabinet or on a secure computer data drive. Once the conversations have been recorded, they will be transcribed anonymously.

The only exception to this would be if anything was said in the conversation that involved risk to self or others. In these circumstances, I would share this information with the relevant clinical staff and my supervisors.

# What happens to the results of the research?

After I've looked at all the conversations and watched them back with the gatticigagits, will be writing a report on the findings. This will be assessed as part of my training. Will make reference to the conversations in the report and there may be some extracts included too. <u>UDIS.will</u> all be anonymous and I will use pseudonyms to protect the identity of those who take part. The final report will be available after I graduate within an online library containing lots of similar academic projects. I will also be writing up some atticiga. <u>Walder</u> way be published in peer-reviewed journals.

Once the report is complete, you are welcome to request a summary. I am also happy to come back and meet with you to discuss the findings.

# What are the risks and benefits of taking part?

I appreciate that the idea of being video recorded may make some people anxious, but the focus of the recording will be on the process of decision making rather than individuals' practice. The research will be of benefit to the service by providing

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information on how clinicians and service users can work together to make collaborative decisions about their care.

### What happens next?

arrange a time to record the agreed conversation between you and a service-user. At this meeting, I will graanisg, a time with each of you when we can watch the tape back together. I will then go away and agagize, the data. We can then arrange to If you are interested in taking part, I will ask you to sign a consent form. I will then meet a few months later to discuss the findings, if you would like to.

If you would like more information, please contact me at one of the addresses

Programme of Clinical Psychology Charles <u>Thackrah</u> Building 101 Clarendon Road umahd@leeds.ac.uk Alice Staniford LS2 9U

# If you have a concern, compliment or complaint please contact:

Carol Martin (Academic Supervisor, University of Leeds)

C.Martin@leeds.ac.uk

A<u>মাঁখাই</u> Gupta (Clinical Supervisor; Consultant Clinical Psychologist) <u>Anjula.gupta@nhs.net</u>

	Consent to take part in: Conve	Consent to take part in: Conversations involving decisions in people with experience of psychosis	Add your initials next to the statement if	
	I confirm that I have read and understand I [insert date] explaining the above research opportunity to ask questions about the project.	confirm that I have read and understand the information sheet dated insert date] explaining the above research project and I have had the opportunity to ask questions about the project.		
	I understand that my participation is voluntary and tha withdraw at any time during recording and until 5 days without giving any reason and without there being consequences. Please contact Alice Staniford I umahd@leeds.ac.uk.if you wish to withdraw from the study.	I understand that my participation is voluntary and that I am free to withdraw at any time during recording and until 5 days post-recording without giving any reason and without there being any negative consequences. Please contact Alice Staniford by email at umahd@leeds.ac.uk if you wish to withdraw from the study.		
	I give permission for member anonymised extracts of transcr will not be linked with the rese identifiable in the report or rep I understand that my responses	I give permission for members of the research team to have access to anonymised extracts of transcribed recordings. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential.		
	I understand that the only time be if the Researcher became someone else.	I understand that the only time that confidentiality would be broken would be if the Researcher became concerned about my safety or the safety of someone else.		
	I give permission for the agreed conversation to be video- this to be transcribed and used in subsequent data analysis	I give permission for the agreed conversation to be video-recorded and for this to be transcribed and used in subsequent data analysis.		
	I give permission for the refle and analysed.	I give permission for the reflective discussion to be recorded, transcribed and analysed.		
	I understand that the data files work leeds Sensitive Data Protocol.	I understand that the data files will be stored securely in line with University of Leeds Sensitive Data Protocol.		
	I agree for the Lead Research contact number) or by email (p correspondence associated will visit to watch back the video).	I agree for the Lead Research to contact me by telephone (please provide contact number) or by email (please provide email address) for any relevant correspondence associated with the project (e.g. to liaise in arranging to visit to watch back the video).		
	I understand that I can contact the Lead Researche any questions about or concerns during the study.	I understand that I can contact the Lead Researcher on (OTXXXXXXXXXXX) If I have any questions about or concerns during the study.		
	I understand that I will have the final report, and to meet with should I choose to.	I understand that I will have the opportunity to request a summary of the final report, and to meet with the Lead Researcher to discuss findings, should I choose to.		
	I agree to take part in the above research presearcher should my contact details change.	I agree to take part in the above research project and will inform the lead researcher should my contact details change.		
Name of	Name of participant			
Participar	Participant's signature			
Date				
Name of	Name of lead researcher			

### **Appendix 3: Recruitment Poster and Flyer**



Do you have experience of psychosis? Are you interested in how you

and your team make decisions about your care?

If the answer is 'Yes', I want to hear from you!

Leeds and York Partnership WHS

UNIVERSITY OF LEEDS

I'm a Trainee Clinical Psychologist at the University of Leeds. I'm currently doing some research as part of my training. I want to find out how you and the people in your clinical team make decisions about

If you're interested in having a chat and getting more information, please take my information below and call or send me a text. We can then arrange to meet and discuss the study further.

I look forward to hearing from you.

Alice Staniford

I'm a Trainee Clinical Psychologist at the University of Leeds. I'm currently doing some research as part of my training. I want to find out how you and the people in your clinical team make decisions about

If you're interested in having a chat and getting more information, please leave your name and a contact number. I'll get in touch and arrange to meet with you to discuss the study in more detail.

Thanks for reading this flyer. I hope to hear from you.

Alice Staniford

Telephone number:

XXXXXXXXXXX Alice Staniford

XXXXXXXXXX Alice Staniford

XXXXXXXXXXX Alice Staniford

XXXXXXXXXXX Alice Staniford

XXXXXXXXXXZ0 Alice Staniford

XXXXXXXXXX Alice Staniford

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Alice Staniford XXXXXXXXXXX

Alice Staniford XXXXXXXXXZ0 Alice Staniford

Alice Staniford

and your team make decisions about your care? If the answer is 'Yes', I want to hear from you!

Appendix 4: List of pseudonyms and associated roles

Pseudonym	Role	
Data Set 1		
John	Psychiatrist	
Kirsty	Care co-ordinator	
Adam	Service-User	
Natalie	Family member (wife)	
Data	a Set 2	
Martin	Care co-ordinator	
Arthur	Service-user	
Stuart	Support worker (private)	
Elizabeth	Social worker	
Sheryl	Support worker (ICS)	
Data Set 3		
Sally	Care co-ordinator	
Barbara	Support worker	
Lydia	Service-user	

### Appendix 5: Example questions from the follow-up interviews

- What was going through your mind at that point?
- What were you feeling at that point?
- Is that a familiar feeling?
- What were you trying to do at that point?
- How did you want to come across?
- What do you make of what [other speaker] is saying?
- What do you think [other speaker] wanted from you?
- Is there anything you particularly liked/didn't like about that?
- Is there anything that you weren't saying?
- Is there anything you might have preferred to say there?
- Is there anything you would have liked to have done differently?