'It hasn't got my view, and it's just kind of like their 2D view. So it's like kind of like flat … instead of a fully fleshed view.' (Jimena)

A critical realist study of shared decision-making in young people’s mental health inpatient units

By
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Thesis submitted for the Degree of Doctor of Philosophy in Sociology
'I, Kate Martin, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.'
Abstract

There is little research about shared decision-making with children and young people in mental health services, particularly inpatient units. Shared decision-making involves bringing the knowledge, values and expertise of young people into the decision-making process, and potentially giving them equal weight alongside professional knowledge and evidence. This thesis presents a critical analysis of how young people and staff in mental health inpatient units understood and experienced shared decision-making. The thesis identifies structures, mechanisms, contexts and relationships that enable or constrain young people’s involvement in making decisions.

This ethnographic study observed two inpatient units in England. Interviews were held with 16 young people aged 13–17 years and 23 staff. The thematic analysis was informed by Archer’s (2000; 2003) theories of agency and Bhaskar’s (1998) concept of four-planar social being, a framework to explore how structure and agency interact.

Shared decision-making requires that the practitioners respect, listen to and take account of the young person’s testimony (their core concerns and inner self). However, the research revealed that these were the very things that were, in many ways, routinely constrained or denied within the environment and systems of inpatient units. Young people’s ability to be involved in decision-making was severely undermined by the significant constraints placed upon them by being displaced in new, unfamiliar and restrictive
environments, which limited not only their privacy and movement, but their autonomy, reflexivity, inner being and moral identity as decision-makers. The different ways young people exercised reflexivity are identified, in order to offer new ways of understanding how they responded to constraints and saw their inner self in relation to decision-making.
Impact statement

Listening, hearing and acting on what children and young people say are three very different things (Roberts, 2017). The primary aim of this study was to listen and hear the views of young people and to contribute understanding to find ways to act on them by finding ways to increase their involvement in decisions about their mental healthcare.

Much research about children and young people remains in the academic sphere and makes little impact on policy or practice (Roberts, 2017). I am therefore committed to continuing this work in order to act on what young people and staff have told me, by working to disseminate and implement the research findings in ways that will make a difference to young people, practitioners and services. In many ways, this research and this thesis are the beginning rather than the end. Perhaps most importantly, young people need to be involved as partners in change in order to ensure that their knowledge, perspectives and expertise are central to future developments.

Firstly, this research will be of interest to young people with current or past experience of using inpatient services. Recently, a young adult with lived experience of mental health problems interviewed and filmed me talking about some of the findings from this study, for her YouTube channel aimed at young people. I am also planning a series of workshops with young people who have used inpatient services to explore the findings with them, to co-develop ways to disseminate the findings to young people more widely, as
well as to develop ideas about what they think needs to change in services as a result of the research.

Secondly, this research will also be of interest to practitioners and those who plan and manage inpatient services. It should help to enable them to recognise the constraints on young people’s decision-making and identify ways the constraints can be overcome to create more time and trust between young people and those working with them. To this end, I will offer to facilitate workshops with the two inpatient services involved in this study, to share the findings and reflect on which systems and processes could change.

Alongside a young adult with lived experience of mental health problems, I was invited to present findings from this research at the annual conference of Milan’s regional mental health services and practitioners (Martin, 2018). I have also been invited to write a chapter for a forthcoming edited collection on participation in health services – *Embedding young people’s participation in health services: new approaches* – which will be published by Policy Press. The findings from this research have also influenced the training and service improvement programmes that I lead through my work to influence mental health services. I have also been invited to work with mental health services in Norway and Canada to explore how shared decision-making can be developed in practice and services.
Thirdly, further development, research and service improvement work needs to be undertaken to work with young people and services in order to understand how to initiate changes to practice and processes which will support shared decision-making (SDM) and to explore the impact these might have.

Fourthly, the findings are also equally important for policymakers to consider how to support the systems and practices required to truly support services, so that practitioner can develop meaningful relationships with young people and involve them in decision-making.

Fifthly, this study has made original contributions to academic knowledge in understanding the constraints on SDM in inpatient settings, and how young people exercise agency and reflexivity in the face of these constraints. The findings from this study contributed to a conference presentation on epistemic injustice, mental illness and children, in September 2018 (Harcourt and Martin, 2018), and to a forthcoming article (Harcourt and Martin, In press). Further academic research is needed to understand how to make the changes required in inpatient services and to monitor their effects.

Finally, I aim to bring together young people, practitioners, service managers, academics (cross-disciplinary, including philosophy, sociology and psychology, law, ethics, amongst others) to explore the research findings. We will co-develop a research proposal to explore how to support inpatient
services, practitioners, young people and parents to engage in meaningful shared decision-making.
Acknowledgements

Firstly, I am deeply grateful to all of the young people and young adults with lived experience who I have worked alongside, for their wisdom, drive and insight. My thanks also to the young people and staff in the inpatient units for making me welcome and for sharing their views, experiences and insight with me.

I would like to express my deepest thanks to my supervisors, Professor Priscilla Alderson and Professor Katy Sutcliffe, for their encouragement, enthusiasm, kindness, advice and most of all, for their patience.

Thank you to my friends and colleagues for their support, encouragement and reminding me that one day I will have time for a holiday.

Lastly, I would like to thank my family. To my mum, Di, for teaching me from the earliest age that all people are just people, and to see and challenge injustices. Also to my brother, Iain, for his strength and determination.
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List of abbreviations

CR – Critical realism
CQC – Care Quality Commission
CAMHS – Child and adolescent mental health services
IRAS - Integrated Research Application System
NHS REC – National Health Service Research Ethics Committee
OCD – Obsessive compulsive disorder
SDM – Shared decision-making
UCL – University College London
UCL JRO – University College London Joint Research Office
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Chapter 1. Introduction

This thesis presents a sociological study that critically analysed shared decision-making (SDM) in mental health inpatient units for young people. The study took place in two inpatient units in England – one suburban and one inner city – with young people aged 13 to 17 years. The main aims of the study were to explore how young people, and the staff working with them, understood and experienced SDM. Further to this, it aimed to identify structures and mechanisms that enabled or constrained decision-making.

Within this introduction I provide an overview of young people’s mental health inpatient units, including the current constraints on young people’s mental health services in England. Following this, I explore the concept of SDM in young people’s mental health policy and practice. I then present my motivations for the study before introducing the structure of this thesis.

1.1 Children and young people’s mental health services

Inpatient units are specialist mental health services for young people (McDougall et al., 2008). The majority (84%) of young people who are admitted are not subject to the Mental Health Act Mental Health Act 1983 c.20 ; (Tulloch et al., 2008). This means that most young people are admitted as informal (voluntary) patients, rather than being detained without their agreement, which is often referred to as ‘being sectioned’. The most commonly reported diagnoses given to young people admitted to inpatient
units include eating disorders, drug or alcohol use, depression, anxiety or psychosis and most are aged 15 to 18 years (Frith, 2017).

There has been much discussion about the rise in mental health problems in children and young people. For example, Fink et al. (2015) reported a 7% rise in emotional difficulties in girls between 2009 and 2014, with other difficulties seeming to remain stable. However, prevalence data over time appears to show only a small increase in levels of mental health difficulties in children and young people (Pitchforth et al., 2018; Sadler et al., 2018). However there has been a significant six-fold increase in reported prevalence of mental health problems since 1995 (Pitchforth et al., 2018). Therefore, the small rise maybe exacerbated by increased acknowledgement and help seeking, alongside cuts to youth and mental health services, meaning there is a significant lack of support for children and young people.

Despite the government stating that mental health is a key priority, child and adolescent mental health services (CAMHS) are underfunded and are being further eroded due to funding cuts (Callaghan, Fellin and Warner-Gale, 2017). On average, only 6% of the spend of local mental health budgets is spent on CAMHS (Children's Commissioner, 2017), yet 50% of mental health problems are established by the age of 15, and 75% by the age of 25 (Kessler et al., 2005). Further to this, only 25% of children and young people with mental health difficulties receive support (Future in Mind, 2015). As the Care Quality Commission (2017b) stated, CAMHS is under pressure from increasing demand – a Freedom of Information request to NHS Trusts in
England by the NSPCC found that referrals to mental health services were up by a third in the three years between 2014/15 and 2017/18 (NSPCC, 2018). When young people are referred to specialist mental health services waiting times are long, with the average wait to be seen being 26 weeks, which has doubled since 2010/11. Similarly, young people’s attendance at accident and emergency departments for mental health has doubled since 2010 (Care Quality Commission, 2017b).

The pressure on CAMHS and the increase in young people seeking or being referred for help from mental health services have to be seen in the context of massive cuts to central and local government funding for children and young people’s services, such as youth services and early intervention services (Action for Children, National Children's Bureau and The Children's Society, 2016). Between 2010/11 and 2015/16 the significant decrease in funding for children’s services has included a £2.4 billion reduction in central government funding and £1.4 billion from local government funding, resulting in a 40% real terms reduction in spend on early intervention services, including youth services (Action for Children, National Children's Bureau and The Children's Society, 2018). Just under half of local authorities (45%) have made cuts of at least 30% in real terms to services for young people (Action for Children, National Children’s Bureau and The Children's Society, 2016).

The pressure on early intervention services and CAMHS is also increasing the strain on inpatient unit places and on young people waiting to be admitted. A survey of members of the Royal College of Psychiatrists
highlighted that 77% reported difficulties in accessing admissions to inpatient units for young people (Royal College of Psychiatrists, 2014). Furthermore, 79% reported safeguarding concerns/incidents whilst young people were waiting to be admitted, and 61% reported young people being held in inappropriate settings, such as Police cells or paediatric wards (ibid.). They cited multifactorial reasons for the challenges of accessing inpatient services, including increases in the numbers of children and young people being referred for admissions, decreased capacity of social care, decreased capacity in inpatient services and decreased capacity of community mental health services (ibid.).

When places are available in inpatient units, they are often a long distance away from young people’s home (Frith, 2017; House of Commons Health Committee, 2014). Whilst it is difficult to capture data on how many young people this affects, a survey of 100 young people (NHS England, 2014) suggests that 16% of young people travelled over 100 miles. Similarly, the lack of places in inpatient units means a significant number of young people are still being placed on adult mental health wards (Care Quality Commission, 2017b; Frith, 2017; House of Commons Health Committee, 2014), despite a duty (Section 31 of the Mental Health Act 2007) and guidance (Department of Health, 2014) stating that young people should be accommodated in age-appropriate environments. Furthermore, this means some are admitted even though it may not be appropriate (or indeed harmful) because it is the only option (NHS England, 2014) because suitable community mental health and social care services are not available (Frith,
There is limited data on the outcomes of treatment in inpatient units (Care Quality Commission, 2017a) and inpatient units are risky. Assessments of the risks of admission to inpatient units often focus on harm to self or others, but other less commonly evidenced risks include dislocation from normal life, identity, friends, education, family and the impact of stigma (Edwards et al., 2015; Hannigan et al., 2015).

There are currently significant constraints on the resources for and types of mental health support available in England. These constraints impact most keenly on the children and young people who are waiting for or accessing help and support. However, these strains will undoubtedly be putting significant pressure on those working in mental health services. As the Care Quality Commission (2017b) highlighted, pressure on mental health services has significantly increased workloads and is having a detrimental effect on staff wellbeing. Therefore, the practice of staff also needs to be viewed in the context of the significant pressure they are experiencing. Whilst approaches like SDM may seem like an additional extra, particularly when young people, services, and practitioners are under such pressure, and given the current scarcity of resources, SDM and collaboration between young people and practitioners is perhaps more crucial than ever.

1.2 Shared decision-making in young people’s mental health services

Involving young people in decision-making is promoted in government mental health policy and guidance (Department of Health and NHS England, 2015;
NHS England, 2016). The Chief Medical Officer for England (2013) stated that SDM should be at the heart of person-centred care for young people (Chief Medical Officer, 2013). Reviews of CAMHS by the Care Quality Commission (Care Quality Commission, 2017b; Care Quality Commission, 2018) state that person-centred care and SDM should be key to improving mental health services and central to providing high quality care. However, the promotion of SDM and person-centred care is juxtaposed with and contradicted by policy that is also influenced by conflicting neoliberal discourses of risk, moral responsibility, and medicalisation (Callaghan, Fellin and Warner-Gale, 2017; Ramon, 2008).

1.3 What is shared decision-making?

NHS England defines SDM as:

a process in which individuals and clinicians work together to understand and decide what tests, treatments, or support packages are most suitable bearing in mind a person’s own circumstances. It brings together the individual’s expertise about themselves and what is important to them together with the clinician’s knowledge about the benefits and risks of the options. This means that lay expertise is given the same value as clinical expertise (NHS England, 2018).

Charles, Gafni and Wheelan (1997) situate SDM within a spectrum of decision-making from paternalism, where the professional makes the decision, through to informed decision-making, where the patient makes the decision independently. Table 1 outlines the key elements of each of these perspectives.

Table 1: Models of treatment decision-making, adapted from (Charles, Gafni and Wheelan, 1997)
<table>
<thead>
<tr>
<th>Model of decision-making</th>
<th>Key elements</th>
</tr>
</thead>
</table>
| Paternalistic             | • The patient is passive  
• The doctor is the expert  
• The doctor dominates the encounter and diagnoses, recommends tests, treatments, or at most gives selected information to the patient  
• The patient is outside of the decision-making role  
• Decisions are made in the ‘best-interests’ of the patient |
| Shared decision-making   | • Decision-making involves at least 2 participants (clinician/patient), but may involve more (e.g. more clinicians or the patient’s family members)  
• Both parties bring expertise and there is two-way information sharing:  
  o Clinician – expertise and knowledge of treatment options  
  o Patient – expertise on values, preferences and goals  
• The clinician elicits patient preferences so that the treatment options are compatible with patient preferences  
• Decision-making involves patient preference and clinician preference  
• A decision is reached and agreed by both parties |
| Informed decision-making | • Information sharing, from physician to patient, enables patient as consumer to overcome an information deficit and make independent treatment decisions – the patient now possesses both treatment and preference knowledge  
• It assumes information empowers patients to be autonomous |
- Decision-making rests with autonomous patient
- The doctor and their treatment preferences are not included within the decision-making role
- An informed patient may actually prefer to make autonomous, shared or physician-led decisions

SDM sits within an ethos of person-centred care, which sees patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs (Health Foundation, 2012; Health Foundation, 2014a; Health Foundation, 2014b). This involves giving weight to patient knowledge and expertise alongside professional or scientific knowledge (NHS England, 2018). Patients’ expertise involves (but is not limited to) knowledge about their needs and how medical regimes will fit with their everyday lives. This includes their values, goals, and what risks and benefits they are willing to accept and what they are willing trade off (Health Foundation, 2012; Health Foundation, 2014a; Health Foundation, 2014b). Patients’ values, preferences and knowledge are vital for SDM because research shows there is a gap between what patients want and what professionals think they want and far too many decisions are made in ignorance because they do not take account of patient preferences (Mulley, Trimble and Elwyn, 2012). All decisions have risks, benefits, and trade-offs and professionals cannot recommend the right treatment without knowing how the patient values these trade-offs (ibid.).

Following a systematic review of conceptual definitions of SDM, Makoul and Clayman (2006) proposed an integrative model of SDM. The aim of this was
to review the range of features from the various definitions of SDM to
determine the most common components, and attempt to develop a shared
understanding and definition of SDM. They categorised these as:

- essential features, which must be present for SDM
- ideal features, which may enhance the experience of SDM but are not essential
- general qualities, which provide an overall sense of SDM, but are not specific behaviours

These are outlined in more detail in Table 2 below.

**Table 2: An integrative model for SDM. Adapted from Makoul and Clayman (2006)**

<table>
<thead>
<tr>
<th>Essential</th>
<th>Ideal</th>
<th>General qualities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Define and/or explain the problem that needs to be addressed</td>
<td>Un-biased information</td>
<td>Deliberation/negotiation</td>
</tr>
<tr>
<td>Present and review options</td>
<td>Define roles (desire for involvement)</td>
<td>Flexibility/individualised approach</td>
</tr>
<tr>
<td>Discuss the pros and cons (as may have different perspectives of the relative importance of benefits, risks etc.)</td>
<td>Present evidence (only available for certain clinical decisions)</td>
<td>Information exchange</td>
</tr>
<tr>
<td>Discussion of patient values and preferences,</td>
<td>Mutual agreement</td>
<td>Involves at least two people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Middle ground</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mutual respect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Partnership</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient participation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Process/stages</td>
</tr>
<tr>
<td>including ideas, concerns and outcomes expectations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Discussion of patient ability and self-efficacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Regularly check and clarify understanding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Shared decision is made or explicitly deferred</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Follow-up arranged</td>
<td></td>
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</tr>
</tbody>
</table>

However, the above approach reduces SDM to a set of seemingly benign behaviours or actions. For example, ‘present and review options’ is deemed essential yet mutual agreement is only desirable. Furthermore, several seemingly important practices, such as negotiation and deliberation, mutual respect, and partnership are seen only as general qualities, which provide a ‘sense of SDM’. It may be argued that these are more than qualities and do not just provide a sense of SDM. These can be the very practices that affect and demonstrate a shift in the balance of power between professionals and patients.

Dominant models of SDM are therefore often critiqued as they are based on individual notions of autonomy and have a narrow focus on the decision, rather than the process (Entwistle and Watt, 2006). This means they are
task-orientated and transactional, focus on information provision to present options to choose from, focus on patient behaviours, and overlook the value and importance of respectful and emotionally supportive relationships that many patients value (ibid.). Broader conceptions of SDM are based on relational autonomy and look beyond the provision of information and include an understanding of the importance of relationships, a wider understanding of ‘sharing’, and the contextual factors of SDM (ibid.).

There is also little research on disagreement or negotiation and the possible power struggles between professionals and patients (Montori, Gafni and Charles, 2006). The increasing focus on seeing SDM as relational means exploring the context and factors that influence decision-making, not just on the decision itself (ibid.). This should include the patients’ and professionals’ subjective experiences of their involvement, such as what they feel about their relationships, efforts and contributions to decision-making (Entwistle and Watt, 2006). For example, as Sutcliffe (2010) identified in SDM with children (chronic care), critical elements of SDM are taking a whole-person approach, facilitating young people’s active involvement in discussions, fostering a sense of trust and partnership, positive and respectful relationships, and making mutual decisions.

SDM therefore also involves seeing and getting to know the patient as a person and recognising their individuality and specificity; seeing the patient as an expert about their own health and care; recognising autonomy; and sharing power and responsibility (Health Foundation, 2014a).
People (predominantly adults) with mental health issues have long advocated for more choice about their care and treatment, and SDM aims to level the playing field by giving people access to the required evidence-based information about treatment, alternatives and recovery (Drake, Deegan and Rapp, 2010).

Deegan and Drake (2006) contend that SDM in mental health promotes a dynamic process where the advantages and disadvantages of treatment options can be assessed and which incorporates the evidence base, the person’s experiences and the practitioners’ expertise, promotes the client’s right to autonomy and enables informed decision-making. SDM is:

   inextricably linked to adult consumer movements, which have fought in the last quarter century against the traditional medical model, which holds that persons with mental illness are unable to make decisions about their own health care (O’Brien et al., 2011, p. 310).

It is argued that SDM is an ethical imperative in mental health where people have the right to make informed choices about what happens to their bodies and minds (Drake, Deegan and Rapp, 2010; Drake and Deegan, 2009). This may be particularly important as mental health decisions are rarely clear cut and often involve complex trade-offs, which are (arguably) best evaluated and assessed by people themselves (Drake, Deegan and Rapp, 2010). As Drake, Deegan and Rapp (2010, p. 9) suggest:

   instead of isolating people in their experience of suffering and resilience, shared decision-making is about sharing and collaborating as partners with medical practitioners.
Drake, Cimpean and Torrey (2009) suggest SDM in mental health care holds promise in increasing satisfaction, informed decision-making, self-management and more meaningful outcomes. Tait and Lester (2005) summarise the benefits of user involvement in mental health care, as people using mental health services are experts about their own illness and need for care. They may also have different but equally important perspectives about their illness and care, may increase the existing limited understanding of mental distress, and are able to develop alternative approaches to mental health and illness (ibid.). Langer and Jensen-Doss (2016) suggest the two dominant arguments for SDM are that it promotes respect for autonomy and improves treatment outcomes. SDM, therefore, is grounded in people’s right to be involved in decisions about their health and healthcare. A review of academic discourse on the rationale for SDM in mental health care identified key themes, which included that SDM is best practice; it is cost effective; it fosters adherence and engagement; people want and are able to be involved in decisions; it is a legal and ethical obligation; it empowers people; strengthens the therapeutic relationship; it draws on experiential knowledge; and it protects people against coercion (James and Quirk, 2017).

Yet, despite the increased focus on SDM, research in mental health is far behind that of physical health (Adams and Drake, 2006). This is particularly so for children and young people’s mental health where there is a paucity of research (Cheng et al., 2017; Simmons and Gooding, 2017). There is also little research into young people’s experiences of acute inpatient mental health care (Stenhouse, 2011), particularly regarding involvement in
decisions about their care and treatment (LeFrançois, 2008; LeFrançois and Coppock, 2014; Stenhouse, 2011). What little literature there is shows that young people do not feel involved in decisions about their mental health care (Care Quality Commission, 2017b; Care Quality Commission, 2018; LeFrançois, 2007; LeFrançois, 2008; Moses, 2011; Offord, Turner and Cooper, 2006; Simmons, Hetrick and Jorm, 2011; Stenhouse, 2011; Tulloch et al., 2008).

SDM aims to bring patients into the decision-making process. This necessitates giving weight to the views, values, expertise and knowledge of the patient, alongside evidence and the knowledge of professionals. This means that people have to be seen as knowers and reliable holders and givers of knowledge. It is therefore important to understand what challenges this poses for young people, and for young people experiencing mental distress in particular (this will be explored further in Chapter 2). Given the paucity of research into SDM in young people’s mental health care, particularly within inpatient units, there is a need to explore and understand SDM in this context.

1.4 My motivations

My interest in decision-making is longstanding. I have worked alongside young people for many years, firstly in care services (children’s homes and services for children and adults with learning difficulties), and later in advocacy, rights, and participation in disability and mental health. The focus of my work to inform services, policy and practice, has been on empowering
young people to influence decisions in their own lives, to speak up about issues that are important to them, and to improve the services and support they receive.

When young people talk about their experiences of services, support, or their relationships with those who matter to them, a strong and recurrent theme is of the importance of being seen, heard, listened to and involved in decisions that affect them. Yet they also commonly say they do not feel involved or engaged and have little control or influence over decisions that affect them. At the same time, professionals often talk of their belief and desire to involve young people more. They believe they are already doing so, or feel constrained by a lack of time, resources and support.

Hearing the many experiences of young people and working in partnership with them to improve services and support has made me particularly interested in how far young people, particularly those experiencing distress or who have communication or learning difficulties, are seen as decision-makers. I have always had a keen interest in why some people are seen as inherently less able to make decisions than others. I see many contradictions in the importance people place on choice and the freedom to choose for some but less so for others. For example, why do some adults, who have taken their own right to make decisions for themselves very seriously, see children’s choices as frivolous or optional? Or why do some professionals expect the people in their services to follow the rules of the service and their professional guidance, yet are frustrated when their own choices are
constrained, or they are not heard or listened to by their managers? I have always been keen to explore these contradictions and understand what is it that enables or constrains decision-making and who is valued or devalued as a decision-maker.

This interest has also been fuelled by my personal experience. As a teenager caring for my nan, whose dementia slowly took away her ability to express herself and her wishes verbally, my family and I endeavoured to find a way to listen to her and maximise what influence she could have on what was happening around her. Professionals often saw her as incapable of forming a view. Yet she clearly communicated what she liked and didn't like if you looked and listened. I have also stood alongside my brother who has complex mental health issues and have seen how professionals value or devalue his views.

There is still little research on SDM in young people’s mental health. In addition, as shown later in this chapter, the research that is available tends to focus on tools to support SDM, rather than on what enables or constrains it. This study is driven by a commitment and desire to understand some of the underlying mechanisms and constraints that affect decision-making, and how young people are constructed as, and see themselves as, decision-makers. It is by understanding these that real change may become possible.
1.5 The structure of this thesis

This section offers a brief overview of the structure of the thesis and introduces each chapter.

Chapter 2 provides a review of the literature related to SDM and young people’s mental health inpatient care. It begins by exploring the legal framework and ethical principles for decision-making for young people under 18 years of age in relation to their care and treatment. Following this, it explores the dominant constructions of autonomy and how young people’s autonomy and capacity to make decisions, or be seen as competent decision-makers and moral agents, are constrained. It then explores some of the key challenges to decision-making in children and young people in mental health services including tripartite decision-making, power and the asymmetry of relationships, paternalism and best interests, and coercion.

Following this, Chapter 3 describes the methodological approaches for this study. It begins by outlining the ontological and epistemological positions of critical realism (CR) that underpin the analytical framework of this research, and explains why these concepts are important for this study. Further to this, it explores how CR was applied within the research and how the four-planar social being (Bhaskar, 1998) and the work of Margaret Archer on agency and reflexivity (Archer, 2000; Archer, 2003) were used during the analysis and to structure the findings. The chapter then details why critical ethnography was employed as the methodological framework, before describing the methods,
and the many ethical considerations in the planning, design and practice of the research. It ends with an explanation of how the data were analysed.

Chapter 4 provides a brief introduction to the findings. The following four chapters then detail the findings from the research, which are structured using the CR framework of the four-planar social being (Bhaskar, 1998; Bhaskar, 2008a). The four-planar social being is a framework to situate events and describes the different, interacting planes that social events occur on and on which individuals act as agents and decision-makers. Each chapter relates to one of the four planes as described below.

Chapter 5, *Restricted bodies, restricted being*, explores plane one, *material transactions with nature*, the physical reality of bodies, and how they interact and transact with the natural world and physical environment. This includes the physical reality of how being admitted into, and the many constraints of being in the restrictive environments of inpatient units, affected young people and their involvement in decision-making.

Chapter 6, *Knowing and doing: distant decisions*, explores plane two on interpersonal interactions and relationships. This includes the constraints on decision-making within relationships and interactions between staff and young people.
Chapter 7, *Social systems that constrain and promote mistrust*, explores plane three on social relations, structures, and institutions. This includes how the systems within the inpatient units affected decision-making.

Chapter 8, *Reflexivity: distress, alienation, and resistance*, explores plane four on intra-subjectivity and subjective agency. This includes the reflexivity of young people and staff, how they reflected on constraints, how this affected their subjective sense of agency, and how they saw their inner selves in relation to being a decision-maker.

Following the findings, Chapter 9 summarises them and draws them together to explore the common themes in decision-making and themes of the self, dignity and moral agency.
Chapter 2. Decision-making and the problems of power and autonomy

2.1 Introduction

As shown in the previous chapter, SDM is being advocated for across health and mental health services. SDM aims to bring the knowledge and values of patients into the decision-making process, yet experiencing distress or being young are often heuristics for unreliability and young people commonly experience not being believed (Harcourt and Martin, In press). It is therefore crucial to explore the power dynamics that influence SDM and how far young people experiencing mental distress are understood as decision-makers. This study explores the dynamics and constraints that influence and affect decision-making in young people’s mental health inpatient units.

This chapter firstly explores the available literature on SDM in children and young people’s mental health services to understand what is known about the possible benefits and young people’s experiences of decision-making. It then explores the ethical principles and legal frameworks for decision-making with children and young people in mental health care.

Following this, it examines what it means to be (and be seen as) a decision-maker, and what problems this poses in relation to age and mental health. It then critically examines the literature to identify the power dynamics and constraints on decision-making with children and young people in mental health services.
Due to the limited research on SDM in young people’s inpatient units, this chapter draws on the wider literature to explore the dynamics that may constrain decision-making. This includes drawing on the broader themes from the literature on SDM as a concept; the literature on SDM from physical health; the challenges identified in the literature from SDM in adult mental health; the issues posed for children and young people and SDM (predominantly from physical health); and the literature on SDM in children and young people’s mental health care.

The reason for doing so is to explore the possible dynamics and constraints on SDM for children and young people, due to their age and status as a child or young person, as well as those that exist in relation to mental health problems and services. This is not to assume that young people’s experiences are the same as adults in mental health services, but rather not to discount them purely on age grounds. There may be similarities owing to the way in which mental health problems are constructed or owing to the power dynamics that exist in mental health services.

This chapter therefore explores:

- the existing research in SDM in young people’s mental health care, including possible benefits and challenges
- the legal framework and ethical principles that govern decision-making in children and young people’s mental health services
- the problems of rational constructions of autonomy
• the problems children and young people experience in being seen as competent decision-makers due to assumptions about their age and mental health
• power and the constraints on decision-making, including tripartite decisions between young people, parents and professionals; paternalism and best interests; and coercion and compulsion.

2.2 Shared decision-making in young people’s mental health care
The following sections draw on the available literature to explore the possible benefits and challenges of SDM in young people’s mental health care.

Young people want to be more involved in decisions about their mental health care (Care Quality Commission, 2017b; Care Quality Commission, 2018; Crickard et al., 2010; Davies and Wright, 2008; Simmons, Hetrick and Jorm, 2011), particularly in the analytical stages of decision-making, such as weighing up the benefits and risks of treatment options (Simmons, Hetrick and Jorm, 2011).

Whilst there is little research or evaluation of SDM in children and young people’s mental health, different models of SDM are emerging. Wolpert et al. (2014) identified five key stages for SDM with children and young people in CAMHs during the therapeutic process, which include young people and mental health practitioners working together to agree key problems and goals; understanding the options available; agreeing which options for help to
try; reviewing progress; and discussing options and making any changes as necessary. Other models to support SDM with young people include those by Crickard et al. (2010) on medication decision-making; Simmons (2012) on steps of SDM in youth mental health care; (Langer and Jensen-Doss, 2016) on SDM and psychotherapy; and Martin (2017) to support open conversations about decisions and to clarify the level of influence young people have. These provide helpful frameworks to elucidate the key steps involved in SDM, but do not take account of the power imbalance between adult professionals and young people.

There are also a small but increasing number of tools to assist and support SDM in young people’s mental health care. In a review of tools and approaches to support SDM in children and young people’s mental health, 22 records were identified and grouped under six types of approach, which included therapeutic techniques, decision aids, psycho-educational information, action planning or goal setting, discussion prompts, and approaches that mobilised patients to engage (Hayes et al., 2018a). However, of the 22 identified, 12 of these were aimed at parents rather than children and young people (ibid.). Whilst tools do not do SDM in and of themselves, they can assist with elements of the decision-making process as, for example, they can help to balance power, make SDM more tangible for young people, and increase their sense of control (Wolpert et al., 2014).
2.2.1 What are the potential benefits of SDM in children and young people’s mental health care?

There is emerging evidence of the benefits of SDM in young people’s mental health, but what there is predominately focuses on community services, rather than inpatient units.

The literature on SDM in young people’s community mental health care identifies a number of possible benefits. For example, young people have specific expertise about their lives and bodies (O’Brien et al., 2011) and involvement in decision-making:

- may enable clinicians and parents to acquire a better appreciation of children and young people’s needs and experiences (Day, 2008).

Furthermore, SDM is key in developing shared goals for therapy (Day, 2008; Feltham et al., 2018; Law, 2018) and encourages transparency and clarity about what is being worked on, and openness about progress (or lack of it) (Wolpert et al., 2014). SDM may be particularly useful to facilitate open and transparent conversations when there is disagreement or resistance to goals or therapy (Feltham et al., 2018). Other possible benefits of involving young people in decisions about their mental health care include that it respects their fundamental right to be involved; respects their autonomy; increases their adherence to treatment; empowers them; and increases their safety by, for example, being able to recognise side effects and knowing what to do about them (Crickard et al., 2010; Davies and Wright, 2008; Richardson, McCauley and Katon, 2009; Simmons, Hetrick and Jorm, 2011). Involving
both children and parents in decision-making may contribute to enhanced treatment outcomes (Edbrooke-Childs et al., 2016).

There is even less research about SDM in inpatient units for young people. Wolpert et al. (2014) led a service improvement project¹ to explore SDM in four mental health services in the UK (three community services and one forensic inpatient service). The project found that SDM can facilitate open conversations even in very stressed contexts, such as forensic inpatient units, which helped young people to make more informed decisions about their own risk and safety and enabled them to better understand restrictions due to risk. Young people felt that being involved in SDM did not change their behaviour or difficulties, but rather changed the way they felt (ibid.). They described how being involved in SDM meant they felt more valued, listened to, empowered and in control, which improved their experience of care as they could take more ownership of their treatment and understand the reasons behind the clinical work (ibid.). Nurses also reported anecdotal evidence of a significant reduction in the use of restraint and risk incidents the more that young people became involved in SDM (ibid.).

In a study on the experiences of young people with eating disorders, young people reported that collaboration in their treatment and therapy was extremely beneficial and enabled them to feel heard rather than presided over (Offord, Turner and Cooper, 2006). The helpful practices they identified

¹ I also took part in this project. My role was to facilitate young people’s involvement in the governance, design and delivery of the project.
included clear, factual information; setting goals and incentives; and staff who listened. Similarly, a study on young people’s views of meaningfulness in inpatient admissions in the USA showed that young people valued goal setting and breaking problems down into smaller steps based on what was most important and meaningful to them (Grossoehme and Gerbetz, 2004).

Experience and engagement can influence how much young people are willing to engage in treatment. For example, an Australian study of young people’s experiences of being admitted to an inpatient unit found that whether or not young people had a choice to be admitted was a key influence on whether they engaged or were dissatisfied (Salamone-Violi, Chur-Hansen and Winefield, 2015).

Thus, research has shown that many young people want to be involved in decisions about their mental health care. They value relationships and interactions that make them feel understood, valued and respected as a person; where they have time to talk things through with someone they trust; where they can deliberate and weigh up different options; and undertake actions, such as goal setting, that facilitate involvement based on what is most meaningful to them.

Young people in inpatient services want to be more involved in decision-making (Street, 2004), yet despite the possible benefits of SDM, many young people using mental health services do not feel involved in decisions about their care and treatment (Care Quality Commission, 2017b; Care Quality
Commission, 2018). This is particularly so for young people using inpatient services (Simmons, Hetrick and Jorm, 2011). In an ethnographic study in an inpatient unit in England, LeFrançois (2008) reported that young people had little or no choice over treatments and were not allowed to attend weekly review meetings, where key decisions were made about their leave, treatment options, and progress. Their involvement was limited to telling their case managers what decisions they would like to be made at the meeting and many young people reported that their views were rarely taken into account (ibid.).

There is a clear lack of research on SDM in young people’s mental health services, particularly within inpatient services within the UK or internationally. The literature available does not explicitly acknowledge or address the wider power imbalances or dynamics that enable or constrain young people’s decision-making, or how young people were constructed as decision-makers and givers of knowledge. What literature there is relating to SDM in inpatient services is within others studies on, for example, patient satisfaction, which describes how young people do not feel involved in decisions, or feel restricted and silenced. However, none of the studies explore the factors that enable or constrain decision-making in inpatient units or how SDM is affected by the power imbalance between adult professionals and young patients. This study is therefore the first to examine how young people and staff understand and experience SDM in young people’s mental health inpatient units in the UK; the factors that enable or constrain SDM in young people’s
inpatient units in the UK; and the first to explore SDM in multiple inpatient units.

The remainder of this chapter therefore firstly examines young people’s rights to be involved in decisions about their care, and then explores the dynamics, challenges, and constraints that affect young people’s involvement in decision-making about their mental health care.

2.3 Law, rights and ethics

Children and young people’s rights to be involved in decision-making are also enshrined in the United Nations Convention on the Rights of the Child (UNCRC). Children’s right to be heard is one of the four core principles of the UNCRC, which is expressed further in Articles 3, 12 and 13. Article 12 states children have a right to form and freely express their views and for their views to be given due weight and Article 13 states children’s right to freedom of expression, and to impart and receive information. Article 3 states that in all actions or decisions made by institutions concerning children, the best interests of the child will be paramount (best interests are explored further in section 2.6.2). As Wiesemann (2016) argues, the children’s rights movement has been the most important factor in increasing awareness of and protecting the moral position of the child.

However, the UNCRC rights are weak or provisional as, for example, they rest on state authorities’ discretion to implement them or depend on adults’
determination of whether a child ‘is capable of forming a view’ or what they determine to be due weight (Alderson, 2018).

2.3.1 What are young people’s legal rights to involvement in decisions about their care?

The law on who can consent to treatment for children and young people varies depending on their age; whether they are deemed to have capacity to consent; and whether consent is for a hospital admission for the assessment or treatment of a mental health problem.

Those deemed as having capacity to consent to treatment are adults (deemed to be competent); 16- and 17-year-olds (although this can be overridden, which is explored further in a later in this section); a child under 16 who is *Gillick* competent; a person or local authority with parental responsibility; and a court (Brazier and Cave, 2011).

Children and young people, who are under 16 years old, can give consent to treatment if they are deemed *Gillick* competent. *Gillick v West Norfolk Area Health Authority*, was a landmark decision that created a new legal recognition of minors as independent rights-holders (Cave, 2014, p. 103) and gave priority to young people’s welfare over parental interests (Alderson and Montgomery, 1996). In the ruling, Lord Scarman determined that:

As a matter of Law the parental right to determine whether or not their minor child below the age of sixteen will have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed (*Gillick v West Norfolk & Wisbech Area Health Authority*, 1985).
There is no specific age that a child is deemed to become *Gillick* competent, but rather this must be assessed for each decision, as children may be competent to consent to some treatments before others. This is particularly pertinent to young people’s decision-making in mental health as, due to a mental health problem:

- a child’s mental state may fluctuate significantly, so that on some occasions the child appears *Gillick* competent in respect of a particular decision and on other occasions does not (Department of Health, 2009).

The Family Law Reform Act 1969 enables 16- and 17-year-olds to consent to treatment. However, the consent of the parent still has to be requested if they are not assessed as being *Gillick* competent (Brazier and Cave, 2011; Department of Health, 2009).

The Mental Capacity Act Code of Practice issued advice on 16- and 17-year-olds (Department for Constitutional Affairs, 2007) and states that most of the Act applies to people aged 16 and over, if they lack capacity to make a particular decision (but does not apply to children). The Mental Capacity Act 2005 c.09 assumes that adults have capacity (but this can be overridden) and has a narrower test for capacity than *Gillick* competence (Cave, 2014). An assessment of a person’s capacity is decision specific and a person is deemed to lack capacity if they are unable:

- to understand the information relevant to the decision
- to retain that information
- to use or weigh that information as part of the process of making the decision, or
• to communicate his decision (whether by talking, using sign language or any other means).

Following the legal ruling in the case of Montgomery, there is a general consensus that SDM is vital to consent in that it requires a dialogue of material risks and benefits of available options, including the option of no treatment (Adshead et al., 2018, p. 630), which raises the status of shared decision-making from guidance to legal requirement [...] because with Montgomery the requirement for shared decision-making is no longer optional but essential to valid consent (ibid. p. 631).

This sets out the requirement for a dialogue which includes the perspective of the clinician and the patient, which is made clear through a two-pronged test of material risk, which recognises that patients and professionals may see risks and benefits differently (ibid). The test includes risk either from the perspective of a reasonable person in the patient’s position (first limb of the test), or from that of the particular patient concerned (second limb of the test) (Adshead et al., 2018, p. 630). This prevents clinicians from not disclosing risks when they deem this is in the ‘best interests’ of the patient, for example, because they worry they patient will refuse treatment if they know the risks (Adshead et al., 2018).

The law on young people’s rights to consent to medical treatment is therefore complicated. The various tests of competence involve the judgement of professionals and are therefore open to interpretation.
2.3.1.1 Consent for admission to hospital for assessment or treatment for mental health problems

The law on minors and mental health is even more complex and complicated. Three main acts regulate admission; the Mental Capacity Act 2005; the Mental Health Act 1983; and the Mental Health Act 2007. The detail within each of these acts relates mainly to adults and it is usually assumed that parents will represent minors under regulations in the Children Acts 1989 and 2004.

There is also important guidance in two related codes, the Mental Capacity Act 2005 Code of Practice (2007) (Department for Constitutional Affairs, 2007) and the Code of Practice: Mental Health Act 1983 (Department of Health, 2008). Guidance that is specific to children and young people can be found in The legal aspects of the care and treatment of children and young people with mental disorder: A guide for professionals (Department of Health and National Institute for Mental Health in England, 2009). This guidance is aimed at mental health professionals and sets out to explain the complex legal framework for the care and treatment of children and young people who may require admission to an inpatient unit.

Children and young people may be formally (involuntarily) or informally (voluntarily) admitted to hospital for assessment and treatment of mental health problems. Formal admission to hospital takes place under Section 2 or Section 3 of the Mental Health Act 1983.
Consent for informal admission to hospital is more complicated. The majority of young people, 84%, are admitted voluntarily (Tulloch et al., 2008) on the basis of parental consent, although the child themselves may be resisting admission and therefore compulsory. Section 43 of the Mental Health Act 2007 c12 amended the Mental Health Act 1983 c.20 (s131) meaning that a 16- or 17-year-old with capacity can consent to informal admission (even if there is someone with parental responsibility) and where they refuse, they cannot be admitted on the basis of parental consent. For children under 16 years old, the Mental Health Act 1983 Code of Practice states that there are certain circumstances when a person with parental responsibility may give consent for them to be admitted voluntarily to hospital for treatment. This can also apply to young people who are 16 or 17 if they lack capacity. However, parental consent in these circumstances may only be relied upon if it falls within the Zone of Parental Control (ZPC) (see later in this section for a fuller discussion of the ZPC), or where it concerns certain forms of treatment such as electroconvulsive therapy (ECT) (Department of Health, 2008).

2.3.1.2 Refusal to give consent for treatment
The law on refusing treatment is even more complex. Whilst young people have the right to consent to treatment, they do not have the same rights to withhold their consent and refuse treatment. Gillick competent minors and 16- and 17-year-olds can have their refusal of treatment overridden by someone who has parental consent (in certain circumstances) or the courts.
It was initially assumed that the *Gillick* ruling applied equally to young people’s right to consent to and refuse treatment, but Lord Donaldson’s rulings in *Re R* [1991]; *Re W (A Minor) (Medical Treatment: Court’s Jurisdiction* [1992]) (summarised in Figure 1) narrowed their rights to refuse. Following the rulings, the consent of only one person with the right to give consent to treatment, the parent or the child, could overrule the refusal of all the others. Therefore treatment can be enforced on resisting children if it is determined to be in their best interests (Alderson, 2007). Minors’ liberty can be restricted and they can be forced to undergo medical treatment for mental health problems without the use of the Mental Health Act (*Re K, W and H* [1993]). If the Mental Health Act is in force and a child is competent, the court’s inherent jurisdiction can override her consent or refusal (*Re R (A Minor) (Wardship: Consent to Treatment)* [1992]) (Paul, 2004).

The concept of the Zone of Parental Control (ZPC) (derived from case law from the European Court of Human Rights) was introduced by the Mental Health Act 1983 Code of Practice (Department of Health, 2008). The ZPC: is a method of classifying the mental health care and treatment of children and young people into two groups: one group that can be subject to authorisation by a parent or someone acting with parental responsibility (PR, a concept defined in the Children Act (1989)); and the other group not being able to be authorised by someone with PR. According to the code, actions that lie within the ZPC are subject to what society currently deems as reasonable for a parent to agree to, and what human rights rulings have agreed with (Watts and Mackenzie, 2013).
The ZPC limits the right of those with parental responsibility to give consent to treatment on behalf of a young person who refuses or who lacks capacity (Bowers and Dubicka, 2010). Consent can only be given on their behalf if the decision falls within the ZPC. Decisions or actions that fall within the ZPC are subject to what society currently deems as reasonable for a parent to agree to, and what human rights rulings have agreed with (Watts and Mackenzie, 2013, p. 39).

Otherwise (even if the parent agrees with the proposed treatment), clinicians must use the Mental Health Act 1983 or seek court authorisation (Bowers and Dubicka, 2010).

The law on consent to treatment is inconsistent and contradictory. Rather than promoting children’s autonomy and participation rights, the recent and present law on consent treats young people’s autonomy rights as weak rights and fragile because their competent consent can be easily overridden (Alderson and Montgomery, 1996; Cave, 2012; Paul, 2004).

2.3.2 Informed consent and medical ethics

Involvement in decision-making is also underpinned and guided by principles of informed consent and medical ethics. The detailed principles of informed consent were first established in the Nuremberg Code 1947, to protect people involved in ‘non-therapeutic’ research following the Nazi medical atrocities, but were later expanded in 1964 to include ‘therapeutic’ research (Alderson, 2017). Consent is a freely made and expressed decision (if it must be given, it is not consent) (Alderson and Montgomery, 1996) without undue
influence. The table below distinguishes consent (reason) from persuasion and coercion.

Table 3: Reason, persuasion, coercion (Alderson and Montgomery, 1996) from the Nuremberg Code 1947.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Persuasion</th>
<th>Coercion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impartial</td>
<td>Over-optimism</td>
<td>Ulterior</td>
</tr>
<tr>
<td>discussion</td>
<td>Deceit</td>
<td>constraint</td>
</tr>
<tr>
<td>Negotiation</td>
<td>Fraud</td>
<td>Duress</td>
</tr>
<tr>
<td>Informed choice</td>
<td></td>
<td>Violence</td>
</tr>
</tbody>
</table>

Decision-making and consent to treatment are grounded in concepts of competence, respect, dignity, informed choice and understanding as, without full informed consent, it is an assault for a doctor to perform a physical examination, provide medical treatment, conduct medical research or even touch a patient (Alderson, 2012; Brazier and Cave, 2011; Cave, 2011). The same ethical principles that govern medical care for children and young people also apply to mental health care (British Medical Association, 2001; Paul, Foreman and Kent, 2000) and although we may not actually ‘touch’ the child during an appointment at a Child and Adolescent Mental Health (CAMH) clinic, our professional contact should be taken to be covered by the laws of consent (Paul, Foreman and Kent, 2000, p. 203).

Competent children and young people’s informed and willing consent is imperative legally and clinically, to observe high professional standards; therapeutically, to promote effective care by encouraging children’s
comments and questions, their willing informed cooperation with treatment and their trust in its efficacy; ethically, to respect patients as persons and to avoid the coercion of fearful, uninformed, resisting children; psychologically, to prepare and support children, especially in the event that treatment is not wholly successful, when prior warning of risks can be vital in helping them to adjust and cope (Alderson, 2017, p. 60).

The four main ethical principles in medical ethics are autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress, 1994). One of the key and most commonly cited ethical principles in relation to SDM is autonomy. Kantian constructions of autonomy commonly underpin moral rights and freedoms, the status of adults (Alderson, 2018), and medical ethics (Heubel and Biller-Andorno, 2005). Kant regarded autonomy as the property of rational wills and agents, where rationality is based on reason (Johnson, 2018). Autonomy is seen as affording freedom, dignity, and worth to individuals, where people are seen as an end in themselves, rather than a means to other people’s ends (Donaldson, 2017).

Autonomy can therefore be defined in two ways – as ‘within person’ qualities that enable rational people to make informed and wise decisions; and as an activity of self-determination, of making informed decisions and of being the author of one’s own life (Alderson, 2018; Alderson and Montgomery, 1996). Respect for autonomy is therefore a critical ethical issue to decision-making as it underpins longstanding questions in mental health, such as how and when services should intervene in people’s lives (Pilgrim, 2017) and whether anyone with serious mental health problems can be regarded as rational and competent to give legally valid consent.
Whilst commonly used principles of ethics are grounded in respect for autonomy, as shown earlier in this chapter, young people using community and inpatient mental health services frequently say they do not feel involved in decisions about their mental health care and treatment (Care Quality Commission, 2017b; Care Quality Commission, 2018; LeFrançois, 2007; LeFrançois, 2008; LeFrançois and Coppock, 2014; Simmons, Hetrick and Jorm, 2011; Tulloch et al., 2008). Whilst young people have legal and ethical entitlements to be involved in decisions about their mental health care and treatment, many are prevented from doing so. Therefore, it is vital to explore the constraints on respect for young people’s autonomy and involvement in decision-making in decisions about their mental health care.

The following sections therefore address the following questions:

- What are the problems with the common definitions of autonomy based on rationality?
- What challenges do children and young people face in being seen as competent decision-makers?

### 2.4 The problems of rational constructions of autonomy

Kantian individual autonomy is based on rationality and reason (Johnson, 2018). Rational constructions of autonomy separated emotion from desire, meaning that preferences could be determined by instrumental reason and rational choice (Archer, 2000). Indeed, throughout modernity, rational autonomy was regarded as the defining feature of personhood and
humankind (Archer, 2000; Smith, 2010) suggesting, therefore, that anyone failing to meet one or other of those standards is seen in some way as a defective person (Harcourt and Martin, 2018). However, there is no reason to assume all or most people are rational all the time; in fact, the opposite may be more likely (Bhaskar, 1998) and there is increasing evidence that people make decisions, including those about their healthcare, less rationally and in a less considered way than current constructions of autonomy and decision-making assume (Vos, Schermer and Bolt, 2018).

Kantian rational constructions of autonomy assume that 'rational' decision-makers use all of the information available to them to strive for the best result, assumes that they make correct estimates of risk, and leaves emotions out of consideration (Vos, Schermer and Bolt, 2018). Indeed, it assumes that the very process of rationally weighing up pros and cons is what will determine our preferences (Archer, 2000).

However, Archer (2000) contends that, as reflexive human beings, we deliberate upon our first order items such as our desires, beliefs, and our ultimate concerns (the things which are most important to us and which are core to who we are as individuals) and use this to determine our courses of action (Archer, 2000) (reflexivity is explored in more depth in Chapter 8). People deliberate in relation to the self and run through what is important to them, their values and beliefs, and ask how what they are deciding about links with the self (Wiley, 2010). People search for an act to achieve their goals, with a particular view in mind (ibid.). People also survey the
constraints of their situations under their own, fallible descriptions and interpretations (Archer, 2003). It does not suggest they have, for example, fully understood their situation (this may be due to many reasons including, for example, a lack of access to information or support) but rather they deliberate in relation to how they perceive their situation and context (Archer, 2003). Thus, rather than rational deliberation driving us to our preferences, our deliberations begin from what is most important to us, our beliefs and ultimate concerns which are core to who we are.

Decisions are made less on rationality and are based more on emotion, trust, intuition and emotional beliefs (Vos, Schermer and Bolt, 2018; Wiesemann, 2016). Our emotions are a reaction to the real world (the natural, practical and the social) and are commentaries on our situations, felt in the present and which urge us to bring immediate adjustment (Archer, 2000). Overly rational constructions of autonomy ignore emotion, contingencies, and do not take account of the experiential, emotional, and embodied knowledge of children and young people with, for example, long-term illness or difficulties who have become deeply informed by their experiences (Alderson, 2018).

Rational autonomy also only focuses on actions and how they are explained in terms of the rational properties of agents or:

those actions which can be adequately reconstructed as the outcome of rational decision-making procedures, and hence to those agents who are at the time of, and in respect of, the action concerned ‘rational’. (Bhaskar, 1998, p. 108)
However, this is not value neutral as it assumes that choices should be made consciously and analytically, because that would lead to ‘good’ choices (Vos, Schermer and Bolt, 2018). This is based on assumptions that adults arrive at decisions rationally in comparison to the emotional or irrational child (Wiesemann, 2016). In addition, there is no way of singling out one course of action as rational in a given situation, as there are an infinite number of different sets of beliefs and desires … in principle consistent with the (rational) performance of the action. (Bhaskar, 1998, p. 108).

Bhaskar (1998) contends that every belief or action has a set of real (causally efficacious) reasons that, along with other causes, explains it. Agency involves intention and intention is always caused by reasons, but people are not always aware of their reasons: beliefs may be unconscious, tacit, or implicit as they may be due to unconscious psychological and non-psychological (physiological or sociological mechanisms) and a visible reaction to deeper, invisible constraints (ibid.). Thus, people may do things because they want to or because they feel they are expected to, and existential crises may be due to psychiatric distress or be induced by significant changes in social relations (ibid.). Predominant behaviourist accounts of rational autonomy do not take account of the complexity of situations and structures that enable and constrain agency (ibid.) and the oppressive conditions that affect a person’s sense of self or that obscure choices (Wiesemann, 2016). It is therefore crucial to examine how social relations may constrain agency and decision-making.
Wiesemann (2016) argues that whilst there is an increasing focus on listening to children and young people, they have largely been ignored in philosophical ethics. Indeed, some understandings of autonomy based on rationality are so demanding that many adults would fail to meet these requirements (ibid.). Overly rational constructions of autonomy do not take account of supposedly pre-rational children and young people, or the nature of autonomy for those in dependent relationships,² or where there is a third person involved in decision-making such as a parent or carer, whom the child may rely on emotionally (tripartite decision-making is explored in more depth later in this chapter).

2.4.1 Moral equality

Assumptions about young people’s capacity, moral agency and ability often lead to them being excluded from decision-making. However, children and young people can and do make informed and wise decisions about their lives, care and treatment. Studies in physical healthcare have shown that even very young children can be informed, responsible and reliable in some decisions about their healthcare (Alderson, Sutcliffe and Curtis, 2006a; Alderson, Sutcliffe and Curtis, 2006b) and mental health care (Davies and Wright, 2008; Delman et al., 2015).

However, given the constraints and challenges of rationality and autonomy, young people’s right to self-determination and involvement in decisions

² Except for the ethics of care but these works have largely focused on those in caring roles rather than those who are cared for (Wiesemann, 2016).
requires an adequate theory of moral autonomy (Wiesemann, 2016). Wiesemann (2016) therefore proposes an ethical theory of moral equality which, she argues, must apply equally to adults as well as children and young people, as moral equality will not be realised until philosophical understanding of adulthood also changes (Wiesemann, 2016). As Alderson (2016a, p. 206) suggests:

children’s knowledge, judgement, foresight, freedom of choice, control and agency are all very limited, but so too are adults’ capacities. At all ages, human agency is constantly constrained by structures and by other agents, by resources and chance.

Wiesemann (2016) constructs moral equality as resting on the following. Firstly, moral equality must regard even very young children as being moral agents as they act and communicate in morally meaningful ways. Moral agents are therefore a person who ‘is capable of moral feelings and who acts in accord with those feelings in ways that other moral agents can understand and share’ (p. 393). Moral equality is therefore based on what children and young people do, rather than only the qualities adults ascribe to them.

Secondly, moral equality is based on a dialectic of autonomy and trust, which sees the moral agent as socially situated. Wiesemann proposes that trust is vital to, and is the social and relational aspect of, autonomy. It is the ethical counterpart of autonomy and should be regarded as an independent subject rather than reducing it in to a single concept like, for example, relational autonomy. This therefore means that trust is given its full moral meaning on the same level as the principles of autonomy. Autonomy without trust is 62
difficult, as we all need to trust something within this process, whether that is information, the people imparting that information, or those close to us (ibid.). Here, autonomy is based on Jaworska’s (2009) concept of minimal autonomy. Minimal autonomy is based on carings (rather than rationality) which are more than preferences: they are part of a person’s very identity and represent the self (Jaworska, 2009). Therefore, for minimal autonomy to be met it suffices that children can reflect on their carings, which may be regularly expected once they have developed a sense of self that allows them to consider alternative possibilities; for example, once a child understands that she can lose something she cares a lot about and thinks about different ways to react (Wiesemann, 2016, p. 2529). Choices can therefore be autonomous, even when they go against a person’s wellbeing or their longstanding values (Wiesemann, 2016).

Overly rational constructions of autonomy pose numerous challenges. They do not consider the power dynamics that affect decision-making, the reality of how people make decisions and pose much higher standards for children and young people. The following sections explore how the autonomy and competence of young people experiencing mental distress in making decisions are constrained.

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3 Carings appear to link closely with how Archer (2000, 2003) defines ultimate concerns. It is our inner carings, our ultimate concerns, which are core to who we are as human beings that shape our deliberations, autonomy, reflexivity and agency.
2.5 The constraints on being seen as a knower and a decision-maker

It is generally accepted that adults should be deciders in decisions about their own healthcare, but this is not so for children and young people, which raises questions about their status and lack of power (Franklin and Sloper, 2006). As described earlier, bringing the values and knowledge of the patient into the decision-making process is core to SDM. Therefore, it follows that for this to be the case, the patient needs to be seen and regarded as a knower and a giver of information and knowledge, and for this to be heard, valued and believed by the hearer. It is therefore important to explore how far young people and, in particular, young people experiencing mental distress, are regarded as knowers.

Historically, children and young people have not been constructed as actors and capable agents (Alderson, 2013; James, 2009; Mayall, 2002; Mayall, 2013; Wiesemann, 2016). Their moral agency and autonomy are largely contested or not recognised, as if seeing them as moral agents is a contradiction in terms (Mayall, 2002). Throughout history, children and young people have been constructed and ‘produced as unruly, empty or innocent’ with the role of adults therefore as ‘monitors, minders and corruptors’ (Tesar, Rodriguez and Kupferman, 2016, p. 170). Hobbes saw children as evil and savage, born in original sin and in need of control; for Locke, children were empty, blank slates in need of filling with knowledge; and for Rousseau, the child was essentially good, yet still dependent and in need of protection (ibid.).
For the past century, developmental psychology has dominated understandings of children and childhood (Alderson, 2013; Mayall, 2002; Mayall, 2013). Psychology is dominated by the empirical and behavioural study of child development (Alderson, 2013). This delineates universal stages of development which direct children and young people up an ordered hierarchy of steps towards the golden end stage of adulthood (Alderson, 2013; Mayall, 2013). This emphasises similarity in the progression towards adulthood, rather than difference or variation, and promotes normative understandings of what children and young people can and should do at set ages (ibid.). This is rooted in biological, functional understandings of development, which have been too certain in seeing universals (Mayall, 2013). These have predominantly emphasised children’s deficits and adults’ competence, which have denied children and young people’s personhood, and justified adult dominance and control (ibid.). Early sociological understandings of childhood were no better – functionalism and dominant interests in socialisation saw children and young people as under the control and power of adults, as empty vessels to be socialised, informed and transformed into members of society, rather than as social actors in their own right (James, 2009; Mayall, 2013).

Development psychology and Kantian theories of overly rational autonomy therefore construct children and young people’s rationality and competence as aligned with slowly developing age stages (Alderson, 2018; James, 2009). Rationality, therefore is primarily seen as an adult characteristic that children
and young people acquire as they grow older (James, 2009). Aligning rationality with age positions childhood and youth as on the way to becoming adult (Prout and James, 1990). Rationality is seen as the hallmark of adulthood and childhood and youth are seen as the ‘period of apprenticeship for its development’ (Prout and James, 1990, p. 10) while they are socialised into rational adulthood. Children and young people are constructed as incompetent, pre-moral, irrational and dependent in contrast to the competent, moral, rational independent adult (Alderson, 2018; James and Prout, 1990; Wiesemann, 2016). Older children are often infantilized by belittling stereotypes (Alderson, 2013), which imply they are in need of adult guidance and protection in decisions about their lives (Alderson and Montgomery, 1996).

Furthermore, this argument constructs young people as *becomings*, where the focus is on protecting the ‘open futures’ of the adults they will become, rather than as *beings* in the present (James, 2009; James and Prout, 1990; Wiesemann, 2016). Wiesemann (2016) describes this preoccupation with adult moral status (and superiority), and positioning young people’s future selves as having priority over their current self, as moral adultism, as ‘it allows for a systematic disregard of the child’s desires in order to benefit her in her future’ (p. 235–238).

Decisions based on future benefit therefore puts the justification for these decisions into the future and the child as an ethical being in the present disappears (Wiesemann, 2016). The focus becomes on the future impact of
decisions, rather than the experience or harm of being overruled or excluded from decision-making in the present (ibid.). This maintains adult control over young people as decisions that adults perceive as undesirable can be constructed as young people’s incompetent decisions (Alderson, Sutcliffe and Curtis, 2006a; James and Prout, 1990; Mayall, 2002; McCabe, 1996).

Psychology is the dominant discipline informing adult-child relations, research, service provision, and ‘those who work with and for children (for instance in health, education, and welfare) tend to be trained within psychological paradigms’ (Mayall, 2013, p. 4). Psychology has therefore had great power to control knowledge of and attitudes towards children and young people’s (Alderson, 2013; Mayall, 2013) rationality, competence and decision-making ability. Children and young people’s capacity to decide may be more affected by adults’ lack of skills in listening than by children’s supposed inability to express a view (Alderson and Montgomery, 1996). Like mirrors, children and young people reflect back the information and support given to them. Therefore, we need to explore the skills and abilities of practitioners and ask whether they can understand the relevant information; retain and explain all the issues clearly and resolve misunderstandings; assist children and parents in their reasoned choice-making; and respect their decisions, putting no undue pressures on them (Alderson, 2007).

Childhood studies sees issues such as competence ‘not as fixed and measurable facts, but as shifting, contingent, social experiences, co-constructed between children and adults. So with children’s competence, so much depends on the information, respect and support that adults give, and on adults’ competence in helping
and understanding children, as well as children's abilities’ (Alderson, 2013).

Experience, therefore, is often more important than age or ability. The experience of a chronic condition can enable children and young people to develop the skills and maturity to make healthcare decisions that older healthy ones do not have as ‘the person who is in the body, and is the body, can have unique insights that may be essential for informed decision-making’ (Alderson, Sutcliffe and Curtis, 2006b, p. 33).

Childhood and youth, and adult-child relations are not fixed biological features – they vary greatly over time and space, and are therefore social states, not fixed biological stages - ‘in their body size, experiences and abilities, beliefs and behaviours, status and responsibilities, many children are ‘like adults’ (Alderson, 2013, p. 9).

More recent explorations of children and young people's competence have demonstrated they are capable of much more than previously thought possible, demonstrating a ‘fault line between their moral competence in practice, and their ascribed low moral status’ (Mayall, 2002, p. 110).

Children and young people can be rational and reasonable – they may further develop these qualities over time, but it is clear that they do possess them (Mayall, 2013) and are social actors who can and do form important and valid views and opinions (Alderson, 2013).
Understandings of children and young people, and their competence and capacity, cannot be solely reduced to age. They are also simultaneously subject to the determinate effects of other structures of class, gender, race, as well as generation (Alanen, 2009). We therefore need to understand children and young people’s lives and experiences as intersectional (ibid.) and examine the environmental, generational and relational constraints on their agency and how they are constructed as decision-makers.

2.5.1 Knowing and distress

SDM in mental health is affected by professionals’ concerns and assumptions about the capacity and competence of people with mental health issues to be involved in decision-making (Capers, 2011; Curtis et al., 2010; Drake, Cimpean and Torrey, 2009; Schauer et al., 2007). It is therefore not just constructions based on age that constrain young people as decision-makers, but also how distress is understood. People experiencing madness and distress have historically had little involvement in decisions about their mental health as ‘mental illness and incompetence were considered the same thing [...]’. The presumption was that people with mental illness – essentially by definition – lacked the ability to appreciate their own need for treatment’ (Saks, 2017, p. 2). Similarly, common current prejudices about people with mental health issues doubt their capacity as knowers; for example, people’s reports about the severity or existence of their difficulties are doubted, seen as being overdramatic, or as seeking attention (Peters et al., 2017). What is common throughout many constructions or understandings of mental health, however, is the frequent perception that
those experiencing distress are, amongst other factors, incompetent, unbalanced, inappropriate or a danger to self or others.

2.5.2 Triple disadvantage? Age, distress and being a patient

Normative assumptions about age, distress and the role of a patient are often seen as a heuristic for incapacity and inability to make decisions or be a decision-maker. Young people accessing mental health services experience multiple forms of disempowerment due to their age, mental health label and service use. There has long been a focus on disturbed or disturbing behaviour of children, and ‘once “the problem” acquires the status of requiring ‘expert’ intervention things can be done to children and young people that otherwise would not be possible’ (Coppock, 1997, p. 153). This legitimates adult power over children (ibid.) As LeFrançois (2008, p. 213) suggests

the very act of diagnosing children with a mental disorder immediately renders the children into a position where their own agency is considered lacking or undesirable. In this context, adults hold sole discretionary power in defining children as irrational, based both on their age and their psychiatric diagnosis, thereby stripping them of any rights they might otherwise have to make decisions that could influence their treatment (p. 213).

Thus, labels of incompetence may be attached to young people based on their age and due to a mental health label, which along with other social relations (such as gender, class and race) serve to enhance notions of incompetence (LeFrançois and Coppock, 2014). The stigma (public and self) of mental health services can discredit young people’s views (O’Brien et al., 2011). As Lambert et al. (2008) suggest, young people who take
psychotropic medications may do so willingly, be strongly resistant or act somewhere in between, but their behaviour is often constructed as expected teen behaviour or a product of their diagnosis, rather than an expression of a rational decision. As (McCabe, 2017, p. 155) highlights, whilst some decisions may need to override the person’s wishes in certain situations, the danger is that this practice ‘leaks’ into other decisions, due to a cognitive bias that people with mental health problems are perceived to be less worthy or capable of being involved in decisions when capacity is intact.

Epistemic, and specifically testimonial, injustice occurs when someone is wronged in their capacity as a knower because the credibility of their testimony is given less weight (credibility deficit), due to identity prejudice on the part of the hearer (Fricker, 2007, p. 1). Fricker’s work originally focused on prejudice related to race and gender, but this has been extended by others to examine how people are wronged based on prejudice related to mental illness (Crichton, Carel and Kidd, 2017; Lakeman, 2010), to children (Carel and Györffy, 2014), and to children and mental illness (Harcourt and Martin, In press).

The concept of epistemic injustice is an important concept in thinking about people who experience a credibility deficit due to assumptions and stereotypes of mental distress (Crichton, Carel and Kidd, 2017). The effects of this are that patient testimonies and interpretations are not acknowledged as credible, and patients are thus undermined in their capacity as knowers and contributors to the epistemic effort to reach a correct diagnosis and treatment (ibid. p.65).
For example, prejudice and stigma lead to assumptions about people being responsible for their mental illness, and therefore their behaviours; people are blamed or held responsible for the cognitive, social, economic disadvantage they experience; and ‘hard evidence’ is seen as more reliable than ‘soft’ testimony (Crichton, Carel and Kidd, 2017). Epistemic injustice can therefore be enhanced by contemporary healthcare practices which privilege certain styles of articulating testimonies, certain forms of evidence, and certain ways of presenting and sharing knowledge, e.g. privileging impersonal third-person reports, in ways that structurally disable certain testimonial and hermeneutical activities (Carel and Kidd, 2014, p. 530).

The testimony of patients can be dismissed or seen as irrelevant, or too emotional, as if being upset equates to being irrational; patients are ‘are often regarded as cognitively unreliable, emotionally compromised, or existentially unstable in ways that render their testimonies and interpretations’ (ibid. p. 530).

Fricker argues that people who are victims of epistemic injustice experience an assault to their capacity as a knower, which is a defining feature of personhood, and which adds a layer of harm of its own, as it suggests the person is less than fully human (Fricker, 2007).

Harcourt and Martin (In press) argue that the entitlement to epistemic injustice should be based on a minimal form of autonomy because, if rational autonomy is the standard, then it follows that those who do not meet the test of being rational are therefore not able to be victims of epistemic injustice. However, when based on autonomy in its most basic form, it holds that
autonomy can still be denied even when a person lacks capacity (ibid.).
Therefore, adults and young people experiencing mental illness or distress
still deserve the right to be heard, to be treated as people, listened to, and
not lied to or deceived, even when their epistemic powers are impaired; they
can also, therefore, still be victims of epistemic injustice (ibid.).

Therefore, as Alderson and Montgomery (1996) suggest, there are four
levels of decision-making with children and young people, the minimum of
which is to be informed. The other levels are then to express an informed
view; to have that view taken into account when decisions are made; and
being the main decision-maker about proposed interventions.

Denying people’s capacity as a knower does not just merely overlook or
ignore their words, it is to deny the core of who they are as a person. As a
minimum therefore, even when people’s epistemic powers are affected, they
still deserve the right to be heard, listened to and treated like a person, and
can still be wronged in their capacity as knowers.

2.6 Help with what and for whom?
To understand the context within which people are constructed as decision-
makers and decisions are being made, it is important to explore how mental
health is understood and how it challenges decision-making and person-
centred care. The following sections will therefore explore how mental health
is understood, how people come to be identified as psychiatric patients, and
what mental health services are and whom they are for.
2.6.1 The challenges of psychiatric positivism

Whilst madness and distress have always existed, how they are constructed and understood, valued or devalued, have changed over time (Foucault, 2001; Pilgrim, 2013; Pilgrim, 2015; Rogers and Pilgrim, 2010). There has been a long debate throughout history on the possible causes, effects, prevention and treatment of madness and distress, with them being understood variously as demonic possession, sin, witchcraft, nerves, idleness or moral weakness, to name but a few (Scull, 2015). Current understandings of distress and troubled or troubling behaviour have been dominated by biomedical illness frameworks (Rogers and Pilgrim, 2010). People’s distress, unintelligibility or troubling behaviour have long been subject to psychiatric power and gaze, with their visible behaviours and expressions of distress becoming ‘known’ and constructed by ‘experts’ (Foucault, 2000; Rose, 2007). This privileges expert constructions of symptoms and visible behaviours (Goffman, 1961; Pilgrim, 2013). The search for the biomedical pathological causes of madness and distress have continued through the rise of genetics and neuroscience (Rose, 2013; Rose, 2007).

Mental health problems are therefore described in the same ways as physical health conditions such as diabetes, which supposes a disease with distinct physical pathological causes and assumes diagnoses and treatment are reasonably exact sciences (Davidson et al., 2016; Johnstone et al., 2018). Psychiatric diagnosis therefore constructs mental health problems as within person defects, but with little evidence of diagnostic categories and
biological abnormality. This relies on subjective judgements and social norms about what people think, feel, say or do, (rather than on signs, such as blood tests, in medical diagnosis), which gives the impression of objectivity, but means that normative judgements become codified as ‘conditions’ (Johnstone et al., 2018; Pilgrim, 2015).

When psychiatric diagnoses only exist in how they are described – they are a tautology rather than an explanation - symptoms are used to identify the disorder and then the disorder is used to account for the symptoms (Pilgrim, 2015). This confuses the map with the territory and mistakenly gives the same ontological status to signs and to symptoms, collapsing complex transitive phenomena into the intransitive (the epistemic fallacy) (ibid.).

Symptoms are therefore reified into psychiatric diagnoses, which medicalise, individualise and decontextualize people’s thoughts, feelings and behaviour, which removes meaning from people’s experiences; overlooks the real causes and complex generative mechanisms of distress, troubled or troubling behaviour; and does not facilitate understanding of how these experiences have come about. Biomedical constructions focus on what is ‘wrong’ and what is visible (e.g. ‘symptoms’ and behaviours), and on the body rather than the person. This ignores how social values and interests affect how people with mental health problems are positioned and constructed (Pilgrim, 2013). Similarly, this focus on internal processes pathologises and obscures the damaging effects of neoliberal political, economic and social structures on distress, troubled or troubling behaviour,
including poverty, inequality, and childhood adversity (Johnstone et al., 2018; Pilgrim, 2015; Pilgrim and Bentall, 1999; Vassilev and Pilgrim, 2007).

At the other end of the spectrum, strong social constructivism regards mental disorder as socially constructed and a by-product of psychiatric activity (Pilgrim, 2013). This ignores the ontology of distress, troubled or troubling behaviour and does not recognise the reality of psychological distress and dysfunction (ibid.). It focuses on concepts to the exclusion of bodies, by reducing the body to what is known about it (ibid.). Thus, anti-psychiatry is dominated by anti-realism which denies ontology (Pilgrim, 2015).

More recent critical realist understandings (CR – is explored further in Chapter 3) of madness and distress attempt to bridge the gap between positivist biomedical and strong constructivist positions. CR aims to bring the body and being back in and acknowledge the ontology of misery or madness, whilst questioning how they are described, understood, valued or de-valued. For example, positivism sees biology as an independent cause of behaviour and distress, but from a CR perspective biology is only one aspect of our being. All of our experience is dependent on our living bodies, which are always in a complex interplay, being shaped by social action and inseparable from thoughts, emotions and meanings (Johnstone et al., 2018; Pilgrim and Rogers, 2003; Rogers and Pilgrim, 2010; Williams, 1999).

In open systems, the causes and generative mechanisms of madness and distress are multifactorial, probabilistic (rather than deterministic or
predictive) and contingent, meaning they are in complex interplay and in flux (Pilgrim, 2015). Generative mechanisms are stratified, occurring on multiple, interacting planes of the physical, biological (physiological, medical or clinical), psychological, psycho-social, socio-economic, cultural and normative mechanisms (Bhaskar and Danermark, 2006).

There is significant evidence of the impact of childhood adversity on all forms of adult distress, troubled or troubling behaviour – with the majority of people who are given a psychiatric diagnosis reporting childhood adversity. Therefore, in contrast to reductionist biomedical diagnoses which desocialise experiences, there are strong causal associations between childhood, social and relational adversity and distress, troubled or troubling behaviour (Johnstone et al., 2018). Psychiatric positivism positions people experiencing distress as the objects of knowledge, which privileges the knowledge of experts over that of the person her/himself (Foucault, 2000; Rose, 2007). It denies the ‘biographically situated meaning’ (Pilgrim, 2013, p. 337) of what the person is experiencing and how s/he understands and expresses what is happening, meaning the personal experience of those experiencing distress or troubled or troubling behaviour is then demoted, as the interests of third parties take precedence in decision-making (Pilgrim, 2015).

Given the multiple generative mechanisms, social issues and determinants that affect mental health, most of which are outside the control of mental health services, medical or individual responses are perhaps not likely to be effective (Rogers and Pilgrim, 2014). Formulations which seek to understand
biographically situated meaning, whilst fallible, are more plausible and respectful of human complexity (Pilgrim, 2015).

2.6.2 Psychological difference: transgressing rules and roles

To understand how people become identified and labelled with psychological difference or become psychiatric patients it is important to look at society. Social contracts in given societies are influenced by normative judgements which expect people to comply with rules, roles and rule-role relationships (Pilgrim, 2015). Mental health problems are therefore usually first identified when people break certain rules or roles in everyday life, which ‘take place in networks of discourse and relationships based on ordinary layperson judgements about what are considered to be ‘reasonable’ ways of thinking, feeling and behaving within a particular context’ (Johnstone et al., 2018, p. 15).

Whilst normative judgements about what is psychological normality or abnormality change over time, all societies have identified different psychological states, with three broad demi-regularities in psychological differences: being persistently miserable; being odd or eccentric; or being disagreeable or offensive (Pilgrim, 2015). Therefore, ontologically, fear, sadness or behaviours which are sometimes unintelligible to others or incorrigible do really exist, but epistemologically, these are described and understood in different ways in different contexts (ibid.) The ontology of madness and distress is therefore grounded in intelligibility and
accountability, which are then situated in real social judgements, not in universal medical facts (ibid.).

The term ‘distress’ alone does therefore not account for the level of suffering people experience or the personal or interpersonal complexity of their experiences (Johnstone et al., 2018). People experiencing distress may seek help for themselves - but equally, those experiencing psychological difference might or might not be distressed, but rather might be causing distress to others around them. This then means services may be imposed upon them by those who hold paternalistic concern for, or are fearful of, their conduct (ibid.). Thus, there is a need to question whose distress is it and what are they distressed about? For example, unintelligible actions which threaten expectations of rules and roles create fear in others which then triggers a social crisis and is responded to by powerful actors who hold lawful powers of detention (Pilgrim, 2015). It is therefore the conduct not the person, that is the problem, meaning madness is only a problem when it is enacted in practice (madness-in-practice) (ibid.)

2.6.3 Mental ‘health’ services? Intervention for what and for whom?
If psychological difference is responded to by enforced intervention when people breach roles, rules or rule-role relationships, then it must be questioned what mental health services are for and for whom.
Constructions of madness and distress, and societal responses to those who have been deemed mad or insane, reflect the normative moral perceptions of a society at a given point in history. From madhouses to asylums, there has been a long history of internment (Scull, 2015) and psychiatric institutions have historically been seen as a way of implementing moral judgements about what society regards as unreasonable or undesirable behaviour (Foucault, 2000; Pilgrim, 2015; Reavey et al., 2017). Psychological differences, particularly those that cause concern to others, are seen as a threat to social order. They have long been subject to social control and – when psychological difference is regarded as an illness – medical paternalism (Pilgrim, 2015).

Whilst modern inpatient units may not reflect the asylums of the past, they still operate significant constraints and power over people (Chow and Priebe, 2013). This can be through the separation of people from society; the power of legal and policy frameworks over people’s liberty and treatment; paternalism and the asymmetry of social power in the relationship between staff and people within units; and in how people develop adaptive behaviours to institutionalisation (ibid.). A loss or lack of reason is ‘at the centre of the social reaction typically evoked by mental health problems’ which is taken-for-granted to warrant paternalistic social control (Tomasini and Pilgrim, 2012) and then legitimates the imposition of the will of others over the will of the self (Mill, 2014).

As Rose (2006) suggests, we are witnessing “a new age of confinement, with the construction of a whole archipelago of ‘secure’ institutions for those thought too risky to share
our everyday world. This tells us something about the limits of normality in our age of choice, consumption, autonomy, self-advancement and personal responsibility—our Age of Freedom (p.466)

Risk is central to current psychiatric policy and seeks to bring the future to the present to make it more manageable through preventative intervention or detention (Rose, 1998). Mental health services are increasingly administrative rather than therapeutic in an attempt to control future conduct which changes the role of mental health professional, placing them in regimes of control in the government of risk (ibid.). The management of risk is prospective – often based on fear of what someone might do (Vassilev and Pilgrim, 2007). Thus, people are increasingly confined not for what they have done, but for who they are or what they might do, alongside new forms of individualisation and processes to observe, monitor and record (Rose, 1998). Detaining people against their will based on imagined future risky behaviours is a very effective form of social control and unlikely to be experienced as kindly when it is against their will (Pilgrim, 2018).

Decisions about risk involve value judgements and reify normative societal views on what is dangerous or risky. For example, people deemed sane by common consent can engage in risky behaviours with limited or no intervention. Yet people seen as ‘mentally ill’ can have their liberty denied (Pilgrim, 2018). Mental health patients are significantly different from those in physical health, as they are the only group of people who can be detained without trial (Vassilev and Pilgrim, 2007). Similarly, most patients can expect their autonomy to be protected and promoted, yet those confined for their distress, troubled or troubling behaviours are subject to compulsion based on
the notion of offering help to those who are deemed to need it but who do not appreciate its need (ibid.). The use of compulsion violates normal expectations in relation to autonomy, beneficence and non-maleficence, which professionals have to justify to themselves. Further to this the group of people affected by these violations are disproportionately oppressed and vulnerable and many of the medications they are given have serious iatrogenic effects (Vassilev and Pilgrim, 2007).

Discussions on good mental ‘health’ services are therefore troubled by debates about uncertain psychiatric diagnosis and coercive social control of those deemed troubling (Pilgrim, 2018, p. 295). There is therefore a paradox in the language of mental ‘health’ - a euphemism increasingly used to talk about the management of psychological difference, troubled or troubling behaviour:

“"Mental health" law invariably deals with the conditions under which a proportion of people with a diagnosis of mental disorder (not all of them) can be lawfully compelled to accept treatment or to lose their liberty with or without trial.’(Vassilev and Pilgrim, 2007, p. 347)

It must therefore be asked, what are mental health professionals offering, to whom, and for what? There are therefore competing interests between the person’s right to act unintelligibly, and of their family and society. Therefore, what is deemed a good service depends on who is being asked as, for example, some may see services as working well when they are keeping troubled people out of sight or under surveillance (Pilgrim, 2018). Mental health services and legislation respond to the needs defined by others rather than needs as expressed by people experiencing distress, unintelligible, or troubling behaviour (Tomasini and Pilgrim, 2012). Mental health legislation is
therefore designed to legally control one group of problematic patients and not about the promotion of mental health (Pilgrim, 2018). The ‘principle of reciprocity” insists that restriction or removal of civil liberties for the purpose of care must be matched by adequate quality of services…society has no right to remove civil liberties from patients for the purpose of treatment (whether in hospital or in the community) if resources for that treatment are inadequate’ (Eastman, 1994, p. 45).

Yet this is not the case for the majority of people who are detained and who have treatment enforced legally or voluntarily (but coerced) (Vassilev and Pilgrim, 2007). Mental health services do not primarily serve the interests of the patient and can therefore not be expected to be patient-centred or promote improved mental health (ibid.). Compulsion and the central focus of risk therefore make both professionals and people untrustworthy -

‘Patients cannot be trusted by staff to act in a non-risky way so will be surveyed and controlled accordingly. Staff cannot be trusted to act in a patient-centred way because they will use their powers delegated from the State to act in third party interests. Prioritising political system and legal system requirements over inter-personal and organizational trust also undermines the need and propensity of professionals to act in a trustworthy way in the experience of those they are treating. P.637 (Tomasini and Pilgrim, 2012)

Person-centred care and shared decision making are therefore perpetually undermined.

2.7 The constraints on making decisions

As shown, there are many constraints that undermine how young people are seen as knowers and decision-makers. There are also other constraints that affect the process of making decisions. The following sections explore how tripartite decision-making, best interests, the asymmetry of relationships
between young people and professionals, and coercion and compulsion affect decision-making.

2.7.1 Tripartite decision-making – whose problems? Who decides?

As identified earlier, dominant models of rational autonomy do not take account of children and young people, or of the role played by their parents or carers in decision-making (Adams, Drake and Wolford, 2007).

The usual bipartite decision-making relationship between professionals and patients is complicated when young people access health or mental health services, due to the involvement of parents (Paul, 2004; Tan and Fegert, 2004).

Young people are often referred to CAMHS based on the concerns of others (parents or health, education or social care professionals) rather than by themselves (Paul, 2004). They can be referred when they do not think they have a problem, do not want to change or where they are not the possessor of the primary problem, meaning that they may be coerced and physically or emotionally ‘dragged to the clinic’ (ibid. p.305). This means there are significant power imbalances as many young people do not even know why they were referred to CAMHS in the first place, alongside little or no agreement between young people, parents or therapists about the problem to be addressed (Garland et al., 2004).
There is also often a lack of agreement about expectations of mental health care between children and parents (Ronzoni and Dogra, 2012, p. 334). A study by Hawley and Weisz (2003, p. 68) in outpatient mental health services found strikingly low levels of child–parent–therapist agreement, with more than three quarters starting treatment without consensus on a single problem. This is supported by research by Garland et al. (2004) who found little agreement in the adolescent–parent–therapist triad on desired outcomes for young people. Two-thirds of the triads did not agree on even one desired outcome for treatment. Thus, SDM may be complicated by the lack of agreement on difficulties and outcomes.

This triad is further complicated by professionals’ views of who the patient really is. In a study of psychologists’ understanding of user involvement in children’s mental health services, several psychologists questioned who the client was – the child or the parent (Dexter, Larkin and Newnes, 2012; Stacey et al., 2008). This can mean it is unclear to whom a duty of care is owed. If a duty arises from the ‘special’ doctor–patient relationship, the clearest duty is that to the child as the referred patient. It is less clear whether parents and siblings count as ‘patients’. Parents may be brought within this special relationship when they act as their child’s proxy decision-maker, advocate or representative. CAMHS professionals might argue that a duty of care to the child implies some duty of care to the child’s family (Paul, 2004, p. 302).

Clinicians feel they need to develop new skills of negotiation and containment to facilitate SDM and differences of opinion (Hayes et al., 2018b). O’Brien et al. (2011) suggest that this difference in preferences and expectations of decision-making and the complexity of parent involvement in
decision-making (in contrast to the one-on-one patient–provider relationship in much of adult mental health) requires a youth–parent–provider model of decision-making as, without this, it is likely that the practitioner will resort to traditional authoritarian approaches, which can bypass the challenges of a collaborative dialogue (O’Brien et al., 2011, p. 310).

SDM may therefore be complicated by the involvement of multiple parties and the lack of agreement with young people about what their difficulties are.

2.7.2 Whose best interests?

As identified earlier, children and young people are in a unique position in that they can agree to and consent to treatment, yet their refusal may be overridden (Brazier and Cave, 2011; Cave, 2012). Young people’s views of their own best interests are often discounted as age-specific and transient or because they conflict with adult views (Paul, 2004). Mental health and psychiatry are positioned as ‘knowing’ what is in the best interests of the child or young person (Burstow and LeFrançois, 2014) and putting emphasis on best interests may be used as a tool to control children and limit their involvement in decisions (Coppock, 2002).

Crickard et al. (2010) report that parents and staff have concerns that increasing the involvement of young people in medication decision-making could result in power struggles about their mental health medications. Young people feel that to prove their capacity they need to concur with clinical advice to demonstrate they can make ‘rational’, ‘competent’ decisions (Mackenzie and Watts, 2014, p. 102) and
the danger is that when children make risky choices or decisions that might result in significant harm to themselves or others (poor outcome), they are said to have failed tests for capacity/competence (tests of function) when actually they passed but their values or the outcomes of their choices were unacceptable to parents, professionals or the judiciary (Paul, 2004, p. 308).

Wiesemann (2016, p. 2374) argues, therefore, that children and young people have no real autonomy in medical decision-making as there are three types of situations of potentially autonomous child decision-making: (1) child and parent want (or do not want) an intervention which their doctor opposes (or favours); (2) child and doctor want (or do not want) an intervention that a parent opposes (or favours) and (3) a child wants (or does not want) an intervention that doctor and parent oppose (or favour).

Consent is the key and only one person’s consent is needed - parents’ consent can override child’s refusal, but the child’s consent can also the override parents’ refusal (Alderson and Montgomery, 1996). Paternalism often prevails when competent children refuse treatment that parents and professionals deem necessary and their refusal is overridden – a trade-off adults are rarely willing to make (Wiesemann, 2016).

Best interests approaches require a trade-off between the child’s actual desires and adults’ beliefs about future benefit (Wiesemann, 2016). The decision is based on the young person in the future rather than in the present and does not take account of the fact that ‘ignoring and overriding individuals’ deeply held views can be very harmful and counter to their best interests’ (Alderson, 2018, p. 25).
Therefore, adults’ understanding and interpretations of what is in the best interests of young people may complicate SDM, as it can be used to discount young people’s views of what they believe to be in their own best interests. This also does not take account of the harms of excluding or overriding young people’s wishes.

2.7.3 The asymmetry of relationships

Young people in inpatient units highlight the importance of having someone they trust to talk things through with (Reavey et al., 2017), yet they also felt they had little time with staff to do so and reported dissonance between their expectations that nurses would come to spend time talking with them, and finding that they rarely did so (Stenhouse, 2011). Furthermore, young people in an inpatient unit described how their voices were silenced in many ways, particularly when their views were not consistent with the views of professionals, which included:

- telling the young person outright that the content and/or form of their expression was inappropriate;
- shouting ‘shut up’;
- explaining that they are psychiatric patients in a hospital;
- calling emergency meetings where the ‘inappropriate’ young person is surrounded by the practitioners with focused attention on making them conform to the practitioners’ expectations of appropriate self-expression (LeFrançois, 2007, p. 96).

Relationships between young people and staff can be undermined by the tensions between the desire of staff to express empathy and offer support and the ‘emotional detachment and control expected by the organisation,
contributing to burnout and moral distress’ (Matthews and Williamson, 2016, p. 1042).

Power is inherent in the relationship between professionals and patients. As Coulter and Collins (2011) suggest, despite the shift to SDM, paternalism is still the predominant model of decision-making in UK healthcare, where the clinician knows best. Patients rarely challenge this and, therefore, their expertise and role in decision-making is rarely acknowledged (ibid.). SDM requires a shift in the attitudes and values of both clinicians and patients, away from the expert clinician and passive patient (Health Foundation, 2012). SDM also needs to take account of the imbalance of medical knowledge and social power in the physician–patient relationship, which is usually weighted in favour of the clinician (Makoul and Clayman, 2006). Power within SDM is further obscured by the predominant focus on the decision-making process, rather than the decision, ‘as the question of who makes the actual decision is seen as less important than the act of both parties engaging in the decision-making processes’ (Simmons and Gooding, 2017, p. 276).

As Delman et al. (2015) highlight, a key barrier to SDM is psychiatrists’ resistance to the client’s perspective. Whilst SDM requires a shift in relationships, research by Hibbard et al. (2009) showed that clinicians favoured patient behaviours that followed medical advice and were least likely to endorse behaviours where patients undertook independent actions, made independent judgements, or sought information independently.
CAMHS practitioners also reported feeling apprehensive about trying new approaches to SDM because they were worried about the consequences of changing their practice, including the possible risk involved, which made them hesitant to try something new, or cause them to feel deskill (Abrines-Jaume et al., 2014). Furthermore, a recent UK study of clinicians’ views on the barriers and facilitators to SDM in youth mental health identified barriers such as uncertainty about the term SDM, concerns about capacity of young people to engage in SDM, overriding a young people’s wishes to protect them, or concerns SDM could make young people’s difficulties worse (Hayes et al., 2018b).

Whilst SDM is about giving weight to the knowledge and expertise of patients, clinicians value behaviours that maintain their expert position, and dislike those that challenged it. This therefore shows a significant gap in how much clinicians say they value SDM and how they experience or devalue the actual shift in dynamics when it takes place. There is a gap between what is needed for SDM and the shift in relationships required to support it in practice. Practitioners may find the role of the active patient more challenging because this shifts the status quo. This may be particularly relevant for young people because they are often expected to be passive.

SDM requires that patients are offered the opportunity to be involved in decision-making (Charles, Gafni and Wheelan, 1997) meaning the power predominately rests with professionals about whether to include the person
or not. Involvement in SDM is therefore open to the interpretation of the professionals and, as suggested, this can mean that when the client is compliant, shared decision-making is a virtue; when there is disagreement about treatment, the client ‘lacks insight’ and shared decision-making is a risk (Drake and Deegan, 2009, p. 1007).

Whilst professionals may support the concept of SDM, another reason it may not translate into practice (Towle et al., 2006) is that it is really still ‘interpreted as compliance with medical instructions, with little evidence of a shift to SDM’ (Rogers et al., 2005, p. 236). As the assessment of patient competence is in the hands of psychiatrists, decision-making is essentially asymmetrical – they can abandon an SDM approach if they decide the person is too ill to make a decision (Seale et al., 2006). As LeFrançois (2008) found, whilst many practitioners used the word ‘participation’, their definition of it was of compliance, and young people experienced it as ‘forced participation’. SDM is therefore often influenced by notions of compliance (Health Foundation, 2014b) rather than a real shift of power.

SDM is therefore more than a discrete event or series of tasks. It needs to be understood as relational and influenced by the power dynamics in relationships between adult professionals and young patients. Perhaps more attention needs to be paid to the required changes in practice and values of practitioners to facilitate SDM, rather than the ability of young people to engage in decision-making.
2.7.4 What choice? What influence? Coercion and compulsion

SDM brings to light existing power relationships in mental health services (Curtis et al., 2010). The power imbalance between services and service users is greater in mental health, due to the presence of coercive power and concepts like adherence (Capers, 2011).

Mental health services have a long history of coercion with many treatments rooted in moral judgements and punitive approaches (Kinderman, 2014). Coercive or involuntary treatments, or practices of containment (like seclusion) ‘are common but profoundly ethical problems within mental health services’ and are often justified on the grounds of beneficence or best interests (Lakeman, 2010, p. 151). A powerful way to justify coercion is to deny that children can reason and to align reason with force; children’s resistance is then seen as mindless ‘self-destruction’, to be overridden by adults (Alderson and Montgomery, 1996, p. 53).

Concerns about coercion (Curtis et al., 2010) and knowledge of coercive treatments and practices can have a detrimental effect on people’s belief in their ability to be involved in decision-making (Capers, 2011). The power and control in adult mental health units conflict with values of SDM because, owing to patients being sectioned or coerced

professionals have, or are perceived to have, the power to override service users’ preferences, and people with mental health problems may be aware of this when they use services […] It would be naïve to assume that this gulf in power would not influence the dynamic of
negotiation and agreement at the heart of shared decisions (Stacey et al., 2015, p. 33).

Mental health patients have described how difficult it is for individuals to challenge the decision-making authority in services, with challenges being ‘shot down’ by professionals or patients being concerned that this could put their access to services at risk (McDaid and Delaney, 2011, p. 736). This is mirrored by patients’ anxiety of being seen as the ‘difficult’ patient and concern about broaching the topic of SDM, due to previous traumatic experiences with healthcare providers (Pathare and Shields, 2012).

Young people reported that whilst respect for their autonomy was crucial to their recovery and self-esteem (Haynes, Eivors and Crossley, 2011), they felt disadvantaged in inpatient care due to a lack of autonomy (Gill, Butler and Pistrang, 2016; Reavey et al., 2017) and were restricted, regimented and controlled in ways that they found unreasonable and unnecessary (Gill, Butler and Pistrang, 2016; Moses, 2011). Some young people with eating disorders felt having less control or involvement in decisions at the start of their admission to an inpatient unit was helpful, but over time they viewed this as overly controlling (Offord, Turner and Cooper, 2006). They also felt control was being taken away from other areas of their lives, adding to a sense of powerlessness (ibid.).

The majority of young people admitted to units in the UK are not subject to the Mental Health Act 1983 (Tulloch et al., 2008), yet they report feeling compelled in other ways. As children and young people’s refusal to give consent can be overridden, it remains possible that in seeking consent
practitioners compel a minor by saying ‘consent or we will seek court authorisation and force you to undergo treatment’ (Cave, 2012, p. 98). Similarly, young people reported that when they refused treatment, they experienced clear consequences, such as an emergency meeting being called or the group going to where the young person was – for example, their bedroom – and being told they would be discharged or have weekend leave cancelled (LeFrançois, 2008).

People may also be coerced or deceived through access to and control of information. Participants in a qualitative study of psychiatrists’ experiences of SDM in discussions about anti-psychotic medications expressed concerns that explaining the adverse effects of medication could discourage medication use and some felt this conflicted with their obligation to fully share information with patients (Seale et al., 2006). The power to give or withhold information maintains the power of the professional in the decision-making process and may be used to coerce people into certain decisions.

The same study suggested that psychiatrists often had a preferred treatment option, with which they were trying to convince the person to agree with, under the illusion of patient choice. In a study exploring psychiatrist experiences of SDM in discussions about antipsychotic medications some reported degrees of deception in their approach to patients (Seale et al., 2006). This could range from not telling patients certain things, to saying things that were not true, all of which involved the feeling that the deception was in the best interests of patients (ibid.). However, if people do not fully
understand the reasons for proposed treatments, it may to some extent be forced upon them (Alderson and Montgomery, 1996).

In mental health services, concepts of compliance are too simplistic (Deegan and Drake, 2006) because they silence or conceal the complexity of treatment decisions (Deegan, 2007). Concepts of compliance or non-adherence emphasise obedience to medical authority (Deegan and Drake, 2006) and locate blame within the individual, whose expertise and rationality go unrecognised (Seale et al., 2006). Thus, in mental illness shared decision-making is predicated on breaking silence and enhancing dialogue between practitioners and clients. The practice of shared decision-making can be seen as emancipatory praxis. When the silencing effect of the compliance/noncompliance discourse is lifted, and people with psychiatric disabilities are invited to talk about their experience […] a much more complex and dynamic picture emerges (Deegan, 2007, p. 64).

People may also feel they have limited choice or influence as, for example knowledge is seen as resident in experts who make assessments and determine what treatments are in the best interest of individuals receiving services. The involvement of individuals is often limited to accepting the expert’s opinion, seeking a second expert opinion, or rejecting treatment altogether (Curtis et al., 2010, p. 15).

In addition, if there are other restrictions on the availability of help and support, people may be faced with a Hobson’s choice of, for example, accepting admission into a unit or receiving no help at all, effectively placing them in a position of being unable to make a real choice (McDaid and Delaney, 2011). It may not be that people do not want care or support, but
that perhaps the care or treatment on offer is not what people want, yet they are coerced into accepting available treatments (Kinderman, 2014).

Thus, SDM may be affected and undermined through the many ways young people’s voices are silenced, the coercive practices in inpatient units, and through tensions of care and control in relationships between young people and staff.

2.8 Summary
There are many significant power dynamics that may constrain young people’s involvement in decision-making about their mental health care. Dominant constructions of autonomy and decision-making competence do not adequately take account of youth or the role of parents or carers, and are based on narrow constructions of rationality. Autonomy based on rationality poses significant challenges for young people’s decision-making, and for how they are constructed as competent or incompetent decision-makers. Decision-making may be further constrained by the many power dynamics in mental health services, such as the asymmetry of relationships, ‘best interests’ and coercion. As mentioned earlier, much of the available literature relates to adult mental health or young people’s physical healthcare. It is therefore imperative to explore the constraints on decision-making in young people’s mental health services. The following chapter will explore the methodological approach of this research to enable exploration of the many possible constraints on SDM in young people’s inpatient units.
Chapter 3. Methodological approach

3.1 Introduction

The primary aim of this research was to critically analyse SDM in young people’s mental health inpatient units with young people aged 13–17 years and the staff who worked with them\(^4\). The key questions were:

- How do young people understand and experience SDM?
- How do staff understand and experience SDM?
- What are the key factors that enable or constrain decision-making?
- How do relationships, structures, routines, and interactions affect decision-making?

Young people’s mental health inpatient units are very sensitive and personal spaces where young people may be experiencing high levels of distress, and where they should expect respect, privacy and dignity. Staff who work in inpatient units also witness (and may themselves experience) distress. These issues were at the forefront of my thinking at each stage of choosing the philosophical and methodological approaches, the design of the research, and perhaps most critically, in my practice as a researcher when in the units.

\(^4\) Whilst parents and carers can play an important role in decision-making, and can be strong advocates they were not included in this study, due to the constraints on time of undertaking the research part-time. Further research with parents and carers is planned to follow on from this study.
This chapter describes why I chose critical realism (CR) as the philosophical approach for this research; the research design and why I employed critical ethnography as the methodology; the many ethical issues I considered and how I put these into practice in the design of the research, as well as in my practice as a researcher; and how I collected and analysed the data.

3.2 The ontological and epistemological positions of this research

As shown in the previous chapter, decision-making is a complex process, influenced by many powerful dynamics. I therefore sought philosophical and methodological concepts and approaches that would enable me to explore the complexities of decision-making in mental health inpatient units. The following sections describe the key philosophical concepts that underpin this research and how they were useful.

3.2.1 The problems of positivism and hermeneutics for social research

There has been a longstanding dualism between positivism and hermeneutics, (Bhaskar, 1998; Bhaskar, 2016) both of which pose challenges when undertaking social research.

Positivism holds that social life can be studied in the same way as the natural world (Bhaskar, 1998; Bhaskar, 2016). The key tenets of positivism contend that facts are objective, self-evident and separated from values, and which can be understood as separate variables outside of their social contexts.
(Alderson, 2013). Therefore, data are seen as independent and pristine, and stable and unchanging over time, meaning positivist social research can discover general laws, replicable findings and reliable predictions (ibid.).

Positivist social research relies on causation between discrete events and cannot take account of the complexity of mechanisms and social life in open systems (Bhaskar, 1998). As such, much positivist social research is individualistic and behaviourist, reducing the object of study to its empirical grounds divorced from context (ibid.).

Hermeneutics developed as a rejection of the positivist tradition and regards the social world as different to the natural world (Bhaskar, 1998; Bhaskar, 2016). Therefore the study of social and human life must be radically different to positivism (Bhaskar, 1998; Bhaskar, 2016). Hermeneutics tends to regard phenomena as constructed by subjective perceptions and values, and negotiated through human interactions within specific social contexts and cultures (Alderson, 2013). Phenomena are seen as dependent on the perceptions of people and as such have few essential qualities, meaning there is no independent, transferable or replicable truth (ibid.). Hermeneutics isolated an essential, distinctive feature of social life, and whilst all social life is conceptually dependent, it does not exhaust it, as the social world also has a material component (e.g. we have bodies) (Bhaskar, 1998). Therefore, to understand the social world we have to understand conceptual and material reality (ontology) (ibid.).

Critical realism (CR) therefore aims to overcome some of the major dualisms inherent in positivism and hermeneutics, such as structure and agency; the
individual and society; and facts and values (Bhaskar, 1998). CR aims to draw on the strengths of positivism and hermeneutics and re-vindicate ontology (ibid). CR is not a new sociology but rather lays the foundations for it. The following sections explore the ontology and epistemology of critical realism and show why these were important for this research.

3.2.2 Being and knowing

This research is informed by critical realism’s (CR) concepts of ontology and epistemology, and of structure and agency, elucidated by Roy Bhaskar (1998, 2008b) and Margaret Archer (1995; 2000; 2003).

Within critical realism, Bhaskar (1998; 2008b; 2016) contends that being (ontology) is separate from knowing (epistemology). This means that there is a real world (ontology) that exists independently of our knowledge of it (ontological realism). Objects of knowledge (for example, being, bodies, natural objects and structures) are intransitive – they are unchanging and exist separately from what we know and understand about them. Our knowledge of being (for example, our beliefs, values, perceptions and understanding) is socially produced. It is transitive and changeable, meaning that our knowledge is fallible and relative (epistemological relativity).

However, whilst knowledge is relative, we can develop strong arguments for one theory over another (judgemental rationality).

Recognising being as separate from, and interacting with, knowing brings abstract concepts about childhood and youth (knowing) back to ‘actual
children, or to the existence of childhood as a social state and status, and to the real personal and political relations between adults and children’ (being) (Alderson, 2013, p. 51). As shown in section 2.5, this underpins constructions of children and young people, driven by the sociology of childhood, where they are seen as social actors and agents, who engage with the world - as beings in the present rather than adults of the future (Alderson, 2013; Alderson, 2016b; James and Prout, 1990; Mayall, 2002).

Separating being from knowing is also critical in research about how mental distress and dysfunction are understood. As described in section 2.5.1, this acknowledges the ontology of misery or madness, whilst questioning how they are described, understood, valued or de-valued (Pilgrim and Rogers, 2003; Rogers and Pilgrim, 2010).

3.2.3 A stratified world – the depth of reality

This study aimed to move beyond descriptive accounts of, for example, how young people do or do not feel involved in decision-making or describing staff reports of their beliefs and intentions to involve young people in decisions, to exploring the underlying, unseen structures and mechanisms that influence why young people are not, or do not feel, involved in decisions. To focus on decision-making as an event or act divorced from its context, may be reductionist and behaviourist (Lukes, 2005). This would focus analysis on power when it is exercised by those who possess it and make the decision, rather than on the various dynamics that influence the context within which the decision is being made (or prevented from being made) (Lukes, 2005).
As described in Chapter 2, rational autonomy and self-determination are not the differential qualities of individuals but the capacity (knowledge, power, and opportunity) and disposition to act in one’s interests (Bhaskar, 2008a). There is a need to look for and overcome the obstacles that affect reasoning (Hartwig, 2007) and young people’s involvement in decision-making.

As well as separating being (ontology) from knowing (epistemology), CR also sees being as having depth. Seeing ontology as having multiple levels is useful in considering the different factors that may influence events. There are two key distinctions of ontology. Firstly is the distinction between closed and open systems. In closed systems, particularly with experimental conditions, it is possible to observe constant conjunctions of events – how mechanisms cause effects and events (Collier, 1994). However in the world in which we live and act – open systems - there are multiple mechanisms at play, which conjointly cause events to happen, meaning there are no constant conjunctions (Collier, 1994). Therefore it is also important to understand the difference between structures, mechanisms and events (Bhaskar, 2017). Events occur regardless of whether they are experienced or not, meaning there are events which are not experienced (Bhaskar, 2017; Collier, 1994). It is therefore also important to distinguish between events and experiences (Bhaskar, 2017).

Through the concept of Natural Necessity, CR sees ontology as stratified through the three interacting levels of reality: the empirical, the actual, and
the real (Archer, 2000; Bhaskar, 1998; Bhaskar, 2008b; Collier, 1994; Fairclough, Jessop and Sayer, 2004). The three levels are as follows:

1. **The empirical** level refers to people’s experiences, thoughts, beliefs, memories, perceptions, interpretations, assessments and measures. Their experiences include interactions with the actual and real (events, structures and mechanisms). However not all events are experienced or observed by people or researchers meaning that only a subset of the actual and real are experienced.

2. **The actual** level refers to objects, beings and structures that actually exist, and interactions and events that occur. [delete, or patterns of events when causal powers and mechanisms are activated and affect change. The natural world and much of the social world exist independently of individuals’ experiences of them and thoughts about them (although the social world depends on collective human agency for its existence). The point here is to recognise the difference between (1) empirical experience and thought (epistemology) and (2) actual being and doing (ontology). This then avoids collapsing the actual into the empirical, things into thoughts, ontology into epistemology. Most events at the level of the actual are not noticed or experienced by people, which offers further evidence that much of the physical and social world exists independently of our experience of it.

3. **The real** level refers to the usually invisible causal mechanisms, motives and powerful influences that underlie the actual and empirical.
The real mechanisms become visible in their effects at the levels of the actual and empirical, which they precede.

The table below shows the different elements of the empirical, actual and real.

Table 4: The empirical, actual and the real (Adapted from Bhaskar, 2008)

<table>
<thead>
<tr>
<th></th>
<th>Real</th>
<th>Actual</th>
<th>Empirical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mechanism</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Events</td>
<td></td>
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</tr>
<tr>
<td>Experiences</td>
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</tr>
</tbody>
</table>

When research with young people only explores the levels of the empirical (experiences and perceptions) and actual (things, interactions and events) it does not take account of the causal real level – the reasons why young people act in the way that they do. Such research is, therefore, at risk of seeing young people’s behaviours as irrational and therefore young people themselves as incompetent or delinquent.

By exploring level three ‘seemingly irrational and contradictory behaviours may be clarified when related to agent’s intentions and also to social
structures’ (Alderson, 2013, p. 60). For example, it may be easy to assume that young people who are expressing high levels of distress, who are shouting or are confrontational with staff are too unwell or too irrational to make decisions about their care. Young people’s behaviour could be seen as a product or expression of their mental distress, ‘all in the mind’, which overlooks real causes and reasons for their anger. By exploring level three means we can delve beyond shallow accounts of staff not making an effort to involve young people in decisions, to look for the underlying mechanisms that affect the willingness and ability of the staff to involve young people.

Similarly, seeing reality as having depth means disability, childhood, madness and distress are stratified and occur on multiple, interacting planes of the physical, biological (physiological, medical or clinical), psychological, psycho-social, socio-economic, cultural and normative mechanisms (Bhaskar and Danermark, 2006).

### 3.2.4 Structure and agency

Decision-making is a complex social process and therefore when exploring decision-making, the experiences and actions of young people and staff cannot be separated from the underlying structures, enablements, and constraints of the context in which they are making decisions. Seeing structure and agency as distinct provides a sound basis on which to explore childhood as relational (Mayall, 2002) and the distinctive features of how structures (ideologies policies and practices) exert power, including through adult power, over children and young people (ibid). Similarly, agency enables us to explore motivations over time, from the past to the future.
(motivations, feelings, goals) in experiences and interactions between young people and adults (ibid.)

To explore only agency and the actions (or lack of action) of young people and staff is individualised as it does not consider the impact of structures and constraints on how and why they acted in the way that they did. This would be an example of upwards conflation, where the social powers of structures and how they influence people are ignored (Archer, 2000). For example, young people’s resistance could be framed as foolish and immature, rather than a protective mechanism against constraints. Similarly, to explore only the structures and constraints would be an example of downwards conflation (ibid.). This would be deterministic and would assume young people and staff are solely influenced by the constraints and have no agency or influence. It is therefore important to understand not only the constraints on decision-making but also how young people and staff react to, respond to, and influence the structures and constraints.

Seeing ontology as having depth, and actions and events caused by underlying causes and mechanisms, means ‘small events, interactions cannot be separated from the systems in which they happen’ (Archer, 1995). To understand this further, the dual concepts of structure and agency are helpful in examining the multiple influences of social events. The concepts of structure and agency are often conflated in sociology, where the focus is usually on structures rather than how people interact with and mediate them (Archer, 2010). CR sees structure and agency as distinct, but interdependent
concepts. Agency presupposes structures – we need structures to be able to act, but structures wouldn't continue to exist unless people reproduced and transformed them (Archer, 2000; Bhaskar, 1998), as outlined in the cycle below (Archer, 1995):

- There are internal and necessary relations within and between social structures (SS)
- Causal influences are exerted by social structure(s) on social interaction (SI)
- There are causal relationships between groups and individuals at the level of social interaction (SI)
- Social interaction (SI) elaborates upon the composition of social structure(s) (SS) by modifying current internal and necessary structural relationships and introducing new ones where morphogenesis is concerned. Alternatively, social interaction (SI) reproduces existing internal and necessary structural relations where morphostasis applies.

To understand how structure and agency interact, it is useful to see social events as occurring on four dialectically interdependent planes (four-planar social being) (Bhaskar, 2008a). The four planes are:

1. Material transactions with nature: the physical reality of bodies and how they interact and transact with the natural world and physical environment
2. Interpersonal, intra- or inter-action and relationships
3. Social relations: relations in social settings, social structures and social institutions
4. Intra-subjectivity: Our internal subjective worlds, subjective agency, reflexivity and internal conversations.
Empirical work often describes the impact of structure upon agency, but less so about how agents mediate structures and deliberate on courses of action (Archer, 2000). Archer (2003) describes how people mediate social structures through their internal conversations in a three-stage process:

(i) Structural and cultural properties *objectively* shape the situations which agents confront involuntarily, and possess generative powers of constraint and enablement in relation to

(ii) Agent’s own configurations of concerns, as *subjectively* defined in relation to the three orders of natural reality – nature, practice, and society

(iii) Courses of action are produced through the reflexive deliberations of agents who *subjectively* determine their practical projects in relation to their *objective* circumstances (p. 135).

The four-planar social being and reflexivity can therefore help us to understand constraints and how people act in relation to the reality of their circumstances. Young people and staff act based on how they *respond to, understand or experience* the constraints around them within inpatient units. This is critical in seeking to understand why young people and staff acted in the way they did. Taken out of context their actions may seem odd or irrational, and we cannot separate young people or staff, their beliefs, reasons or causes of action from the structures, constraints and power dynamics (Archer, 2000) that shape the inpatient units. Later chapters show how I applied critical realism to inform my analysis.
Reflexivity and how people act in relation to their context is also crucial in how we understand young people with mental health difficulties as reliable informants in research. Many of the young people involved in the research were very distressed, and several were sectioned under the Mental Health Act 1983 c.20 meaning they were deemed to lack the capacity to make certain decisions. As highlighted in Chapter 2, young people’s capacity and competence are often called into question owing to their age or mental health problems. Being very distressed or under a section (and thus deemed to lack capacity to make certain decisions) does not stop young people experiencing and interpreting the world around them. If people’s actions or behaviour are often divorced from their reasons they may appear odd or irrational. This research sought to explore how seemingly irrational decisions or actions actually often have a rational basis given the circumstances, if related to how the person understood, experienced and interpreted their environment; how this influenced how they acted; how they perceived themselves as decision-makers; and how the environmental, relational and systemic influences enabled or constrained their actions and involvement in decisions.

3.3 Research design
The following sections describe the research methodology employed to explore the underlying mechanisms and constraints that affected decision-making in the units for both staff and young people. In considering the methodology, I also describe the ethical planning and practices utilised to make sure the research was conducted sensitively within the inpatient units. I
then move on to describe the methods used to recruit sites and participants and to collect and analyse data.

3.3.1 Critical ethnography

Critical ethnographers ‘describe, analyse, and open to scrutiny otherwise hidden agendas, power centres, and assumptions that inhibit, repress and constrain’ (Thomas, 1993, p. 3). Therefore, in my study critical ethnography was employed as the research seeks to identify the constraints on young people’s involvement in decision-making. Being in a setting enables ethnographers to observe events and how values, beliefs or behaviours interact within them (Bryman, 2008). This can be particularly useful in healthcare to identify the influence of informal systems created by individuals or groups, and how knowledge is locally produced in particular settings (Savage, 2000). A principle of CR is *immanent critique* and the importance of critiquing problems from within the system being examined, rather than just putting forward externally based objections (Bhaskar, 1998). Critiquing from within makes it easier to understand the internal problems that need changing, the perspectives of those who support and maintain the system, and gain their support in changing and improving it (Bhaskar, 1998; Bhaskar, 2017).

This research takes a critical stance from the position that social research aims to identify social ills and the reasons for inequality, and aims to use this knowledge to challenge inequality, overcome ills, and improve well-being (Bhaskar, 1998; Price, 2015). Facts have values, but if they are assumed to
be value-free, knowing is collapsed into being (ontic fallacy) and facts become fetishised and separated from values, which desocialises science and knowing (Bhaskar, 2009). Beliefs and action are intrinsically connected, meaning our beliefs and values are causally efficacious (Bhaskar, 1998). We must, therefore, question the formation of beliefs (ibid.) and cannot criticise actions without criticising the beliefs or structures that informed them. This means that human sciences are necessarily non-neutral [...] they are intrinsically critical (both of beliefs and objects) and self-critical [and] accounts of social reality are not only value-impregnated but value-impregnating… (Bhaskar, 2009, p. 169). Therefore social science is necessarily non-neutral as it involves practical intervention in social life, which entails value and practical judgements as this explanatory critique leads us to identify the wrongs, ills and the false beliefs to find ways of improving the world (Bhaskar, 1998).

This position was a crucial foundation for this methodology because my reasons for doing this research were to explore and undercover some of the many invisible, but powerful, constraints that affect decision-making with young people in mental health care settings, to seek ways to overcome these and to find ways to improve decision-making.

Being in an inpatient unit also required me to develop respect and trust with young people and staff and, as Allbutt and Masters (2010, p. 212) put forward, this means it is imperative that researchers understand their own values and articulate those values so that potential participants [staff and young
people] are able to make a well-informed decision about whether or not to take part in a study (Allbutt and Masters, 2010, p. 212). Thus, being clear about my value positions as a researcher and of the research was important ethically.

3.3.2 Why interviews and why observations?

Interviews give insight into the internal private worlds of people (which only they know), and into how they viewed the constraints of the social context within which they acted (Smith and Elger, 2012). Interviews can only ever be partial accounts but, in a layered ontology, they are not just a narrative account, they can give insight into real events and structures (ibid.). Understanding reflexivity and reasoning – how young people and staff responded to the constraints within inpatient units – was vital to develop a richer, deeper understanding of agency and decision-making in constrained circumstances. For example, it could be easy to assume that young people would be passive because of their youth, or distress. However, exploring their reflexivity (as shown in Chapter 8) showed the many other causes of passivity, as well as the ways they expressed their agency and self-determination. The interviews were therefore used to seek to understand how young people and staff understood and interpreted their experiences of decision-making; how they understood the enablements and constraints on decision-making; and their reflexivity – how they responded to the enablements and constraints and then determined how to act.

As this study was exploratory, the interviews were designed to be in depth and using a guided conversation approach (Lofland and Lofland, 1984). In
this approach, the researcher is guided by the participants in how the conversation is directed and the researcher uses questions as prompts to encourage all relevant issues to be explored. This ensured that I could explore all the main issues, whilst not overly constraining the young people and staff during the interviews. The key topics explored in the interviews included:

- how SDM is understood
- how young people and staff experience and engage in SDM
- the types of decisions that young people are involved in and the issues that are considered when making decisions
- the benefits of SDM
- the issues and challenges that affect SDM
- the factors that support SDM.

I also aimed to seek consent to observe key meetings and events, such as ward rounds, to enable me to understand how the staff and young people interacted, and how decision-making happened within these contexts.
3.4 Research methods

3.4.1 Recruitment of sites

The following sections describe how I identified, recruited, and gained access to the two inpatient units for this research. I initially aimed to undertake research in four sites – two community mental health services and two inpatient units. Within the two community services recruiting young people was challenging. The staff within the community services identified young people who might be interested in being interviewed. Despite many efforts, only two young people were recruited. The main issues were staff time and capacity to recruit young people. Both services experienced significant crises during the research period, which meant they needed to delay the research several times or were unable to approach young people about involvement, as they understandably needed to focus their efforts on more critical issues. After this period, the staff were still very overstretched and reported feeling overwhelmed.

This study therefore focused on the research undertaken in two inpatient units. The following sections, therefore, describe only the recruitment and access to the two mental health inpatient units.

3.4.2 Ethics approval

Ethics approval was gained from UCL Joint Research Office and from the NHS Research Ethics Committee (REC), with REC reference: 15/LO/0377. Approval was granted for me to:
• be in the unit and have informal conversations with staff and young people; for example, to talk about the research, and develop trust in order to invite young people and staff to be involved in the study formally; and to make general observations, for example, to understand the place, space and layout of the unit.

• to interview staff and young people, and undertake formal observations (for example of ward rounds) with consent.

Following approval from the NHS REC, I then sought approval for each inpatient unit from the relevant local research and development office. This study also adhered to the *Statement of Ethical Practice* (British Sociological Association, 2017). Table 4 shows the timeline of the ethics application process within the timing of the whole research project.

**Table 5: Research timeline**

<table>
<thead>
<tr>
<th>Month</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>December 2014</td>
<td>Integrated Research Application System (IRAS) form ready to submit to NHS REC. Approval sought from UCL Joint Research Office</td>
</tr>
<tr>
<td>February 2015</td>
<td>Approval received from UCL JRO to submit the application to the NHS REC.</td>
</tr>
<tr>
<td></td>
<td>NHS REC application submitted.</td>
</tr>
<tr>
<td>May 2015</td>
<td>NHS REC favourable opinion received.</td>
</tr>
<tr>
<td>May–September 2015</td>
<td>Approval from local research and development offices for each site.</td>
</tr>
<tr>
<td></td>
<td>The applications for each site were</td>
</tr>
</tbody>
</table>
staggered throughout this period, to enable me to start research in the sites consecutively, rather than simultaneously.

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>November 2015–March 2016</td>
<td>Research in inpatient unit 1</td>
</tr>
<tr>
<td>February 2016–July 2016</td>
<td>Research in inpatient unit 2</td>
</tr>
<tr>
<td>August 2016–February 2017</td>
<td>Transcription and analysis</td>
</tr>
<tr>
<td>March 2017–September 2018</td>
<td>Further analysis and thesis writing</td>
</tr>
</tbody>
</table>

Gaining ethics approval is an important, yet challenging process for many researchers. For this study, it was particularly challenging, as it needed to go through the NHS Health Research Authority ethics review system. In the very bureaucratic and time-consuming system, the application forms and research ethics committee (REC) review are designed for clinical and scientific research (Murphy and Dingwall, 2007). It was not easy to fit a social research application into these requirements, and was still more complicated for ethnographic research, in mental health inpatient units, with legal minors.

Informed consent and freedom from coercion are vital in any research involving people, RECs tend to consider consent to biomedical or clinical research, which tends to involve a discrete event. Ethnographic observations, however, are long term, on-going interactions, where consent is negotiated and renegotiated throughout in relational and sequential processes (Murphy and Dingwall, 2007). Observations of groups in hospitals wards may involve opt-in and opt-out arrangements with different individuals. The specific nature of the ethnographic research interactions over time, and the risks, may be harder to determine in advance and will tend to be
identified and negotiated throughout the process whereas REC expect everything to be documented in advance (Ibid).

I felt the ethics approval process did not reflect or address important ethical issues I envisaged I would encounter during the study. The ethics approval processes predominately focussed on technical details of the number of events or interactions, and on documentation, such as information sheets and consent forms. While these are important elements of gaining informed and willing consent, they focus primarily on the technical aspects of consent, rather than the contextual and relational issues that influence informed consent to long-term research in the sensitive environment of the mental health inpatient unit. For example, there was limited opportunity in the REC process to include information about or explore: how I would conduct myself ethically within the units; how I would present my role and position as a researcher clearly, differentiating myself from the adult professionals in the units; and how I would deal with dilemmas that might arise when young people became embarrassed, distressed or perhaps angry. The ethics approval processes were driven by psychiatric positivism, which required a list of which diagnosed mental health conditions I would be researching, but not information related to researching complex relationships, and healthcare systems, asymmetries of power, and the views of young people and staff about those systems.

I am interested in working with other social researchers and those who sit on university or NHS RECs, to explore their experiences of the system and to see if any improvements might be made.
3.4.3 Gaining access to the inpatient units

I have worked in the field of young people’s disability and mental health for some years in advocacy, participation, decision-making and co-production. I was conscious that mental health services have been under significant strain for many years and that this had led to poor effects on young people, families and staff.

Through my work, I was aware that services and staff also often feel criticised for not involving young people in decisions about their care, without understanding the many constraints that staff, services, and young people experienced. They often felt as if policy documents or reviews on mental health (Chief Medical Officer, 2013; Department of Health, 2014; Department of Health and NHS England, 2015; NHS England, 2016) merely stated they needed to involve young people in decisions, but often lacked detail or did not acknowledge the complexities of doing so. Therefore, I feared they might, understandably, be suspicious of my aims and intentions as a researcher. Therefore, rather than approach services directly, I first approached individuals working in mental health with whom I had had some contact professionally. This enabled me to utilise existing relationships with people (who had at least some knowledge and understanding of my work, values and reasons for doing this research) to introduce me to the sites. However, whilst my contacts helped me to gain access through initial introductions, I was completely independent from the people on the wards I observed and recruited, so this did not compromise the actual research.
I was introduced to four inpatient units by a senior psychiatrist from a community mental health team. We had not worked directly together, but he was aware of my work to increase young people’s involvement in decision-making and my belief that this needed to be understood systemically, rather than blaming services or individuals.

Two of the units expressed an interest, and I arranged to meet with a senior psychologist from each unit. While both were interested in decision-making, they were also uncertain and therefore keen to explore my intentions. For example, one of the psychologists was worried when I said I would also be conducting research in another inpatient unit because they thought I would be making direct comparisons between the services. I explained that my desire to research in two services was to understand the broad range of factors that affect decision-making, rather than to compare the services and pitch one as better than the other. I also stressed that I aimed to understand factors from multiple levels and perspectives; for example, what was it that hindered the ability of staff to involve young people and what factors affected young people’s experience of involvement in decisions?

3.4.4 From ethical planning to ethical practice

The following sections describe how I practised ethically as a researcher in the units. The sections cover how I initiated the research and introduced

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5 Examples of my work and the projects I have developed can be seen at www.commonroom.uk.com, www.opentalk.info and www.mefirst.org.uk
myself to the units; how I practised as a researcher and endeavoured to be reflexive throughout my time in the units, ensuring that I adapted my practice accordingly; and how I collected the data.

3.5 Initiating the research

Once access to the sites was approved, I contacted the local collaborator in each site to discuss and agree on a plan to initiate the research. I gave the unit information sheets and consent forms (for staff, parents and young people) and large posters about the research to place in the staff rooms and communal areas on the ward for the staff and young people. These remained in place during the whole research period. The site lead explained to the young people and the team that I would be coming in to meet them at a community meeting (a regular, bi-weekly meeting between the staff and young people).

I then attended the community meeting to introduce myself, explain what the research was about and what this would mean practically. For example, I explained how much time I would be spending in the unit, what I would be doing and not doing when I was in the unit, and the differing ways they could get involved formally if they wanted to. I told the young people I would be back on a specified date within a week of the meeting.

3.5.1 First visit

On my first visit to each unit, I said hello to the young people and staff and then said I would be in a particular side room so they could come to chat if they wanted to know more about the research or me. I deliberately decided
to start off in a side room, so that I did not encroach on the young people’s living space. This seemed to work well and, in each unit, several young people came to see me. I kept this informal, and we chatted about the research, why I was doing it and I explained the meaning and process of consent. In one unit, the young people showed me around - as one young woman proudly said, ‘you’ll need to know where the loos are’. I was very conscious to explain clearly what I would be doing and perhaps just as, if not more, importantly what I would not be doing in my time in the unit.

I was keen to introduce myself to the staff and to begin to gain their trust. I made sure to spend time with some of the staff in communal spaces, such as the nurses’ office or staff kitchen so that I could talk to staff informally about my research. I also asked them questions to familiarise myself with the unit and to begin to show I was eager to understand their perspectives.

### 3.6 Being in the unit and data collection

As described in section 3.4.2 on ethics approval, there were the following elements to my on-going time in the unit:

- being in the unit and informal conversations
- recruiting and interviewing young people and staff
- formal observations of key meetings, such as ward rounds.

The ways in which I approached and conducted each of these are described more fully in the following sections.
3.6.1 Being in the unit

As described earlier, I had ethics approval to be in the units and to have informal conversations and time with young people and staff, for example, to explain my research and enable them to get to know me.

I let the staff and young people know when I would be visiting the unit each week so they would be aware when I would be there. On each visit I would inform the nurse in charge that I had arrived and would introduce myself to the young people and staff on shift. I would also check if there were any young people who had been admitted since my last visit, so that I could ensure I introduced myself and my role, give them an information sheet and make sure they knew they could ask me or a member of staff any questions about who I was, what I was doing, or what the research was about. I also reiterated that they could let me or staff know if they did not want me to talk to them or go in to areas where they were.

Inpatient units are highly personal spaces, where young people may be distressed, feel vulnerable, fear an intrusion of privacy or coercion. In restrictive environments, such as mental health inpatient settings, young people may fear (or experience) loss of control, a denial of their agency, and loss of independence and autonomy. Ethics and problematic issues in research can often be reduced to technical questions about processes and procedures, but must also include the ethics of actual conduct of the researcher (Rose, 2007). It was vital for me to consider and continually reflect on how I acted within the unit, and how the young people could perceive my role and the research. For example, young people may be
anxious that involvement in the research could impact on their immediate care, treatment, and relationships with other young people and staff in the setting.

Furthermore, I was conscious that, given the nature of the environment, young people may have found it difficult to say no to being involved (Curtis-Tyler et al., 2004). I was therefore conscious and reflexive about the types of conversations I was having with young people during my time in the units and to ensure they understood what my role was and was not. For example, during the initial and on-going visits, I was keen to explain, and ensure the young people understood, that these informal conversations were not part of the research. I was keen for them to understand that these were for them to get to know me, the research, and to make an informed choice about whether they wanted to opt in to be involved formally. With some young people, I talked through examples to help them to understand the difference between me being in the unit and us having informal conversations about, for example, what the research was and why I was doing it, compared to them being involved in an interview.

I was also aware of how suspicious or worried the staff might be about my research and the need to balance relationships with both young people and staff. I was there to understand the experiences of young people and staff and needed to develop trust with both. I was conscious that young people might perceive me as a member of staff from the unit, or that staff would think I was only there to listen to young people. I was therefore acutely aware
that I could easily be perceived to ‘take sides.’ For example, during one introductory meeting with the young people, I was sitting in a small lounge area having a cup of tea and a chat with three to four young people. It was relaxed and, as well as explaining the research, we also chatted about other topics, getting to know each other. At times we were laughing, and the atmosphere was relaxed and friendly, which was a great moment in starting to gain trust with the young people. At the same time, I could see this was difficult for the staff.

When I went into the nurses’ office shortly after, a nurse looked frustrated and commented that it ‘sounds like you were having fun.’ After a short pause, she sighed and said ‘if only we had the time to do that.’ While this could have caused a fracture in the relationship between the staff, and me as a researcher I empathised that this must be hard for the staff and explained these were the very issues I was trying to learn about and that I wanted to understand what was difficult for the staff. This made them much more relaxed towards me at that moment and then we talked more about the research and the interviews.

Time and transparency were therefore crucial in developing trust with young people and staff. I was open about the work I did outside of my PhD research and explained that I tried to work alongside staff and young people to improve mental health services. I was clear about the aims of my research and that I hoped to understand what works and what is difficult about decision-making, in order to find better ways of making decisions together. I
used examples from my previous work or from the research literature to reinforce that I understood the experiences of both staff and young people.

I was also reflexive and adapted my approach as I became aware of new issues. As described in Chapter 5, young people in the inpatient units felt frequently observed by staff or felt they lacked privacy, and many found this to be a very challenging experience. This quickly became apparent in the early interviews and informal conversations, and I was therefore conscious that I did not want to add further to young people's feelings of being observed.

I was reflexive about how I acted in and around the unit. I wanted to be there in a way that made young people feel comfortable to talk to me about the research if they wanted to but not feel pressured to do so. The staff and I explained (on several occasions) to young people that they could let me or staff know if, for example, they did not want me to be near them when I was in the unit. However, I was also conscious that young people might not feel able to say this. I was therefore also very conscious about my use of space in the unit and where I spent time with young people, in a way that meant they could choose to come to talk with me about the research. I also looked out for other cues and signs in their body language that could indicate young people did not want me in their space. In one unit the communal spaces were large and open. While this may not have afforded the young people much privacy on a day-to-day basis, it meant I felt my presence was less intrusive of their space. In the other unit, the communal areas were much
smaller – my presence felt at times very intrusive and so I avoided those spaces where possible.

Mealtimes or eating together with staff and young people are often good, informal ways to get to know each other. However, in the first inpatient unit I was in, many young people found mealtimes highly distressing. Therefore, I agreed not to enter the dining room at mealtimes. Instead, I spent time in the living room, or in smaller side rooms, where I could sit and have a cup of tea with the young people so that we could get to know each other and they could ask about my research. There were also many times when I was close to young people experiencing significant distress. At these times, I would respect their privacy and dignity and move to another area.

3.6.2 Recruiting young people to interview

As described, during my early visits, all young people were offered an information leaflet about my research, and time with me or a member of staff within the unit to talk about it (and this was offered to all new young people who arrived in the unit during the research period). I was conscious that young people might not have been interviewed before and that they may feel pressured to be involved. For example, I was aware that the distinction between my role as a researcher and a member of staff might not have been obvious or that they might not have had experience of expressing their right to say no when an adult asked them to do something. Therefore, I spent a few visits to the units just chatting to the young people and letting them get to know a bit about the research and me.
I was careful to show that I was a researcher and not a member of staff (although also being careful not to undermine staff in any way) and what this meant. I spent time talking to the young people about the research (including the consent process), and why I was interested in this subject as described in the previous section. Rather than ask young people directly if they wanted to be involved in an interview or observation, I explained the ways in which they could let me know if they wanted to be involved and encouraged them to approach me. When young people expressed an immediate interest, I still gave them time to think it over before talking about the next steps.

Once young people expressed an interest, I talked through the information leaflet with them again to ensure they understood what the interview would entail. I was particularly keen to ensure they understood anonymity, confidentiality, and their right to change their mind and withdraw at any time without having to give any reason whatsoever (and being clear this would in no way affect their care). Checking their understanding of confidentiality was vital. For example, when I mentioned confidentiality, several young people said something along the lines of ‘yeah I know … it's confidential unless I tell you something that means I'll harm myself or someone else.’ They had clearly heard the standard line on confidentiality but I was keen to check their understanding of what this meant. When asked, many did not know what sort of things they would have to say for me to need to break confidentiality. They also did not know what I would share or how. For example, they did not know if I would only share information about what had concerned me or the whole
interview, or whether I would talk to them first or do it without their knowledge. It was crucial to check their understanding to ensure they were making an informed choice about their involvement.

Young people expressed interest in being interviewed in different phases. Some were interested early on in my (or their) time in the unit. Others wanted some time to think about it, and I asked whether they would like me to approach them again or if they would prefer it if I waited for them to approach me. Some wanted to speak to other young people who had been interviewed to see what it was like, which proved useful, although I was still careful to check their understanding as, for example, one young person said to another ‘it's great, you get to say what you like and she listens. She doesn't even tell you off if you swear.’ I was careful to check they understood what the interview was about and its purpose.

Other young people said they did not want to be interviewed and I checked with them how I should approach them as I was going to be coming back into the unit regularly. For example, I enquired whether I should check in with them again or not – I did not want them to feel overlooked if others were being interviewed, but I also did not want them to feel I was going to keep asking or make them feel pressured. For example, one young woman said she did not even want me to say hello or acknowledge her. I was very conscious of respecting this on future visits. She would often watch me intently when I entered a room and I was careful to respect her wishes. Some weeks later she said she had changed her mind and wanted to be
interviewed. Whilst it was not fully clear why she had changed her mind, it seemed that this was partly due to respecting her right to say no.

Once young people had expressed interest in being involved in the research, I then agreed with them how to seek consent from their parent or guardian. Gaining consent was a challenging process logistically. For example, I spoke to all parents over the phone and then agreed with them how to give them the information sheet and consent form to sign (see appendices 1, 2 and 3). I sent some by email or post, and others were left in the unit for them to collect from staff. This meant some were not given out, parents forgot to bring them in, or signed forms were mislaid in the unit, which caused delays in interviewing as, for some, it took 2–3 weeks from the point they said they wanted to be interviewed to gain parental consent. I kept them updated throughout but, unfortunately, two young people left the unit before I could finalise the consent process with them.

Once I had gained parental consent, I gave young people choices about when and where in the unit they would like to be interviewed.

### 3.6.3 Interviewing young people

Given the levels of distress young people experienced and to allay the concerns of staff for the young people’s wellbeing in the interviews, I agreed I would let the staff know which young people I would be interviewing and when. I also agreed to check in with the staff before each interview with a young person to find out if there were any concerns about them taking part at
that time. This only affected one interview where a young woman had become extremely distressed. For a period of time she moved to the paediatric intensive care unit (PICO), which was a smaller unit within the main inpatient unit. The staff felt she was too distressed to be interviewed. I went to the PICO to talk to her and the staff, and we agreed to postpone the interview.

At the start of each interview we talked through the information sheet once again, before they signed the assent form. Whilst the language of assent was a requirement of the ethics approval, I was keen to give primacy to the young people’s informed and willing consent (e.g. young people’s consent was sought before I approached their parents for their consent). I talked about the key themes and discussion points before or at the beginning of the interview as some were anxious or uncertain about what an interview would involve. This appeared to reassure them. I was also keen to explain that there were no right or wrong answers – I just wanted to understand their views and experiences.

I interviewed 16 young people in total. Table 5 shows the pseudonyms and ages of the young people.
Young people were asked how they preferred to describe their gender and ethnicity. The following table shows how the young people who were interviewed described their ethnicity.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Darina</td>
<td>16</td>
<td>Female</td>
</tr>
<tr>
<td>Emily</td>
<td>15</td>
<td>Female</td>
</tr>
<tr>
<td>Jaime</td>
<td>17</td>
<td>Female</td>
</tr>
<tr>
<td>Jelena</td>
<td>16</td>
<td>Female</td>
</tr>
<tr>
<td>Jimena</td>
<td>16</td>
<td>Gender Fluid</td>
</tr>
<tr>
<td>Louise</td>
<td>16</td>
<td>Female</td>
</tr>
<tr>
<td>Matt</td>
<td>16</td>
<td>Male</td>
</tr>
<tr>
<td>Melissa</td>
<td>17</td>
<td>Female</td>
</tr>
<tr>
<td>Miranda</td>
<td>15</td>
<td>Female</td>
</tr>
<tr>
<td>Rebecca</td>
<td>17</td>
<td>Female</td>
</tr>
<tr>
<td>Robert</td>
<td>17</td>
<td>Male</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asif</td>
<td>17</td>
<td>Male</td>
</tr>
<tr>
<td>Dan</td>
<td>15</td>
<td>Male</td>
</tr>
<tr>
<td>Hamza</td>
<td>17</td>
<td>Male</td>
</tr>
<tr>
<td>Ikeoluwa</td>
<td>17</td>
<td>Female</td>
</tr>
<tr>
<td>Siobhan</td>
<td>15</td>
<td>Female</td>
</tr>
</tbody>
</table>
Table 7: Ethnicity of young people

<table>
<thead>
<tr>
<th>Self-described ethnicity</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladeshi British</td>
<td>1</td>
</tr>
<tr>
<td>Black African</td>
<td>1</td>
</tr>
<tr>
<td>Black British</td>
<td>1</td>
</tr>
<tr>
<td>British Romanian</td>
<td>1</td>
</tr>
<tr>
<td>Latino</td>
<td>1</td>
</tr>
<tr>
<td>White British</td>
<td>10</td>
</tr>
<tr>
<td>White Other</td>
<td>1</td>
</tr>
</tbody>
</table>

The young people interviewed had been given or described themselves as having a range of psychiatric diagnostic labels. These included: anorexia, psychosis, borderline personality disorder, panic, anxiety, depression, drug use, anti-social personality disorder, obsessive-compulsive disorder, compulsions, eating difficulties. Many also said they had experience of self-harm and/or suicidal ideation or attempts.

I have not included diagnostic labels in Table 5 above as many young people disputed the labels given and I did not feel these were relevant to understanding their experience. Where this is relevant, it is highlighted in the findings.
3.6.4 Recruiting staff to interview

In total, I interviewed 23 staff from two inpatient units. As shown in the table below, they have a range of roles including support workers, nurses, therapists, and psychiatrists.

In the early visits, I put posters about the research in the staff areas, such as the staff kitchens and nurses’ office, and also handed out information sheets during informal conversations with staff. Many staff showed interest and quickly signed up to be interviewed in the early stages of the research. There were some, mainly those who it seemed were uncertain of me or my research who said they wanted to be involved after getting to know me over the course of several visits or weeks. Staff were given information sheets, which I discussed with them and then they signed a consent form.

The following table shows the names and professions of the staff who were interviewed. These were predominantly women who were white British, which appeared to reflect the make-up of the staff teams.
Table 8: Table of interview participants – staff

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Role</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbie</td>
<td>Senior nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Emma</td>
<td>Psychologist</td>
<td>Female</td>
</tr>
<tr>
<td>Frankie</td>
<td>Support worker</td>
<td>Female</td>
</tr>
<tr>
<td>Gail</td>
<td>Art therapist</td>
<td>Female</td>
</tr>
<tr>
<td>Jenny</td>
<td>Senior nurse (matron)</td>
<td>Female</td>
</tr>
<tr>
<td>Jess</td>
<td>Support worker</td>
<td>Female</td>
</tr>
<tr>
<td>Jodie</td>
<td>Support worker</td>
<td>Female</td>
</tr>
<tr>
<td>Lauren</td>
<td>Psychiatrist</td>
<td>Female</td>
</tr>
<tr>
<td>Nelia</td>
<td>Psychologist</td>
<td>Female</td>
</tr>
<tr>
<td>Sara</td>
<td>Psychiatrist</td>
<td>Female</td>
</tr>
<tr>
<td>Seb</td>
<td>Family therapist</td>
<td>Male</td>
</tr>
<tr>
<td>Theresa</td>
<td>Nurse</td>
<td>Female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Role</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catherine</td>
<td>Support worker</td>
<td>Female</td>
</tr>
<tr>
<td>Iain</td>
<td>Nurse</td>
<td>Male</td>
</tr>
<tr>
<td>Jen</td>
<td>Senior nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Jonny</td>
<td>Psychiatrist</td>
<td>Male</td>
</tr>
<tr>
<td>Lisa</td>
<td>Support worker</td>
<td>Female</td>
</tr>
<tr>
<td>Mark</td>
<td>Nurse</td>
<td>Male</td>
</tr>
<tr>
<td>Martha</td>
<td>Senior nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Patsie</td>
<td>Nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Rivka</td>
<td>Student nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Saanvi</td>
<td>Student nurse</td>
<td>Female</td>
</tr>
<tr>
<td>Sue</td>
<td>Senior nurse</td>
<td>Female</td>
</tr>
</tbody>
</table>
The following table shows the self-described ethnicity of the staff who were interviewed.

<table>
<thead>
<tr>
<th>Self-described ethnicity</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afro Caribbean</td>
<td>1</td>
</tr>
<tr>
<td>British Asian</td>
<td>1</td>
</tr>
<tr>
<td>White British</td>
<td>17</td>
</tr>
<tr>
<td>White Irish</td>
<td>1</td>
</tr>
<tr>
<td>White Other</td>
<td>3</td>
</tr>
</tbody>
</table>

### 3.6.5 Formal observations

In addition to interviews, I was, as described earlier, also initially keen to seek consent from young people to observe key meetings, such as ward rounds, to understand more about interactions and dynamics in these situations. However, following only a few interviews, it became apparent that young people often felt very outnumbered or uncomfortable in ward rounds or formal meetings. The young people also spoke a lot about how their views or expressions were not believed unless they were backed up by the observations of staff or other markers, such as blood tests. Therefore, I felt that trying to observe ward rounds would place too much strain on an already stressful situation for young people and may increase their experience of their views not being believed.

Despite not undertaking these observations, the accounts of both staff and young people were remarkably consistent regarding their experiences of
ward rounds and of the wider constraints on decision-making in the unit, as shall be explored more fully in chapters 5–8.

3.6.6 Taking notes
As described, no formal observations took place during the study. I did take notes during the research period, but I was conscious to ensure these focused on the process of the research. For example, they included my thoughts and reflections on the interviews to inform my thinking, analysis, and future interviews. I also took notes on my reflections of how I was conducting myself in the unit to ensure I could continue to be aware of, and adapt my practice on future visits. I was conscious about how making notes on the ward might be perceived, particularly as I was keen to reinforce the distinction between my being in the unit, versus interviews and formal observations. I therefore waited to take any notes until I had left the unit after each visit.

3.6.7 Ending the data collection
I had approval to undertake research in each unit over a period of four months. Thus, the exit from each site was in part driven by the time limits of the ethics approval. It was also driven by saturation of themes from the accounts of young people and staff interviews. I was open and honest with both young people and staff about the duration of the research from the very first visit, and intermittently throughout my time in the units so they were aware of how long I would be there. During the last month of the research, I reminded both staff and young people of my leaving and made sure to thank
the young people and staff for their time and insights and for allowing me to enter their space before I left.

3.7 Data handling and record-keeping

As soon as young people and staff agreed to take part in the research, they were asked to choose a pseudonym (or given one if they chose not to) and allocated a unique code. From this point on, this code or their pseudonym was used on any data collected from interviews.

The interviews were audio recorded using a Dictaphone. At the beginning of the interview I asked young people for their name, age and how long they had been in the service. I did not switch on the Dictaphone until after these details were discussed, to reinforce the message that all interviews would be kept anonymous. The audio files were saved using the participant's unique code and saved on an encrypted hard drive in a locked filing cabinet. The files were saved on a separate drive to the one containing the participants' personal information.

The audio recordings were transcribed. Due to the high number of interviews to be transcribed, I transcribed five to familiarise myself with the process and then sent the rest for transcription. They were transcribed by a professional transcription company who specialised in social research. I was sure to clarify their terms and conditions, including their secure transfer arrangements and to ask them to confirm all recordings would be deleted.
Once the transcription files were received, I reviewed each one to check for and remove any identifying information, such as names of staff. However, there were few changes required.

3.8 Data analysis

NVIVO was used to upload transcriptions and analyse the data. Using NVIVO proved useful in the early stages, to host the large amount of data I had collected and to organise the data into themes and subthemes.

I analysed the data using thematic analysis and followed the process from Braun and Clarke (2006) using their six stages, which they describe as familiarising yourself with your data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report. These stages are described in detail below.

First, I familiarised myself with the data. As many of the interviews had been transcribed professionally, I read through each transcription while listening to the audio recording to check for accuracy. All were highly accurate. I also listened to them to gain a feel for each interview. I made notes during this first round of familiarisation.

Second, I immersed myself further in the data by rereading the transcriptions to develop initial codes. I revisited each interview at least twice during this phase as the more interviews I coded, the more codes emerged, and I wanted to ensure I had not overlooked these in earlier interviews.
In the third stage I searched for themes. Once the initial codes were developed, I reviewed these to begin to identify overarching themes. Once I had inductively developed initial ideas for the themes, I then looked to see how each theme might fit within the levels of the four-planar social being.

Once the initial themes had been developed and structured using the four-planar social being (see later chapters), I again reviewed and revisited the original transcripts several times to deepen the analysis. As new themes emerged, I wanted to re-explore the data to see if this would help me to see the data in new ways or identify new sub-themes. This also enabled me to be confident that the original data fully supported the themes I was identifying. Additionally, I was unsure where several codes would fit, and so I revisited these to see if they fitted within an existing theme, would form a new theme or whether they were not allocated to a theme at all.

I then gave initial names to the themes and subthemes within each level of the four-planar social being. I began to make links between the themes within and between the different levels. This was an iterative process – delving into the meaning of themes further meant I saw new links between different elements of the data.

Finally, I structured my findings into four chapters, each based on one level of the four-planar social being. While the main themes and meanings were mostly developed in the previous stages, during the drafting of each chapter I
was continuing to refine how I was presenting each theme to ensure they were communicated clearly. It was at this stage that I also reduced the length of many of the quotes, as I had left them longer during the early stages of analysis. I also checked the quotes to ensure they were good examples of the point they were illuminating, and to make sure they involved the range of interviewees. Editing the quotes was in some ways the most challenging part – adjusting the written words of a conversation I remember so clearly at times felt as if I was silencing their voices in some way. However, this was also useful as it made me review what I had written to ensure I had appropriately reflected participants’ views in each theme.

3.9 Summary
This chapter has described why and how critical realism has been chosen and applied within the research; explained why critical ethnography was employed as the research methodology; explored the ethical considerations during the planning of the research; and recounted how the data was collected and analysed.

The following four chapters detail the findings of this research.
Chapter 4. An analysis of decision-making in young people’s inpatient units

The following four chapters detail the findings from the research. This chapter briefly describes the inpatient units where the research took place. It then provides a short introduction to each of the subsequent four chapters.

The research was carried out in two mental health inpatient units. The names and locations of the units have been kept anonymous. The first unit was a suburban mental health inpatient unit for young people. Up to 16 young people could be in the unit at any time, with three places reserved for young people experiencing eating disorders. The unit was on a large suburban site with many other mental health units and services. While the young people’s inpatient unit was in a relatively new and modern building, there were many old hospital buildings on the site, which young people would have had to go past on their way to the unit.

After the reception area and through a locked door was a corridor of offices and meeting rooms. These began with the consultant psychiatrists’ offices and seemingly continued to follow the perceived (or actual) hierarchy – next was the doctors’ office, then the psychologists’ office, and after this an office for other kinds of therapists. On the other side of another locked door were the nurses’ office and the young people’s living space and bedrooms.
The living space was made up of a large wide corridor, off which branched a large communal living room, a large dining room, an art room (which was only open at certain times), staff kitchen (locked), medication room (locked) and a kitchen area for the young people (locked). At the far end of the corridor were the young people’s bedrooms, but these were locked during the day as it was deemed too risky for young people to be out of the view of staff. They were only allowed in their rooms at bedtime and, therefore, young people spent most of their time during the day and evening in communal spaces. There was an outside courtyard, but this was not accessible at all times. The large size of the living areas in the unit made me feel that my presence was less obtrusive, due to the range of neutral space in which to be with the young people. This meant that it felt more comfortable to spend time with the young people

The unit was short staffed. Some new nurses and support workers had been recently recruited, but the unit still frequently used agency staff who were not regular, so they did not know the unit and were not known by the unit (the impact of this is explored more in Chapters 6 and 7).

The second inpatient unit was located in a city. It had 12 places for young people, a paediatric intensive care unit (PICU) for an additional four young people who needed very high levels of support, and a day service that supported young people who were not inpatients. The unit was on the same site as several adult mental health units, but the whole site was much more modern and looked like any generic healthcare building.
Beyond the reception and locked door, the layout was circular. On the ground floor were the nurses’ offices, the young people’s bedrooms, the day service, medication rooms and other small rooms, all of which surrounded an internal courtyard that always seemed to be accessible. The doctors’ and therapists’ offices were on the first floor and were referred to by some staff and young people frequently as ‘the upstairs’ or ‘the people upstairs.’

The lounge areas in this unit were much smaller. There were separate male and female lounges with only a few chairs or seats in each. The young people were also allowed in their bedrooms, which gave them much more privacy. The smaller size of the communal spaces seemed more private for the young people but meant that as a researcher I felt much more intrusive. There seemed to be fewer neutral spaces for me to spend time with young people and staff.

The unit seemed to have consistent staffing levels and when staffing cover was needed, the unit only used their bank staff, rather than using external agency staff. This meant the staff were known, knew other staff, knew the way the unit ran and were usually more known to the young people.

4.1 An introduction to the findings
As described in the methodology chapter, the four-planar social being is a framework to situate and explore the multiple levels on which social events occur. It is useful in understanding the distinctive, but interdependent, roles
of structure and agency, and describes social events as occurring on four
dialectically interdependent planes (Bhaskar, 2008a). Each chapter explores
one plane of this framework, as described below.

Chapter 5, *Restricted bodies, restricted being*, explores plane one and
material transactions with nature, the physical reality of bodies and how they
interact and transact with the natural world and physical environment. It
explores young people’s experience of being in the inpatient unit and how
this affected their involvement in decision-making.

Chapter 6, *Knowing and doing: distant decisions*, explores plane two and
interpersonal, intra- or inter-action. It explores how relationships and
interactions between staff and young people in the inpatient unit affected
decision-making.

Chapter 7, *Social systems that constrain and promote mistrust* explores
plane three on relations in social settings, social structures social institutions.
It examines how processes and systems of the inpatient units enabled or
constrained decision-making for staff and young people.

Chapter 8, *Turning thinking into doing: reflexivity, alienation and resistance*,
explores plane four on intra-subjectivity, subjective agency and reflexivity. It
examines how young people and staff experienced and understood the
enablements and constraints of their environment; how powerful or
powerless they felt as decision-makers; how they responded to and
navigated the many constraints of the units; and how they then acted in relation to decision-making.
Chapter 5. Restricted bodies, restricted being

The first level of the four-planar social being focuses on material transactions with nature and how people interact and transact with the physical world and environment. This chapter explores the physical reality of how being admitted into, and being in, the restrictive environment of an inpatient unit affected young people and their involvement in decision-making.

The first section explores the physical restrictions and constraints young people experienced. This includes young people’s experiences of the process of admission; being physically dislocated from society, trusted relationships and known places; and the impact of restrictions on young people’s bodies, privacy and use of space.

The second section examines the impact of staff observations on young people; how young people’s being was reduced to other people’s perceptions and interpretations of their bodies and behaviour, overlooking young people’s real thoughts, feelings and motivations; and how these (partial) observations then became notes to form accounts about, rather than with, young people.

5.1 Being restricted

5.1.1 Being displaced: ‘They just took me’

They didn’t give me a choice. They just went, ‘No, we’re ringing your parents now or you’re going to get an ambulance, that’s it,’ and um, I didn’t even know why I was coming here at the hospital. They said,
‘You’ve got to get in a car,’ and I was confused why I’ve got to get in a car and they took me here so I didn’t know.

Rebecca, young person

Similarly to other young people in the unit, Rebecca described her admission as being uncertain and disorientating. Young people remembered having little real involvement in the decision or process of being admitted, or not even knowing where they were going. Their admission began with a lack of choice or control. As Dan describes, this initial lack of choice set the context that, for him, limited all other choices:

Umm … The day that they sent me here, I kind of accepted that like, well, I don’t really have a choice, like I’m gonna be sent here anyway.

Dan, young person

5.1.2 ‘It felt like prison’

For some young people, their admission into the inpatient unit was also their first contact with any form of mental health service, as they were admitted after having their first mental health crisis. They were either sectioned or admitted with the consent of their parents. They described having (or remembering) little or no involvement in the decision-making process or little explanation about what was happening to them. Some described being aware of the challenges caused by their mental health crisis (of already being confused and distressed) and understood the need for others to be involved in making the decision for them to be admitted. However, they described that not having involvement or explanation was frightening, confusing and disorientated them even further.
Hamza described the confusion he felt during his admission after his first episode of psychosis.

All I remember is I went [accident and emergency] for a second time and basically I saw another psychiatrist and I was speaking to her, and they didn't tell me what was going on. And I was left in that confusion for quite some time. So it was all very, very confusing. Even, thinking of it now, it was all very confusing. I don’t even know what was going on. So... all I remember is this, this confusion, basically. I think that's the one thing that I kind of feel sad about. [I wanted to know] what was going to happen to me and what the doctor thought of me and stuff like that. I wasn’t getting enough feedback, basically. They took my blood pressure and they took my blood… they took my blood samples to check if I had any drugs and stuff. But I didn’t know that I was going to be transferred into a hospital. I didn’t know that.

Hamza, young person

He did not remember having any involvement in the decision to be admitted but recalled seeing hospital staff talking to his family out of his earshot. He recognised that he had been unwell, as he believed his mum when she had told him he ‘had been acting strangely,’ but the lack of discussion or information meant he did not know where he was going when he was taken to the mental health inpatient unit. Whilst he struggled to recall some of the details of the words or actions of others, he remembered how he felt:

When I came here, I didn’t know that I was going to stay here and this is the place for me to stay now. I just ended up here. Because I was taken into some sort of van, an ambulance van thing, and I was kept in the back. It was enclosed and I thought I was going … I don’t know. It felt like prison and that. So I didn’t really know what was happening. I didn’t … I had no idea what was happening. They just took me. Took
me. And that's it. I was in the ambulance. I didn't know where I was going. I didn't know where.

_Hamza, young person_

Jen, a senior nurse, explained that many young people arrived at the unit not knowing that they were going to a mental health inpatient unit:

They come in and they're like oh, I didn’t realise I was going to be in this situation in a mental hospital. So often you're sort of having to tell people who have newly arrived, if you're sectioned you're going to be here and you can’t leave until someone says that you can.

_Jen, senior nurse_

5.1.3 The lesser of two evils

Other young people said that, while they had agreed to be admitted, they felt they had no other choice but to agree. They wanted to remove themselves physically from their families to stop being a burden and take the pressure off their parents of having to worry and care for them. Before she came into the unit, Emily said her parents would ‘be texting all day, phoning all day’ so she felt being admitted reduced the anxiety for her parents and for her.

Some of the young people who had longer-term mental health problems agreed as a ‘last resort’ to get better through more intensive therapy. For others, while they had agreed to be admitted voluntarily, they did so only because they believed that they would be sectioned if they chose not to go.

I said I didn’t want to come here, and they said I had to come here informally otherwise they were going to section me. So I didn’t really get a choice, even though I am like an informal admission, I would
have been forced to come here, so… I think that was quite pointless to be honest.

Louise, young person

5.1.4 ‘I didn't know what to expect’

It was very distressing at first. I remember the first day I just wanted to leave, like straightaway, I just hated it and, I just felt like it was completely the wrong thing and that I’d be way better at home, and it was making me worse.

Jaime, young person

Before admission into the inpatient unit, most young people had little or no understanding of what inpatient mental health services were or what to expect and were not given (or did not remember being given) information before or during admission:

Umm, yeah, I think it just took, it took me one week to actually realise what had happened and start making those connections. After like a week or so I ended up knowing where I was and why I was here and, and all that. What this place is. Plus a system of how this place works. I didn’t really know initially. Now I know it’s a mental health centre for young people.

Hamza, young person

I remember my mum said that I’m going for an assessment and I thought I was only going to be here for like a week because I didn’t, I didn’t really know what it was. Like, they just said, oh, you’re going to go to [inpatient unit] and they didn’t really explain that I was probably going to be here for a while.

Melissa, young person
For some young people, their expectations of inpatient mental health hospitals were influenced by stereotypes portrayed in films of asylums and of straitjackets.

Before I came here I had no idea it would be like this. I thought it would have straightjackets, white padded rooms. I have more freedom that I thought I would, but it's still weird.

*Matt, young person*

I was quite worried about it, like, I’d only ever seen stuff like on TV. They kind of portray it as a place where it’s really like, I don’t know what the word is, like, really ‘hospitally’ [sic],

*Darina, young person*

Even after they had realised the units were not like these stereotypes, there were many other aspects of the physical environment that they found strange and unfamiliar.

Some things are weird to get used to, like there’s no toilet seats as people can use them to self-harm. So that’s weird.

*Matt, young person*

Um, they didn’t explain to me and I didn’t really know what it was about, I just, kind of, went here and then found out that I wasn’t allowed a phone, I wasn’t allowed to smoke and I kind of went a bit mental. I just didn’t really know what was going to happen, at all.

*Melissa, young person*

They did not know what it would be like, in terms of place or routines, which made them frightened, scared and uncertain of expectations or their rights. As Sue, a senior nurse, explained, young people’s experiences of being brought into the unit meant they were often suspicious of staff:
Yeah, well they’re totally suspicious of us, like ‘who are you people, you brought me in by, or the police car like.’

*Sue, senior nurse*

Therefore, young people’s experience or perception of having no choice began before and during admission, meaning that from their initial entrance into the unit they felt disempowered. Even those who had some level of involvement in admission decisions felt as if they had no real choice, as they agreed to admission as the last resort for help or because they did not want to be a burden on their families.

Young people were suddenly in a new and strange environment, away from family and friends they knew and trusted, and places that felt familiar, to a place some understood as being based on stereotypes of asylums or prisons. This made them uncertain, suspicious and unsettled. The journey and the arrival into a strange, unknown environment meant young people were removed from their known points of reference – they were physically dislocated and out of place. These experiences communicated that they had no real choice and being in the unit therefore began with a lack of expectation of having any choice or control.

**5.2 Restricted bodies: ‘You just feel trapped’**

Don’t feel like really much freedom here. You can’t walk around the unit, you’ve got to stay in one room. You can’t wear this, you can’t do that, you can’t … it’s just really restricting so you don’t really get much choice.

*Rebecca, young person*
While there were some obvious, visible signs of restrictions, such as locked doors into or within the unit, there were many more constraints on the use of space. The inpatient units were unlike any other environment the young people had known or experienced. They were displaced and physically separated from any environment or relationships they knew and thus had little or no knowledge of how to be or act.

I suppose maybe being shown around [the unit], or something, beforehand, because then you don't have to like jump in and not know where anything is.

_Miranda, young person_

This left them feeling uncertain, unsure what to say or do, looking to other young people who had been in there longer for guidance, or just passively following what staff asked them to do. It was hard for them to speak up or express a different opinion if they had no understanding of what was expected of them, of what was right or wrong in their particular environment, or what they could expect from others. Their physical uprooting led to uncertainty, which in turn led to constraints on their bodies, as they were uncertain of how to be or act in a such new, unfamiliar environment.

5.2.1 Constrained and bored bodies: ‘I’ve only been for a walk twice since I’ve been here’

I’m angry because there’s nothing to do here. We’re supposed to be here for our benefit but there’s just nothing happening.

_Matt, young person_
Like, I just hate it. It just makes me bored and, like, you don’t know what to do with yourself here, really, because I… it’s just a bit, every day is the same and then you get home from school, well back from school, and then there’s nothing really to do, ever. I mean, I have a few groups a week, but not that many.

_Melissa, young person_

The ward doors were locked, and young people were unable to leave without permission. For many young people, not being able to go for a walk was keenly felt. Matt, similarly to other young people, felt frustrated at not being able to be outside and had only been for a walk outdoors once in the two weeks he had been in the unit. While in each unit there was a courtyard area, this was still within the confines of the building and was not the same as being outside. This meant young people were also separated from nature, open space and fresh air.

Sometimes I want to go on a walk and they’re like, “Oh, yeah, if we had the staff we could do it. Like, oh yeah, we can go, yeah, we can go to Costa and stuff,” and then you find out that they can’t and it’s like, well, you shouldn’t have told me that, because it’s, it’s just not good. I’d just prefer they told me, like, “No, that can’t happen,” so I know in advance, because I, like… being let down is quite a big, like, makes me feel really… it’s like a trigger.

_Melissa, young person_

Young people had to apply for leave to go home and visiting times in one unit were restricted to certain days. Emily had been in the unit for seven weeks and she had not had home leave. Along with insufficient time outside, this led her to ‘just feel trapped’. Rebecca describes feeling restricted:
We can’t um, can’t go ring the phone at this time and then you can’t have visits on this day and you can’t, you know, go to your room yet. It’s just no reasons to it.

*Rebecca, young person*

Mobile phones were not allowed and the use of the phone on the ward was only at certain times. Therefore, they were very disconnected from friends and family, and their social and cultural lives.

It’s mainly the staff that have the say. Um, even just like general things like going to bed or using the phone or, just, I don’t know, just daily things. Like, if you wanted to call your mum at the beginning of the day to remind her to bring your socks, or something to an evening session, they wouldn’t let you.

*Miranda, young person*

One of the things that we’ve been talking about here a lot is about use of the internet and mobile phones and things, which we have a no use, um, policy on here. But I think what we’re doing is removing the reality; we’re not offering them an opportunity to use it safely, deal with the consequences of for us to discuss it ... We … I feel like we’re maybe missing a bit of a trick here as far as general adolescent development is concerned by just avoiding it.

*Abbie, senior nurse*

The typical day-to-day choices young people were used to being able to make in their lives, were restricted within the units. For example, this included daily routines where young people had set times to get up and set mealtimes. Jimena felt she was being scheduled as being in the unit got ‘repetitive day after day’. Miranda described feeling very constrained:
Um, even just like general things like going to bed or using the phone or, just, I don't know, just daily things. Like, if you wanted to call your mum at the beginning of the day to remind her to bring your socks, or something like, an evening session, they wouldn’t let you.

Miranda, young person

Owing to the physical restrictions on the use of space, young people were unable to do many of the small, everyday things that they were used to taking for granted.

Stuff like food, you don’t really get to choose what you eat, like, it’s kind of, they just cook it and don’t really tell you what it’s going to be and it’s horrible.

Melissa, young person

They were unable to make hot drinks when they wanted to as the kitchen was locked, or some could not go to the toilet without letting a member of staff know. Similarly, normal day-to-day activities were often given a therapeutic frame – for example, in one unit cooking a meal (something that most teenagers may be used to doing or helping with at home) had now become an activity led once a week by occupational therapists, rather than a usual daily living activity. Young people had little opportunity to contribute to normal household or daily living tasks that they may well be expected to at home. They had become positioned as people for whom things were done for or to.

Within the units, young people’s use of space was highly restricted. They had little freedom over how they moved around in the unit and little privacy. In one unit the young people’s bedrooms were locked until bedtime and they
had to spend their time in communal spaces. In the other unit, although young people could use their bedrooms during the day, their movement and use of space were still limited. They could only go into specific rooms or areas if there were enough staff to be with them, which was often not the case. Therefore, they had little or no privacy or time alone, which for some caused great frustration. Some described how when they could not go to their rooms, they would try to gain privacy by hiding under blankets.

As teenagers and young adults, they were used to having significant amounts of freedom and control over aspects of their daily lives, which had then been curtailed in the unit.

I don’t really think I’ve had any personal decisions. Yeah, just saying that I’ll come in. That was the biggest decision I’ve had to make. Since then, no other decision. It’s all been made for me.

Robert, young person

They had to ask permission to do things that previously they were able to do independently which caused them intense frustration:

I mean it is quite structured here. Like in terms of their day-to-day stuff, there isn’t like loads of room for choice.

Patsie, nurse

These restrictions over their daily lives, activities, and use of space reduced not only their choice but also their control over their bodies. These small, everyday incursions mounted up and told them they needed to comply with the routines and restrictions of the place rather than exercise individual choice or control. They also disempowered young people as they were
prevented from doing many of the things they found helpful to manage their distress:

I fall asleep and then a couple of hours later I wake up and I wouldn’t be able to get back to sleep so I’ll just be sitting here. So yeah. And especially being in a new environment like at least when I’m at home, I can go and just get a drink of water.

Robert, young person

Many resisted these restrictions to varying degrees (as described further in Chapter 8). As Jelena said ‘I can't even go for a piss without asking permission’, communicating her exasperation and frustration at having no control or freedom. It made her and other young people feel constrained, cooped up, agitated and powerless, conveying the power of the place over them as people. If they could not make everyday choices, such as when to have a drink, where to be, when to have privacy, how could they influence more significant decisions about their care and treatment?

This place is really strict and it’s not even strict for safety, like, because they’re trying to be over safe here. I don’t feel safe here at all and it’s just silly rules, like really like ones I don’t even understand … we couldn’t apparently drink from milk cartons or we can’t go ring the phone at this time and then you can’t have visits on this day and you can’t, you know, go to your room yet.

Rebecca, young person

5.2.2 ‘I’m slipping into bad habits again because I want a sense of control’

The restrictions on their day-to-day lives resulted in young people having little or no choice about their use of space, their bodies and actions. Not having
influence over even the smallest aspects of their lives made a few young people seek control elsewhere.

It’s just frustrating because the only thing here that they don’t control is food, and that is literally it. But if I was on a meal plan, they would be controlling my food intake as well. Whenever I try and control my food, it’s bad because that’s how I ended up anorexic … And it’s just like it took me like over a year to get over it and the fact that like now I’m slipping into bad habits again because I want a sense of control.  

*Jelena, young person*

Others tried to assert some element of control through their use of space. Many were tired, bored and agitated through the lack of physical freedom, lack of space or being able to go outside. They felt contained, and many pushed back against this to reclaim or control the space and, for example, wipe staff names from the board.

The greater the restrictions young people experienced, the more critical the smaller choices and decisions became in order for them to assert some level of control and express their individuality.

Give people a choice. I mean it’s a fundamental thing, isn’t it? That reminds me of something. When I was very small, having cereal one morning and my dad had got sterilised milk and I was only little so I was maybe no older than four and I didn’t like it and he kept saying, ‘Have milk,’ and I was like … I couldn’t tell him that, ‘Actually, Dad, that’s disgusting,’ (laughing), do you know what I mean? But … and it was my mum saying, ‘She doesn’t like it, give her the other one,’ you know? And there are things like that aren’t there; it’s very … something very small but [so important] … And I… and I don’t understand how people don’t realise that because to me, that’s, that’s just common sense.  

*Gail, art therapist*
However, whilst Gail and some other members of staff could see the importance of small choices people usually take for granted in their lives, the significance of this was consumed by the need to run the unit or it was difficult for staff to see the importance when they were stressed, busy or short-staffed. For some staff, the control of the physical space was the only way they could care for and keep young people safe. They needed to know where young people were and to keep sight of them to ensure they were safe and not harming themselves. While they recognised that the lack of privacy was an issue, they were unable to see any other way of keeping young people safe (as explored further in Chapter 7).

5.2.3 The physical separation of being and therapy

The units physically separated young people, nursing and care staff from the therapists and doctors. The doctors’ and therapists’ offices and spaces were separated from the space where young people, nursing and care staff spent their time. This was significant for young people, and nursing and care staff who all commented about the ‘others’ upstairs or on the other side of the door.

Young people, nursing and care staff were keenly aware of the lack of time doctors and/or therapists spent on the ‘ward’. This meant they saw them as distant from the reality of being on the ward and from the experiences, thoughts, and feelings of young people. When they did, it was for short,
infrequent meetings. Young people usually had to go ‘upstairs’ or ‘to the other side’ for their therapy sessions or meetings about their care. They felt physically distant and separated from those they regarded as therapists and/or decision-makers regarding their care, who spent little or no time just being with them in the unit. This is explored more fully in the following chapter.

I think it's very much a slow process. It feels like you only have one therapy a week, but you've lived through the whole week.

_Darina, young person_

Their use of time was also clearly demarcated along with their space. Young people expected the whole time and environment to be therapeutic. Some were angry, disappointed and frustrated that their time modelled that of the outside – they spent their time on the ward and had weekly therapy sessions outside of the ward on the therapists'/doctors' side of the building. Some had expected intensive therapy and then felt cheated that most of their time was just being on the ward and only receiving therapy once a week. Their hopes of intensive therapy were, for some, replaced by the feeling of being contained and prevented from harming themselves.

### 5.2.4 Medicated bodies and being medicated

In one unit, young people could talk to the onsite pharmacist about the side effects of medications, which they valued in terms of getting information, but they did not feel as if they had any choice. Others described being given
medication with little or no information about what it was for or about side
effects.

I took some [medication], but I don’t know what it was. I was just… It
was just given to me by a nurse and I took it. I didn’t get a say, but I
was told what it was and what it does and stuff like that. Given
information about side effects and just how the medicine works and
what it’s used for and stuff like that. It was enough, but not at the right
time, as in it was only after I was given it. It would’ve been much better
if I’d have known before [as it’s] something that’s going into my body. I
just didn’t, I, I’d love to have more information. I’d like to have
information about it beforehand, basically. I’m meant to know this stuff
before… everything before.

*Hamza, young person*

Others talked of medications being changed with no explanation. This made
some fearful, uncertain and resistant to taking medication in case it was a
mistake or because they wanted to know what they were for. Some did not
appear to question this and assumed they were expected to comply. Others
described how they had no choice and how they would otherwise be
restrained and forced to take medication.

The side effects of some medications had very real effects on the body,
including, for example, changes in hormone levels, which could cause males
to experience changes in breast tissue. Others made young people very tired
or drowsy, and they described how this made it difficult for them to
concentrate or think clearly.
Their bodies experienced very real effects of medication through side effects or from being forced to take medication, affecting young people’s sense of agency and autonomy. They felt their bodies were ‘done to’ by medications or by people. Either way, it communicated control of their body by something other than themselves.

5.3 Being observed

They would watch you, when they give you the medication. So it was hard.

_Ikeoluwa, young person_

As described earlier, young people had little privacy and were also closely and frequently observed, which they found troubling. Nurses and support workers undertook regular observations of young people, usually at intervals of 10–20 minutes, which were then recorded. Some young people, who had been assessed as needing constant supervision, had one-to-one support and needed to be in arms reach or in sight, including when they went to the toilet. Others had close support and observation for part of the day; for example, young people with eating disorders had support whilst they ate their meals and afterwards, to ensure they did not try to exercise.

Being so closely observed was a new and strange experience for many young people:

Especially on one-to-one, some stranger just drinking their tea, watching you as you just lie awake; it’s a bit odd. They sit outside your
room but they have the door open all night, look at you as you sleep. I found it a bit peculiar.

*Robert, young person*

Being observed made some young people feel as if the staff observed but did not care (the impact of this is explored more fully in the next chapter). They described being on one-to-one support but just felt watched, with little or no conversation or interaction with staff, especially when it was agency staff.

Someone sits there but they wouldn’t say anything. Someone sits with you, but they don’t, like, support you [...] they just supervise you. It’s quite awkward.

*Miranda, young person*

For some young people, regular observations helped them to feel safe, as they knew staff were checking on them. However, for many, observations were difficult and made them feel very conscious of how they acted. Jimena described how this made her very anxious about what staff would think about her or do as a result:

*I know that I don’t push the boundaries as much as other people, because … I kind of shut down, and just kind of freeze. But … So even like little things that I do, I’m afraid that I will get put on section, just terrify me …*

*Jimena, young person*

This signified the power of staff over young people in a very visible way and led some young people to feel monitored rather than cared for. Young people felt that when staff were doing observations, they should talk to them
privately or discreetly to understand how they were feeling and to enable them to be honest. Rebecca describes how she felt embarrassed:

> They ask how you are in front of everybody and you’re not exactly going to go, ‘No, I’m awful,’ to everybody. Yeah, then they sit and talk about it. Like, they even talk about my care. Awkward. This is in front of everybody.
>
> _Rebecca, young person_

While observations were a routine part of their shift, many staff did not value them. They wanted to spend time informally with young people (as described more fully in the following chapter) but were prevented from doing so owing to a lack of staff or needing to fulfil the routines of the shift, which they found challenging and lacking. For other staff, observations were reassuring as the structure of routines signified they were doing something to keep young people safe. For some, this was driven by a deep fear of young people hurting themselves or each other. However, Rebecca and other young people questioned how observations were meant to keep them safe in comparison to proper time and interactions with staff:

> They don’t check you’re safe at all, like even 20 minutes … you could do anything in 20 minutes and they’re not even checking if you’re safe.
>
> _Rebecca, young person_

### 5.3.1 Being reduced to observations: ‘They can’t really read your mind, can they?’

Jimena explained how invisible the assessment process felt to her when she was first admitted. After admission, she described waiting for her assessment to start. Her previous experience of an assessment has been with community
mental health services where her therapist had ‘like a frickin’ wad of, like, 10 papers and questions to ask you’. The assessment had therefore been obvious, visible, and she was noticeably involved in it. After two weeks in the inpatient unit, she asked a nurse when her assessment would start and was told ‘oh no, we’ve been assessing you the whole time...’ This concerned Jimena as she felt she was ‘more internal’, making it harder for the nurses to assess her as they could only base this on her what they could see, and therefore ‘focused on the one thing, instead of everything’.

A number of other young people echoed Jimena’s worries and were concerned about being assessed or judged on their visible actions and behaviours, rather than their real underlying feelings or motivations. Many felt that staff could not possibly know, through observations, how they were feeling physically or emotionally. They felt that only they could tell staff about their physical and emotional experience and state, yet felt observations took precedence over their felt experience:

Like, no matter how much they’re trained and no matter how much they try, the professionals don’t know what’s going on in your head as well as you do. Your body knows everything about what’s going on.

_Siobhan, young person_

For Robert, he came to believe others over his own feelings:

[Staff say] ‘Oh, I’ve seen an improvement in his mood so...’ But that could be anything; that could be like some ... something at home ... it might be nothing to do with therapy. So it would just be, I don't know, 'I’ve seen this happen so he must be better.' I thought ‘Well, I don’t feel better but they're saying I must be better,’ I was just thinking, ‘Well, it must be just like the normal way people feel, then. Everyone
must feel like this, then.’ But then it took me a long time to realise not everyone’s like this.

*Robert, young person*

This made them feel as if things were being done to them, on what other people thought they needed, rather than on what was important to them as individuals.

Um, I suppose, like, if you tell them what’s wrong then they can help you in the ways that you need helping [rather than] what they think you need.

*Miranda, young person*

### 5.3.2 Being overlooked

Being observed with no discussion made young people feel as if they were merely bodies. It meant young people felt as if their bodily appearances and actions, as observed by staff, took precedence over their expression of their physical and emotional feelings, experiences, and states. This left some feeling as if they were being guarded and supervised. It was a powerful practice, which signified the power of staff over them, particularly as they had little understanding of why this happened or what staff were recording or observing.

This was particularly difficult for young people who were quieter, and who felt overlooked. They felt watched, but that no one was noticing their feelings or how safe they felt. They were in what was supposed to be a safe environment, but no one knew how they truly felt which, for some, mirrored how they had felt on the outside before they were admitted. Some young
people felt that to be heard or noticed, they had to show anger, frustration or other ‘difficult’ or externalised behaviour. This could overshadow young people who were quieter and could often escalate to more and more extreme behaviours to feel noticed:

… and also to stop kids getting pathologised. So often kids on psychiatric units and you’ve got … the … there’s a kind of currency or the currency is mental state so in order to get noticed or witnessed, you have to prove, you know, self-harm or show rabid behaviour.

*Seb, family therapist*

Many young people felt their behaviour had to become extreme to get help. Many said that they often tried to talk to staff, but that staff were busy, and it was only when they became very (visibly) distressed that they were given help and support.

‘It’s weird [as] it just seems like you have to get to such an extreme for them to actually do something.’

*Melissa, young person*

when you ask to talk to a staff member, they’re like, ‘Yeah, sure, okay,’ and then they won’t actually talk to you for ages until you keep bugging them or … unless you kick off … like I’d be banging my head on the walls and then they’d come and like talk to me and I’d be like, ‘you talk to me when it’s too late.’

*Jelena, young person*

This also made young people who were more self-conscious and would internalise their feelings feel uncared for and overlooked. They felt that it was those who expressed their distress externally, and visibly, that got time and attention from staff. They wanted staff to be proactive in asking them how
they were feeling, rather than waiting for young people to approach them or needing to get visibly distressed. Jimena described feeling ‘a state of exhaustion’ by thinking about what she should do, knowing that how she appeared on the outside carried more weight than her verbal expressions.

Young people understood that staff were busy but were frustrated as they felt that if staff could give them the time when they asked for it, their distress or behaviour would not escalate. They felt that expressing their frustration physically placed them in a no-win situation. They felt frustrated at not having any choice, being so restricted and constrained, and felt their valid expressions of frustration were sometimes reduced to behaviours rather than the reasons for their actions. This frustration built up and could cause them to express this anger through their behaviour or lash out because the message they got was that only extreme behaviour was noticed or because they could not contain it any longer. Yet they also described how expressing anger or frustration could have physical consequences and could result in restraint, being removed from the ward to another area of the unit, or being given medication.

Jelena had broken her foot in a previous suicide attempt. She described a situation where she was in pain and asked a member of staff for some painkillers, who said they would get some for her. An hour later they had not brought them. Jelena said she understood they were probably busy or helping another young person but by this time she was in increasing pain. She went to knock on the nursing office door and was told she would have to
wait as ‘she knew it was handover’. She recounted that she explained to the nurse that she had already waited an hour and had been patient but now really needed them, but was again told to wait. She said she became very distressed and started to bang her head against the wall.

Young people felt judged by their actions, not by their reasons, which made them feel even more frustrated. They felt this became a no-win situation and further reduced the likelihood of being listened to:

It’s just really frustrating really and then they make more decisions about you. It just gets really frustrating and then gets to a point where like all your frustration builds up and then, it just I don’t know about anyone else but for me it all comes out in like an unhealthy way, but it’s purely because they’re making me frustrated and they’re not helping me to deal with it.

*Jelena, young person*

As Abbie described, it is essential to understand what may be driving young people’s behaviour and to respond by trying to understand the real underlying causes, feelings, and frustrations, rather than responding to or trying to control behaviour:

So, one of the things that I always do and I’ve tried to kind of model for the team, especially the new ones, is when someone is getting distressed or angry, I always tend to say, ‘What do you need? What do you need?’ And immediately, you’re saying, ‘I’m looking at you and you’ve got an opportunity to tell me and if you say, ‘I need you to fuck off,’ I’m going to say, ‘That’s fine. I’m going to be just here. I’m just here. I’m here to support you. I’m here to keep you safe but if you need me to be over there, I’m going to be over there. That’s fine.’ And it doesn’t immediately have to be, ‘Alarm!’, you know, ‘two-person escort down to the assessment side,’ you know. I think some of that is
just about … it’s about your own tolerance and your own confidence and feeling okay to sit with that for a bit. I think for some people, they see the first little outburst, they just pull an alarm because they’re just thinking, ‘Oh, it’s all going to go wrong.’

*Abbie, senior nurse*

Emotions are a reaction to the real world and commentaries on our situations, of body/environment, subject/object and subject/subject relations (Archer, 2000). Young people's anger and frustration may be reactions to the situations they are in, not irrational behaviours or 'symptoms'. They need to be explored and understood with young people, rather than separated from their context and meaning.

Observations positioned staff as knowing more about young people's feelings than young people knew of themselves. They also made young people feel conscious of their actions, how staff would interpret them and how this would affect their care, reputation and role in decision-making. On the one hand, those who were quiet felt overlooked and worried that staff did not understand the extent of their internal distress, frustration or dissatisfaction, and would assume they were okay or 'better' than they were.

Observations made some young people worried about being discharged before they were ready, as their mental health was being judged on visible, external signs rather than their real distressing feelings and thoughts.
As Rebecca described, her obsessive feelings and behaviours had not improved, and she still had the same number of compulsions. She was supposed to have exposure work seven times per day. The exposure work was core to her treatment and caused her high levels of visible distress (yet she recognised that this was what she needed). However, her exposure work rarely happened as much as it should and, as such, she was not doing the very things that caused her to become visibly distressed. She said staff then fed back to her that she seemed to be doing well and getting better. She was very concerned when she was told she could soon be discharged:

It's getting me down [...] I'm not even better at all, like maybe my moods are a bit better but my OCD has not improved one bit. I've not come over any compulsions at all, like not one. I've not got out of one and I've been here for three months. It's really bad.

*Rebecca, young person*

Young people's real being, thoughts, and feelings were reduced to staff perceptions or interpretations of their visible behaviours. This sent a strong signal to young people that staff interpretations carried more importance than their views. This falls into the epistemic fallacy, where being (ontology) is collapsed into knowing (epistemology) (Bhaskar 1998). The reality of the young people’s minds, bodies, daily life, their hopes and fears were reduced in the staff’s assessments, mistaking their perceptions and observations for independent reality (*Alderson, 2013; Bhaskar, 2010*).

Young people’s words or actions are often observed and (mis)interpreted by staff. There are staff accounts of young people’s behaviour (signifiers) and
staff concepts (signified) of young people’s needs, which staff have reduced into young people’s words and behaviours. This does not take account of the actual experiences, feelings, and needs of young people (referent). Young people, their feelings and distress (referent, their reasons, and motives) are excluded and absent. Figure 1 presents the semiotic triangle, which illustrates the connection between the signified, signifier and the referent.

Figure 1 The semiotic triangle (Bhaskar, 2010)

1. Signified

2. Signifier

3. Referent

5.4 Being reduced to notes

The semiotic distancing continued when staff reduced their observations of young people into notes, which were then passed between staff in shift handovers, in young people’s records, and into weekly ward rounds.

Young people’s real thoughts, feelings and needs, reduced by the observations of others, were then recorded in notes, which acted as a
physical substitute for the views of young people. Young people were very conscious of being observed and of notes being made about them. However, they were not involved in writing the notes and were physically separated from the process, seeing the observations of themselves being recorded, discussed in handover, and taken into ward rounds. The practical reality of their feelings being reduced into notes and the aesthetics of seeing these being discussed from a distance, communicated to young people that others’ views about them were more powerful than their own.

When they have handover, it kind of feels that they’re talking about us behind our back. It would be nice to know the kind of things that they’re telling people.

*Rebecca, young person*

This was concerning for them because they felt as if decisions were based on partial, inaccurate information about them – information based on their observable behaviours, not the real, underlying feelings, causes and motivations. They were conscious that if staff were making notes about them based on observations and passing theses notes onto other staff then things must be miscommunicated or misunderstood. This made young people feel unsafe. They wanted communication to be open, direct, and to be involved in writing their notes so that they knew what was being written:

Yeah, and sometimes it’s like, with your doctor I think it’s really important ‘cause they’re making all the decisions about you but, it’s a bit like, I feel like it’s a bit like Chinese whispers sometimes between like all these people like, you, they’re writing notes on you, and then someone else is reading notes and they’re passing it on in all these like handovers, and like stuff, and I feel like, how stuff must get missed, or miscommunicated or like, not understood or, it just must
happen, and that just feels really unsafe. So sometimes I wish I could be like more, it could be more direct communication. I think [being able read the notes] would be good ‘cause sometimes you might not agree with what they’ve written and I feel like you should have a say in that.

*Jaime, young person*

Reflecting with staff could be therapeutic and could help young people to learn how to manage his/her mental health:

> It would be quite good if they went through what they thought, how they thought you were doing with you, at the end of the day. ‘Cause especially days like today, this morning was really bad, so if somebody would sit with me and I could say how I felt then and how I feel now, and what I think helps then I could kind of think about how that helped me, ‘cause then, I could, maybe use that again.

*Rebecca, young person*

Observations and notes are not value free, factual accounts. As Abbie described, staff could project their own emotions on to the way young people’s notes were written, especially after a stressful shift. These notes were then handed over to the next staff on shift, which then affected their perception of the young people. The new staff could then be more restrictive towards them:

> We need to be really mindful of using the correct spaces for our own debrief and our own rant and, um, and that what we pass in information is about the young person’s feelings and emotions.

*Abbie, senior nurse*

Observations were recorded into notes and passed on in ward rounds and into young people’s records, which turned observations into notes and ‘facts’
about young people’s being. This is an example of the ontic fallacy, where knowing is collapsed into being (Bhaskar, 2009), and observations into desocialised ‘factual’ accounts of young people’s real being, thoughts and feelings. Young people therefore felt as if their personhood, their real thoughts, feelings and values, were being reduced into other people’s interpretations of their bodies, behaviours and actions.

5.5 Summary
There were many obvious physical constraints that excluded young people from decision-making at admission, on the ward and during observations. Perhaps more importantly, there were many other less obvious or subtle ways that communicated to young people that they could not influence decisions about their care.

Young people’s entry into the units was characterised by little or no real involvement in the decision-making process. This, therefore, initiated their time in the unit with a lack of choice or control. A lack of control was then further constrained by the significant restrictions on young people’s actions, freedom and use of space. Being physically dislocated, separated from known people and places, and sited in a completely alien environment meant that they were uncertain how to be or act, which caused them great uncertainty, frustration and distress. Control over our bodies and actions are core to being human and who we are as people. Our ability to act, our
freedom to do otherwise and self-determination are central to our perceived and actual freedom (Bhaskar, 2008a).

Adolescence means 'becoming adult' in our society and is expected to be a time of increased awareness of bodily changes connected to changes in social activities, status, freedoms, explorations and resistance to being confined as younger children usually are. The typical impatience with restraints during 'normal' adolescence is regularly criticised or even pathologised as negative, undesirable behaviours and, for those diagnosed as mentally ill, there is the double dismissal of unreasonable behaviour being seen as needing to be controlled and reformed. Our being is realised, in part, through our interactions and transactions with our natural environments (Archer, 2000). When young people’s use of space and movement is restricted, it is not just their physical bodies that are constrained, it inscribes in to them that their very being and personhood is restricted.

Emotions are a reaction to the real world, commentaries on our situations and of body/environment relations (Archer, 2000). Thus, young people’s behaviours are, in part, natural and rational reactions to the significant physical restrictions and constraints that prevent them from being and doing what they want, need and hope to do and be, yet they are often seen as irrational or difficult.

It is vital to recognise the impact of physically removing young people from what and who they know; how being displaced through being confined in
environments that are so alien prevents them from knowing how to be or act; and how, by physically restricting and constraining their use of space, young people are made to feel as if they have no choice or influence, or ability to act freely or make even the smallest choices that most take for granted. Treating them as if they cannot know, understand or discuss their own problems reduces them to bodies to be treated and managed, and not as though they can be informed trusted partners in their care.

Young people were made to feel even more powerless over decisions that affected them through being observed. This focus on observations has a long history in mental health services where psychiatry has focused ‘on the surface of the body posture, gaze, movements’ (Rose, 2007, p. 193) as the way into someone’s subjectivity. There is a long history of interpretations of conduct (Rose, 2007, p. 194) and therefore visible, ‘symptoms’ and behaviours, rather than the meaning individuals place on their experiences (Pilgrim, 2013). There is an irony that distress and treatment concern the mind, but this is another instance of how psychiatric practice is based on physical medicine in ways that reduce suffering to observations of behaviours. Observations cannot account for the private, internal self and the deliberations that only people themselves can know, as much of our inner lives do not manifest themselves in visible actions and are ‘hermeneutically sealed from extrospection and knowable only by our first person selves’ (Archer, 2003, p. 22). These practices ignore and overlook young people’s being and their real self. They privilege the biological over the social and, as
such, privilege meaning made from observations of bodies and behaviours, rather than meaning made with people.

Observations become notes, which are turned into ‘facts’ and truths about young people. This can have determinate effects on decision-making and relationships between young people and staff (this is explored further in the following chapter). The process of observations and note-taking sent a clear and powerful message to young people that staff observations and (mis)interpretations were a substitute for their real thoughts, feelings and inner self. It signalled that staff accounts formed into notes, to which young people had no access, were more powerful than their own, real views, feelings and thoughts. In turn, this communicated to young people that they had little or no power, influence or role in expressing or documenting their feelings, or in influencing decisions about their care.

Disciplinary power is exercised invisibly but those subject to it are made visible via a ‘ceremony of objectification’ through observations and documentation (Foucault, 1997). These are one-sided forms of power-knowledge (ibid.) exercised through and over young people’s bodies by observations and unknown records. It is not only physical restrictions, but opaque practices, which convey power over young people through their bodies.

Therefore, when we constrain young people’s bodies and autonomy, it is not just their use of space that is restricted; when their real thoughts and feelings
are reduced into observations and notes, these are not just benign processes. On the contrary, they restrict and deny the self.
Chapter 6: Knowing and doing: distant decisions

6.1 Introduction

The second level of the four-planar social being is interpersonal relationships. This chapter explores the relationships between young people and staff in the unit, and how these relationships and interactions enabled or constrained decision-making.

This chapter has four main sections. The first section explores what young people valued in relationships with staff and the importance of time as care; the contradictions in caring relationships; and the impact of relationships on decision-making. The second section explores how young people were distant from decision-makers and decision-making, and how they felt absent from or disempowered within the decision-making processes. This is deepened in the third section, which explores knowing, and how young people’s views were subject to credibility deficits (epistemic/testimonial injustice) and how their credibility was further undermined by doubt and mistrust. The final section explores the impact of enacting distant decisions and how staff often lacked the means or rationale to be able to implement decisions.

6.2 Time as care

This first section explores what young people saw as kind, caring relationships with the staff in the inpatient units; the importance they placed
on relationships for decision-making; and the constraints that affected their relationships with staff.

6.2.1 ‘They was just like older brothers and sisters’

Even the first day, staff were really nice, funny … Yeah, they made it like more homely, because they would sit down and they’d play games. They was funny. They would like crack jokes with me and stuff, come sit with you while you’re watching TV. Dunno, they was just like older brothers and sisters (Laughs).

_Dan, young person_

Most young people described positive, caring relationships with staff as being one of the most critical factors in feeling cared for, heard and understood. Many described the importance of spending time with staff in order to feel cared for. When time equalled care, it consisted of being able to interact in normal, human ways (as they would expect to do with people they lived with intimately outside hospital) and have conversations about seemingly insignificant things, as well as about their treatment and care. They valued simple things, such as just being able to spend time talking or doing things together, talking about day-to-day topics rather than just conversations about their care, as well as humour and warmth. Real conversations and interactions, over observations and the unseen notes made about them, signified that staff saw them as a person rather than a patient. This made young people feel known, understood and more able to talk to staff about how they were feeling. This enabled the staff (usually support workers) to get to know young people, their thoughts and motivations rather than a
perception based on observations. Dan, like others, highly valued time to talk with staff who were empathetic:

Oh, umm, they just seem really understanding about like what’s going on. And like they’re not judgemental. Like you could talk to them about anything and they’ve probably heard it before.

Dan, young person

He had developed trusting relationships with some staff in this unit and spoke highly of them. He contrasted this with poor relationships with staff during a previous admission in a different unit, which had made him feel lonely and out of control.

Well for me, it made me feel umm, again, like lonely, like no one understood me, no one cared, umm, I felt like all the control was just gone, like it wasn’t in my hands. It was just like some person in an office making the decisions for me.

Dan, young person

When these interactions worked well, they were two-way and staff allowed young people to get to know them as people too. Staff also valued the time to develop relationships with young people, and many of the staff on the wards felt this was the reason they did their job. They recognised that young people were expected to share a lot of deeply personal information with them and, as Lisa described, it was also important for staff to be open and talk about aspects of their lives with young people too:

I’m not guarded either, like they can ask me a lot of questions. You know, I talk a lot about my home life, like they know I’ve got a fiancée, but they love it. They’re girls; they like to know I’m getting married one day and what wedding I’m gonna have. I think, if I’m asking them a lot, I’ve got to give a little bit as well, do you see what I mean? They don’t
know his name, they call him Mr. Fiancé, which is quite sweet but … if you give a little, you get a lot back I think, so it’s just about having that relationship.

_Lisa, support worker_

When staff shared something of themselves, this enabled young people to trust them. As Darina explained, she found it ‘easier to trust people’ when she got to know something about them. The willingness to share signified to the young people that staff saw them as real people who were valued.

For young people, there was a great need for normal mutual exchange of the kind they would expect between friends and family they trusted. This helped them to feel like a person rather than a patient, as someone who was trusted as well as trusting, and known rather than just observed. They felt this enabled staff to learn something of their internal private world, rather than seeing them as a collection of behaviours.

6.2.2 Hollow time: presence v. care

I think the staff that are just doing it ‘cause they have to, they’re the ones that just leave you to do what you want when you’re in a really bad place.

_Darina, young person_

While many young people spoke of positive relationships with staff, a lack of time with staff was keenly felt and experienced as a lack of care. Young people described being able to know which staff cared and which ones ‘were just doing a job’ through whether staff spent time with them, recognised when
they were struggling, or whether staff responded when they plucked up the courage to ask to talk. Darina went on to describe how she had felt distressed and had written it down and given it to a nurse. The nurse had not come back to talk to her, which had left her feeling unheard and ‘like she doesn’t really care’ about her feelings. It also made her feel unsafe, as the nurse had not responded to her communication of distress.

Many young people described how they had expected staff would spend more time with them, but the lack of time made them feel uncared for, unsupported and unheard. While young people associated care with time, time did not always equate with care. Many described examples of staff being physically present, but that this time and presence felt as if they were being monitored rather than cared for:

I had the impression that they just didn’t wanna be there, like they just sort of, they were just sitting there, I was just sat there crying and not doing what I was supposed to do and, and they didn’t say anything.

*Jaime, young person*

### 6.2.3 ‘I just feel like I'm lucky if I get out at the end of the day and everyone's alive’

Even though nursing and support workers recognised the importance of time to develop kind, therapeutic relationships with young people, many of them spoke of feeling frustrated and distressed about the lack of time they could spend with them. A new support worker described how she thought she would be able to spend quality time developing relationships with young people, empowering them and encouraging choice, but instead, she was so
busy that she often ended her shift just being thankful the young people were alive. This made her feel frightened and upset that they were not able to care in the way she wanted to.

The lack of time was particularly frustrating as staff recognised that the therapeutic relationship was critical for young people’s care. Many young people had had negative experiences and did not trust adults, meaning the time to develop trust was even more crucial.

6.2.4 ‘It’s more bank staff than regular staff, and the bank staff can be quite insensitive’

I didn’t wanna talk to anyone, cause I didn’t know anyone, I didn’t trust anyone. Because I was on a one-to-one and people switched every hour. A different stranger every single hour. I couldn’t get to know anyone.

*Jaime, young person*

The time to develop and maintain good relationships was also affected by the number of different staff young people saw each day. Young people talked about the difficulty of there being so many staff and staff regularly changing shifts. This prevented them from knowing whom to talk to or getting to know staff. One of the units had developed a bank of staff and so did not use external agency staff, which enabled them to get to know the unit, its ethos and practices, and to develop relationships with the young people (or at least to be familiar rather than a complete stranger). However, in the other unit, owing to such significant staff shortages, there was a high number of agency
staff. Young people frequently described not knowing who the agency staff were as they often didn't introduce themselves and would sometimes just come into a room and sit down. Young people were unsettled by this and felt that this showed a deep disrespect, ignored the norms of good relationships, and disregarded the unit as an intimate, private space.

Several young people commented that the agency staff did not understand them and were often more insensitive than regular staff. This affected their confidence to ask for things and meant they did not know whom they could talk to if they felt distressed or needed support, which made them feel unsettled and unsafe:

I find it really hard because I don’t know if they’re bank or not. Because there are just so many staff. I have kind of filtered down the regulars, but umm, it’s just … the bank staff sometimes don’t really know what they’re doing? So if you have a one-to-one with them, it’s not really the best.

Jimena, young person

This was also acknowledged by staff who recognised that the high number of staff and frequent shift changes made it hard for young people to feel able to speak up and talk to staff. Even when they did speak up, this could sometimes get lost, because many people and changing shifts meant things could be missed and not passed on or communicated to other staff:

Staff are always moving and changing around, so whether their voice gets heard and whether it gets passed on and that kind of thing. Communication doesn’t always work and things aren’t always handed over and some things don’t get raised.

Jane, senior nurse
6.2.5 Contradictions of caring relationships

There were frequently contradictions between the intimacy of relationships, which young people needed to trust and feel heard in, and detached institutionalised processes that were often profoundly unsettling for young people. Nurses and support workers were at once there to care for young people and make them feel heard and safe yet, at the same time, they had to undertake practices that could contradict that aim.

As described in the previous chapter, staff had to make regular observations of young people, which were then recorded in notes about, rather than with, young people. Therefore the role of observer conflicted with the ability of staff to spend the time with young people that they needed to feel cared for and heard:

It just has to be down to power. If people would just put their egos down a bit, we might get a better collaborative relationship going. I just think sometimes decisions get made that the person thinks is in the best interest of the child but actually, it’s not in the best interest of the child, and it’s more for them.

*Gail, art therapist*

Nursing and care staff were also in a role of authority. They had to run the ward to various rules and routines (discussed further in the next chapter), which they then needed to ensure young people followed, positioning these staff as in control. Most young people described not having or not being aware that they had a choice and felt they had to follow the instructions of staff.
Alongside observations, this made young people feel as if they had no choice, but were constrained and restricted. Their time, use of space, daily routines and meal times were subject to the rules and routines of the unit. As Asif described, the only choices they had were pre-approved by staff and what staff had ‘deemed fit’. They had little privacy, and their actions were observed, monitored and recorded.

Some staff found this difficult because they understood the importance of choice and control for young people. However other staff felt differently because they regarded their role as being in control of young people. These staff were more directive, as they did not want to appear to be weak. They viewed choice and negotiation as letting young people ‘win’ and worried about the loss of control:

Abbie: I think there’s certain individuals – I can think of two in particular in this team – who would under no circumstances let a young person win.
Interviewer: Right. So what is it for them, then?
Abbie: Authority.
Abbie, senior nurse

On occasions staff also had to intervene physically. While restraint seemed infrequent, it was particularly distressing for young people who felt they needed to comply with staff or they would be forced to comply. The spectre and influence of restraint affected even those who had not experienced it. It positioned young people as needing to follow the authority of staff. Whilst many staff wanted to develop caring relationships, they were also distressed
by the use of restraint. Care was undermined and contradicted by the use of restraint, and it must be considered whether relationships can be caring when they involve physical intervention.

6.2.6 Summary

Young people felt that time with staff was crucial in order to feel cared for, to develop positive, trusting relationships and to feel known and understood by staff. However, time did not always equal care. Relationships were undermined by staff being present but not meaningfully interacting with young people.

Relationships could be undermined by the role of staff in observing and monitoring young people, needing to implement rules and routines, and by not having the time to be able to spend with them. These powerful, but often hidden messages positioned young people as subject to the authority of staff, implying they should be deferential. Therefore, while some staff were actively trying to empower young people, their efforts could be subverted by the many other powerful messages young people were receiving about their expected passivity, compliance and deference: the carers and the cared for; the observers and observed; the knowers and the known.

6.3 Distant decisions

While relationships with staff were important to young people to feel heard, known, and able to be involved in decision-making, this section explores how
distant young people felt from decision-makers and decision-making. This includes the impact of hierarchies and the separation of doing and deciding; the limited time young people spent with decision-makers; how limited young people’s involvement was in decision-making processes such as ward rounds; and how young people felt they had little influence in decision-making.

6.3.1 The separation of doing and deciding
As described in the previous chapter, the physical space of the units separated care from therapy and medicine. Young people, nursing and care staff described how doctors and therapists spent little time on the wards. Further to the physical separation, this also represented the separation of doing and deciding.

We’re there to implement things, not create rules, and I think that’s where doctors see us. Just implementing them, not involved in the decisions.

*Jess, support worker*

Staff described the decision-making hierarchy as starting at the top with the psychiatrist being ultimately responsible for decision-making overall, and the psychiatry team and then the therapy team as responsible for decisions about young people’s care.

Many of the nurses and support workers described being at the bottom of the decision-making hierarchy and many felt very frustrated by this. They felt positioned as being doers, not decision-makers. Despite their experience and
relationships with young people, they felt powerless in influencing decisions. They felt their role was to implement decisions, rather than be involved in making them. They described these roles as ‘deciders’ (doctors and therapists) or ‘doers’ (nurses and support workers).

6.3.2 Distant decision-makers

As mentioned earlier, young people felt able to trust and be heard by staff who spent time getting to know them, usually support workers and nurses, as they spent the most time together. Young people described frequently using support workers as a sounding board, and some support workers also saw it as their role to give young people the time to talk, deliberate and to encourage them to speak up for themselves. However, like many of the young people, some nurses and most support workers saw themselves as having little influence on decision-making and were rarely involved in decision-making processes. As Jess described, this meant they developed close, personal knowledge of young people, but were not involved in decision-making processes:

We’re with them all the time, so we know their likes, we know their dislikes, we know them as people in the sense of what could be. You know, they tell us a lot of things, that context gets lost with the doctors. Most decisions get made in admin, ward rounds, CPAs and as much as all the doctors say they want us in there, they never do.

*Jess, support worker*

Young people, nurses and support workers felt that the doctors and therapists rarely spent any time on the ward or with the young people. This
was also frustrating for the therapists and doctors, who described being so busy they could not spend time with young people. The absence of time affected the process of making decisions as the staff who had the most influence over decision-making spent the least time with the young people. Although time and trust were essential for young people to feel able to influence choices and decisions about their care, they did not have the time to develop trusting relationships with the staff who were most influential:

We don’t really see the senior staff members. One of the main reasons why we actually like the junior staff members better than the senior staff members because they spend more time with us. Then you can relate and build up a relationship with the young people and it’s really, it’s really good.

Asif, young person

They felt doctors and therapists were distant from the reality of time on the ward, the interactions between young people and staff, and did not spend much time getting to know the young people, how they were feeling or being:

I’ve been here six months and I’ve never seen a doctor hang out with a young person. I don’t even know his name, they don’t even know who he is, they’re like, ‘Who’s that guy?’ Why can’t a doctor come for half an hour and just sit with them, or a therapist or a clinical psychologist?

Jess, support worker

Decision-making was predominantly seen as limited to ward rounds, which happened once a week. There was little or no opportunity for young people to talk with their doctors outside of the ward round:

I suppose … like I, I sometimes go in there and I’m getting asked these questions and I would just agree, well, like under pressure. But
then when I leave, I’m like, ‘Oh, I want … ah, I’ve got something now.’ I’ve thought about it and … It’s more just like a pressure kind of thing. Then ‘I want to change my answer,’ kind of thing.

Robert, young person

In both units, decision-makers and decisions felt far away and distant from young people. Young people had little time to discuss, understand, deliberate and decide with decision-makers and this made young people regard these staff as deciding about them rather than with them.

The staff (nurses and support workers) with whom the young people spent the most time, and who had the most proximate and personal knowledge of them, had the least power or influence in decision-making. The staff (doctors) that spent the least time with young people or who rarely spent time on the ward and therefore had more distant, textual knowledge of young people, had the most influence and power in decisions about them.

6.3.3 Ward rounds: decision-making as an event not a process

Many different staff involved in young people’s care attended the ward rounds, which were led by the consultant psychiatrist and included nurses, therapists and junior psychiatrists. Ward rounds were facilitated differently in each inpatient unit. In one unit, young people attended their ward round for part of the meeting, after the staff had first spent time discussing them. In the other unit, young people would meet with their psychiatrist before the ward round, so that they could talk to the consultant on their own, but did not
attend the full ward round meeting. They would then receive feedback on the
decisions staff had made.

While young people valued the time with their consultant and felt it was
easier to talk with them alone, they were uncertain about what was discussed
in ward rounds. They got feedback but this often lacked an explanation of
how or why a particular decision had been made, and they missed the
valuable discussion, negotiation, and understanding (this is explored in more
detail later in this section). In both units, the ward rounds were held outside
the ward, meaning the young people had to leave the surroundings that were
most familiar to them.

Nurses, support workers and young people frequently described ward rounds
as the only real opportunity for decision-making. Many nurses and support
workers did not see themselves as decision-makers and so did not recognise
or give much credence to the many choices and decisions they were making
with young people day-to-day. Thus, young people, nurses and support
workers felt as if there were few opportunities to be involved in decision-
making:

Ward round. That’s the only really time. Like if you bring it up with your
doctor and just say – like if you caught her walking up and down here
and you just said, ‘Oh by the way, can we up my meds?’ or ‘Can we
like take me off my meds?’ She’ll … they’ll just say, ‘We’ll discuss it in
ward rounds.’

*Jelena, young person*
Young people (and some staff) found this very frustrating. A week felt like a very long time to wait to make a decision about their care, especially when it felt urgent and they were living with the frustrations and consequences in the meantime. This meant young people’s requests built up and they felt very pressured during the short time of their ward round to ‘get it all out’. Others said by the time ward round came, they just didn’t bother as the repeated staff responses of ‘we’ll discuss it in ward round’ made them feel dismissed:

Because once a week ward round is like once a week for like, what, like 20 minutes, 15 minutes, it’s like, not a lot of time, it’s quite a lot of pressure to like think of what I’ve got to say, everything that I need to say, otherwise I’ve got to wait a whole week. So you say something like ‘can I do this?’, and the nurse will be like well, ‘we’re gonna have to wait to speak to your consultant about that’, so you have to wait a whole week to see them.

_Jaime, young person_

The lack of time and relationships with the key decision-makers made young people feel unable to speak up in ward rounds. They wanted more time with doctors to develop relationships and trust as well as more time to think, talk and deliberate with doctors, to enable them to be more involved in the process of decision-making.

6.3.3.4 Power of multiple people: ‘It's a bit nerve-wracking’

They were speaking all the time and it felt like you could kind of hear them making decisions about your life.

_Slobhan, young person_
When young people did attend their ward round meetings they described how difficult it was to feel able to speak up. They said there were many staff in the meetings, and described how they felt outnumbered, intimidated, and unable to speak up. This made them feel as if they had to agree with the staff. As Melissa described, ‘I’m quite bad at talking about how I feel, so in front of loads of people it’s even worse’. Jaime found ward rounds intimidating and uncomfortable, which meant she would ‘suddenly forget what to say because you’re just in a room with loads of people.’ Miranda echoed this:

Yeah, but the thing is, like, because there’s a lot of people in there, it’s quite hard to, like, talk to people when it’s loads of people. You kind of just have to agree with them because you don’t want to… I don’t know, it’s… you don’t really want to talk in front of everyone.

*Miranda, young person*

Where young people did describe feeling heard, they related this to the presence of a staff member they knew well on the ward round or owing to the presence of an advocate. This made them feel as if someone was on their side. However, the staff in the ward rounds were also usually the ones with whom young people spent the least time. The support workers, the ones who spent the most time with young people and to whom young people said they felt more comfortable talking, were often absent from decision-making processes. This meant that the ‘people on the floor who see them the most don’t always get the time to go into the meetings’ (Jodie, support worker).
While some staff recognised the importance of involving support workers in decision-making processes, a lack of time or staff often prevented the support workers from leaving the ward to attend the ward round. As Rivka, a student nurse, explained, the hierarchies in the health system made staff (especially those who were more junior) feel disempowered and unable to contribute ideas. Decision-making often lacked both the voice of young people as well as the voice of staff who they trusted and who could advocate for them:

I think that’s a shame because often the people that spend most time with the young people [nurses and support workers] they spend huge amounts of time [with] young people and have hugely great ideas on what that young person wants and what might support them and, I don’t necessarily think that is heard.

*Rivka, student nurse*

Lauren, a psychiatrist, explained how she was trying to create a more collaborative decision-making culture, to ensure all staff were involved and felt heard, but she was frustrated that staff shortages meant support workers were frequently unable to attend meetings. She was visibly frustrated about this, and expressed that this negatively impacted on young people’s care and the culture of the ward:

I think there used to be a very hierarchical ethos here, and I actually think the support workers are with the patients the most and we should hear what they’ve got to say. I want everyone to feel safe, so they can talk about, ‘This is my opinion, but it might not be the same as yours, but let’s discuss it.’ And it doesn’t, you’re not going to be criticised for having another opinion. Because we need to know what everyone’s opinions are if the patients going to get the best outcome.

*Lauren, psychiatrist*
While Lauren, and other staff, were trying to change practice and culture, this was slow and difficult (this will be explored further in the following chapter).

6.3.3.2 ‘They’ve got notes’

Interviewer: Okay. And what do you think would help you feel more listened to in those meetings?
Ikeoluwa: Umm … If, if they … If they, umm, told, told about the notes, because all the time, they make notes and then you don’t get told what the notes are.
_ikeoluwa, young person_

As discussed in section one, young people felt their visible behaviours were observed, and not their real underlying feelings. These were then recorded in notes, which were partial and did not reflect young people’s real experiences, thoughts or feelings. Most decisions were made within ward rounds, which young people either only attended part of or felt they had little influence on. Young people described how they felt powerless against the notes made about them. They felt it was the notes rather than their voice that influenced the decisions, which had real effects on their treatment and support. Decisions were distant from young people’s real thoughts, feelings and views, and were based on the views and knowledge of professionals about them.

While young people recognised the importance of the views, knowledge and expertise of professionals within decision-making, they needed these to be
considered alongside their own views and knowledge. As Jimena described, decisions did not take account of her views: ‘it’s just kind of like their 2D view...so it’s like kind of like flat ... instead of a fully fleshed view’

Being in a room with so many professionals, who had access to notes about them and to which they did not have access, made some young people feel as if they had to agree to decisions. They described feeling unable to challenge a decision or not having any time to process or deliberate, meaning that they passively agreed to ‘go with the flow’. After the ward round, once they had had time to think and digest what had been discussed, they then became unhappy with what had been agreed:

Um, it doesn’t really give you time to kind of ... to question or look down another route. You just get told this information and you’re just like, ‘Okay, I have to do it because they’re telling me to,’ in a sense. I sometimes go in there [ward round] and I’m getting asked these questions and I would just agree under pressure. But then when I leave, I’m like, ‘Oh, I want ... ah, I’ve got something now.’ I’ve thought about it and ... It’s more just like a pressure kind of thing. Then ‘I want to change my answer,’ kind of thing.’

*Robert, young person*

Staff also questioned whether or not young people could say, ‘I disagree’, if they really disagreed as ward rounds could ‘be overwhelming’ (Emma, psychologist).

Some young people only attend part of their ward round, or they do not attend at all. As Louise explained, ‘I don't know what they talk about when I'm not in there...’ This, combined with not having access to notes, made her and
other young people feel uncertain and conscious about what was discussed when they were not there. It made them feel as if the decision had already been made without them and that their involvement was tokenistic:

I feel like they have to ask us what we feel but, even though they’ve always liked when you go into ward round, they always discuss you before. So they normally write out a plan of what they’re gonna do.

*Jelena, young person*

Young people questioned how meaningful their influence was as, despite being involved in ward rounds, they experienced changes to their care, and therefore decisions made without them:

Just like they came back from ward round with the medication. You might not even talk about anything that you would think suggests, ‘oh you mean more medication’, and then they could still come back with it.

*Slobhan, young person*

### 6.3.3.3 The absence of space, privacy and time to deliberate

Within the units, there were multiple smaller teams of staff with various roles, including nursing and care teams, therapy teams, psychiatry teams and management. The different professional teams brought different perspectives and contributions to young people’s care and, while multiple perspectives could be beneficial, it could also make decision-making more complex and complicated.

You’ve got so many layers of shared decisions in an inpatient setting; you have the, ‘Do we share the decision as a team?’ And then need to sort of navigate that process with the young person’s family? Or am I
as [a] professional not sharing the, you know the decision that the rest of the team is? So that can be quite tricky.

*Emma, psychologist*

Decision-making was therefore complicated by a conflict between whether decisions were first reached by the team and then discussed with a young person, or whether the decision was first reached with a young person and then shared with the team. Sharing decisions with the team first could risk alienating young people and restricting their influence, but reaching decisions with young people first and then discussing this with the team meant decisions could be reversed, as other team members might not agree. As Emma continues, collaborative agreements with young people can be questioned by other professionals who may hold a different view, but are vital to the very effectiveness of therapy:

I’ve certainly had experiences where I have, umm … made a shared decision with a young person about the work that we do, and other members of the MDT [multi-disciplinary team] had different ideas about what we ought to do. But then you’re sort of back to the idea of, ‘Well if the young person’s not going to engage in that therapeutic work, I can't force them to.’ And I think it’s just having those conversations maybe with professionals that umm … Don’t really do therapy, and maybe don’t realise that it’s a different treatment to medication … Yeah, I think so. And I think, I mean I guess in my mind there’s a bit of a split between umm medical kind of interventions, medical kind of treatments which is I do to you, and, and … Umm, therapeutic interventions which are much more collaborative …

*Emma, psychologist*

As Lauren, a psychiatrist, explained, there were often dual decision-making processes happening with the team and with young people, which were
complicated to negotiate. She had to discuss decisions with the team as well as with young people, meaning there were ‘two processes going on’. This was complex as she had to hold everything and everyone in mind, ‘taking account of everybody’s position’ which could be challenging as there were often different opinions about each decision, and it was necessary to balance ‘what the young person wants and what we feel is appropriate’.

Many staff described how difficult it was for the different teams to agree on what the best or appropriate options for young people might be. Different perspectives on what might be the right thing for a young person had to be taken into account, and this could restrict the influence a young person had over decisions about his/her care:

The problem is it’s such a complicated unit because you have the nursing team, you know, the medical team, the therapy team and everyone might have a different opinion and depending on how people feel about a young person, you know … and people might have different feelings about the same family and what can sometimes happen is the staff team replicate the dynamics that go on in the family so, you know, take the position of the child or take the position of the parent or get angry and say, ‘Oh, we’ve got to leave,’ and those processes are really hard to pick up sometimes.

*Seb, family therapist*

The important processes of thinking, deliberating and processing often took place between staff rather than with young people, meaning they missed out on this crucial part of decision-making. To feel able to be involved in decisions about their care, young people wanted time to explore, discuss, think and understand, together with the staff.
Young people highlighted that the process of decision-making was just as, if not more, important than the outcome. The lack of deliberation with young people meant their involvement focused more on the outcome, and not the process. This overlooked the emotional process of decision-making and the time young people needed to be able to take in information, options and feelings. Young people wanted to talk with professionals to make sense of things and make meaning together:

The [doctor] was really great at listening to everything I'd say. If I was talking in bullet points, she would make them make sense with me, making it more full.

*Jimena, young person*

This open discussion was also significant for Rebecca, because a lack of discussion fuelled her intermittent beliefs that staff were trying to harm her:

‘cause I get like delusions, so, [the delusions] made me think that they were putting something in that could harm me. That'll go on for like five days and then I won’t take my medication, then suddenly I’ll start taking my meds again. But then the whole thing restarts, because I’ve stopped taking them, so it takes a while to work again, it’s really, it’s really hard.

*Rebecca, young person*

### 6.3.3.4 Time and thinking together as trust

As Abbie (senior nurse) described, ‘everyone needs time to think’. Open deliberation and time to process was even more crucial, given the strange environment within which young people were making decisions. As she recognised, staff needed to understand that young people were removed
from everything they knew – their home and friends – and were living with strangers in an unfamiliar environment which must take ‘quite a lot of strength’ and emotional capacity to tolerate.

The time and space to have discussions enabled young people to develop trust in professionals. Discussion and deliberation were usually the most important aspects of decision-making for young people, because this made them feel heard, seen and known. In addition to influencing the outcome of a decision, talking openly and frankly about the different options or restrictions enabled young people to understand and learn how to make decisions. It also enabled them to understand why certain restrictions were in place, and how to influence, manage or negotiate them, rather than just feeling as if they had been imposed for no reason.

The discussion and deliberation also enabled young people to learn how to manage painful emotions – they could reflect with staff, weigh up the impact and consequences of their actions, reflect and think through how else they could manage stressful situations, and understand that they had choice and agency over their actions. As Jess explained, the process of decision-making was vital to help young people learn, weigh up consequences and feel in control:

A lot of them are quite impulsive, but when you take them through the steps and you go, this is why we’re doing it, this is the consequences if you don’t do it, what do you think? They’re like okay, yeah I didn’t think about that. Umm, lay all the choices out, umm, give them examples of all of them, consequences of all of the choices that they may make, umm, just guide them I think, guide them but don’t tell
them, and that’s what teenagers hate, being told what to do. So the laying out of the options, and thinking what are the consequences, what, what, let’s think about these. Going, even just sitting with them and having them drawn out and saying you know, okay, what will happen if we do let you go on leave? Do you think you can keep yourself safe? Or, what will happen if we keep you on the unit? Will you get frustrated? Will you attempt things?

Jess, support worker

As Jimena explained:

If you knew everything and like had all of the decisions, and the discussions, just everything was out there on the table … And you work through it together, you’d be more respecting and allowing and ‘Okay, she knows what she’s talking about. I’m going to trust her that she will help me.’

Jimena, young person

Young people wanted to have the opportunity to raise issues and talk to the people they saw as decision-makers on a more regular basis than once a week in a ward round. Young people felt staff needed to be more proactive to ensure they had a regular time to talk about their care, treatment and support:

It’s like when young people need help they don’t normally go up and say I need help. You normally see it in like little signs that they do like may, like they may, they may, they may want a one-to-one and speak to someone but it’s like a lot. One of the few things that, you can do is, you can actually speak to them. You can speak to them yourself because you know when, you know when you say young people should have more of a say in what they’re doing, that’s a continuous process, you ask them, no one is the same, everyone’s different so you have to keep on continuously asking them, asking them.
Asif, young person

Young people felt that specific sessions, outside of ward rounds – used to discuss and review their care plans and any worries or concerns they had, and to enable them to prepare for the ward round – would enable them to be more involved in decision-making:

I think maybe have specific sessions, where you have a say and like that’s the whole point of the session. Your personal care plan. So maybe we should have a weekly session with your primary nurse when she goes, ‘This session’s specifically for any worries you have’ and then, because you know that’s the point of the session you might feel more able to have more say in general. Or may at least make you feel like you know exactly what’s going on which I guess is sort of something to do with control because you’re a bit lost.

Siobhan, young person

Above all, young people wanted to be known, to know others and to be able to trust.

6.3.3.5 Summary

The process of ward rounds communicated to young people that they were in a position of powerlessness. Ward rounds were frequently seen as the only forum for decision-making and the rounds therefore placed a significant level of importance on one meeting over the many and varied choices and decisions in their day-to-day lives or interactions with staff on the wards.

The staff (doctors and therapists) who seemed to have the most influence on decision-making were also the staff who spent the least time with young
people. This meant that young people could not develop trusting
relationships with them and that the decision-makers’ knowledge of young
people was partial and distant.

The language, ethos and routines of ward rounds are dated and refer to
paternalistic times when patients were in beds and doctors would visit each
patient in turn. This language does not, therefore, communicate a sense of
empowerment or involvement of young people. Ward rounds were held
outside of the ward, meaning young people had to leave the space they
knew the best and go to a meeting with many staff, most of whom they knew
the least. They had little or no time to talk to the decision-makers outside of
ward rounds and therefore missed out on the vital deliberation of the
decision-making process. Decision-making was more of an event than a
process.

Young people’s lack of involvement in contributing to their notes, not knowing
what had been written about them, and staff discussions about young people
without them there, positioned observational and distant impersonal
knowledge as superior to their personal knowledge and testimony. This was
frustrating not only for young people but also for some of the staff in ward
rounds, who talked of trying their best to involve and empower young people
in decisions. Thus, the good intentions of staff were outweighed by the power
vested in the invisible but powerful messages young people received.
However caring and thoughtful the discussions and deliberations of staff were, the exclusion of young people from these communicated to them that others' knowledge of them was more important than their own. This was exacerbated by young people experiencing changes to their care happening without their knowledge or involvement, which made young people feel done to, rather than with. It communicated that they were expected to follow staff instructions or decisions rather than being involved in sharing decisions. If deliberation and decision-making do not involve young people, a vital form of knowledge is absent and consequently makes the decision-making partial.

6.3.4 What influence?

6.3.4.1 Involved or informed?

I think it’s just like the doctors’ decision.

*Miranda, young person*

We’ll be saying, ‘You need to be weighed,’ or, ‘You need to eat,’ or you know, ‘We’ll monitor you for your safety.’ We will say those things, but it will be in such a way that the young person agrees and, umm, maybe has some additions or modifications. But the core of it [care plan] is probably what we think should happen.

*Sara, psychiatrist*

As Saanvi, a student nurse, describes, when young people were involved in discussions, she and others questioned how much real influence young people had and whether they were *involved or informed*:

Umm, see, about medication, I’m not sure if that is always a shared decision. [The discussion with the young person is] informative and
that will inform the young person about all the side effects and they will, kind of take on board [the young person's views] and offer to change the medication. So, I guess in that way it's kind of a shared decision, but it's very vague.

_Saanvi, student nurse_

During interviews staff were asked to describe examples of how they involved young people in decisions or to think of a time when they thought they had done so particularly well. When describing their approach, staff used language such as ‘I weighed up…’, ‘I thought about…’ Many concluded that their examples were less collaborative than they had thought. Staff described _thinking_ through the key steps of making a decision internally or with colleagues – thinking about options, weighing up risks and benefits, and thinking about young people’s views. While they were thoughtful with regard to young people, they were often not explicitly involving them in the process.

As Sara, a psychiatrist, described, the level of influence she allowed young people to have depended on how invested she was in a particular option. If she believed firmly in one, she would inform young people why that was the best one. If she did not have a preference, _then_ she would give that choice to them:

_I tend to set the scene first of all very clearly that we’re the, we’re the staff, we’re the doctors. We’ve got some understanding of the condition that they have. Umm, I tend to give quite clear advice with the reasons behind and the pros and cons. If there are things which it really doesn’t matter which way it goes, then I’m, you know, say, you know … Obviously include people very much in those decisions and say, it really doesn’t matter and you can think it through and either one is fine. But if there’s one where it really do-… Where I really do think_
one option is better than the other, then I'll be very clear about that. Yes, yeah. I’d explain to them why I’ve come to that decision, and that is about weighing up pros and cons of the different things. So I’d, I’d do that, but I’d explain how I’d weighed it up.

*Sara, psychiatrist*

The above highlights how the deliberations of staff and their professional knowledge was given primacy over young people’s knowledge. This then restricted the influence of young people, especially in more serious decisions that might matter more to them. When discussing options, Sara, like some other staff, described times when young people were able to choose between two pre-agreed options but were not involved in deciding what those options could be. The option to refuse was rarely mentioned. Real choice surely only exists if there is the freedom to say no.

Matt described how staff ‘might ask you and hear you, but they won’t listen’ as nothing changed as a result. He and others associated being listened to with some form of change as a result.

*Interviewer:* And how does that leave you feeling, after the meeting, if you’ve wanted to say something but didn’t feel able to?

*Miranda:* Um, I don’t know, it’s like nothing’s really happened, in a way.

*Miranda, young person*

When staff talked about discussing decisions with young people, they often described listening to young people’s views, which they then used to inform
their decision, rather than young people having influence or involvement in negotiating or deliberating what the best option might be.

As Siobhan and others explained, this felt as if they were being informed rather than involved:

It was more like, “This is a worry so this is what we’re going to do.”
Rather than “This is a worry, what do you think?”
*Siobhan, young person*

Professionals’ views of what was in the best interests of young people often took precedence over young people’s involvement and influence over decisions about their care:

The overall decision regarding their treatment is down to the consultant. The young person might say they don’t want to take a particular medication and they might state the reason, and then the doctors, we do with ourselves, we continue to do research to see which is the best medication for them, but we’ll still bear in mind that, you know, we had our own idea of which medication would have been the best one.
*Martha, senior nurse*

Decision-making is not just technical, it is also an emotional process. As staff had weighed up the options, pros and cons, the decision, therefore, seemed right and evident to them because they had gone through the process of deliberation. However, explaining a process of deliberation is not the same as deliberating *with* young people. It informs them of the process rather than enabling them to experience it, or reflecting with young people on their carings and ultimate concerns. Young people’s compliance with decisions made in their best interests and informing and explaining to them why this
was the case were, therefore, dominant themes in professionals’ descriptions of decision-making. It was as if being thoughtful about young people was understood as involving them.

Some discussions of the risks and benefits of decisions about medications, for example, were weighted to ensure young people complied with taking the medication. Saanvi, a student nurse, described seeing discussions with young people where she felt risks and benefits of options were not discussed as much as they should have been as ‘the priority is that they take the medication.’ She felt that the ways that doctors phrased things or how much information about side effects they shared was weighted to ensure young people agreed and were compliant with the doctor's decision.

However, she felt that young people were entitled to know all the side effects, especially as some drugs, such as Risperidone, could increase ‘prolactin in males and [cause] them to have breast enlarged tissue’. She described how she had challenged a doctor who did not want to share information with a young man who had ‘a risk of non-compliance’:

So I take it on myself to, to talk about [risks and benefits]. One of the medical team were quite concerned that their issue was kind of, ‘No, we don’t want him to be scared, he’s got to be compliant.’ But I, I really strongly felt it should be shared and for that person to make their decision. And so, I was going to sit down with [the young person] and do the pros and cons of the change and things like that.

In the end the pharmacist came and had a chat. And so when I went round, he was like, ‘Oh no, it’s fine I’ll change.’ He was like, ‘Yeah I know about prolactin and stuff.’ I was like, ‘Do you know what prolactin
is?’ He was like, ‘Hormone.’ I said, ‘Yeah, so you know that your oestrogen and your testosterone could increase, and you might have a side effect of breast tissue, but it’s unlikely.’ And that person was shocked by that. And then I said, ‘Also, if the breast tissue does become, just tell us straight away and we can work on it.’ And then that person felt quite reassured by it. I still think it’s important for them to be aware of the pros and cons of anything, really.

Saanvi, student nurse

When young people were given information, this was often to make them understand why staff had made a certain decision, rather than to give them choice or influence. For example, some young people described talking to a pharmacist about medications, but this was often after they had been prescribed the medication to enable them to understand why they were on it.

I really think it’s very important for them to talk to us because it just, it just helps a lot more when you know what’s going to happen. It allows you to prepare for it and act in a certain way, like… whereas, if you’re not told the information, you don’t know what’s going to happen and you start, I don’t know, you start actually then making up certain thoughts of what’s going to happen and you start thinking a lot more about it. A lot more stress, basically. Whereas if you’re told, you know what’s going to happen, and you’re much more accepting of it.

Hamza, young person

Some staff avoided sharing the risks and side effects of medications because they felt it would make young people refuse. The provision or withholding of information was at times used as a tool to conceal, convince and coerce, rather than to share knowledge, inform and empower young people in their thinking and deliberating. There were therefore contradictions and conflict in the teams between those who believed information was there to convince or
persuade young people to accept staff decisions and those who saw information as a right to empower and inform them (including the right to refuse).

Because mental health, it’s not the same as physical health, basically, and I think, because mental health… there’s a lot of individualism and a lot of your say. A lot of effect that it has… a lot of it depends on you. *Hamza, young person*

The language of compliance and non-compliance is a powerful indicator of approaches to decision-making. Young people experienced being able to agree but not disagree with professionals, as if disagreeing was being non-compliant. Non-compliance suggests young people are doing something wrong rather than expressing disagreement or having the right to choose otherwise. As Saanvi continues, information given to young people can be affected when staff regard sharing information as a loss of professional control, as this gives young people the power to choose otherwise or disagree:

[I] don’t even like that word [compliance] really, but I’m just using it because people use it. It’s basically the fact that somebody doesn’t always want to do something. Complying is like ‘I will do as you say …’ Or, it’s either ‘he’s compliant, he’s non-compliant’, it’s like you’re just putting them into categories now. The other day I was going to write ‘complied with meds’, and I changed it to ‘took his medication.’ Because I just thought I just don’t like the word. *Saanvi, student nurse*

As described in the previous chapter, young people felt disempowered and restricted by the routines of the unit because they had little choice or control
over their use of space or even over small day-to-day decisions. This made some feel as if they were just expected to go along with any instructions or decisions of staff, even those about their treatment or medication. The restrictions on their physical space (Chapter 1) as well as the many rules and routines (explored further in Chapter 3) made them feel as if they should be deferential towards staff and just do as they were told.

6.3.4.2 What decisions?
Owing to decision-making being predominantly regarded as only happening during ward rounds, young people felt frustrated that there was only one, short opportunity in a whole week of being in the unit, and which only related to decisions about some, but not all, aspects of their care and support. Young people often did not know if or what influence they had on decisions because it was unclear to them which decisions they could be involved in. There were few visible signs of decision-making for young people. For example, all notes and records were held by staff or within the system.

Some young people talked about having some involvement in developing their care plans, but did not have their own copy. This prevented them from accessing information, which communicated that decisions were made about them, not with them, and reinforced the power of staff over young people. Most young people wanted access to information and plans (rather than all information being held about them), to create shared meaning and expectations.
It was clear that young people saw many more opportunities for choice and control than they were involved in. Support workers and nurses also talked of many examples where they were making decisions, or negotiating the implementation of decisions, with young people but they often did not see them as such (perhaps as they saw their role as doers rather than deciders).

Firstly, young people wanted more freedom and influence over being in the unit and choices about the use of space, day-to-day routines such as mealtimes, bedtimes, access to make drinks and snacks, and activities. They wanted to be able to have some individual choice and control, as well as exploring and negotiating the challenges of living in a group. Whilst the units had community meetings (involving all young people and staff) once or twice per week, many young people were quiet and did not speak up. They wanted more informal, regular and day-to-day conversations and discussions instead, as one might expect in other intimate living situations.

They also wanted more clarity and involvement in the purpose of the admission and the help and support they received. Many were unclear about the aims or goals of their admission. As Seb, a family therapist, acknowledged, ‘sometimes there are clear goals about why they’re here and sometimes there are not and, dare I say, often not’. This was disorientating and young people described their care changing or fluctuating. A lack of clear aims and goals was confusing. Young people described how they were given unclear statements such as ‘when you’re safer’, without a concrete
understanding of what they needed to do to be safer or even understanding what being safer meant. Others described how their diagnosis would change without their knowledge or involvement. They wanted to be involved in discussions to develop shared meaning and understanding of what the difficulties they were experiencing were.

Additionally, they wanted a shared, clear sense of direction and discussions about what support they could have (including the opportunity to not accept certain options) and to be involved in reviewing their experience of these. They also talked of the importance of agreeing how decisions were enacted, and their experience of care and support. The discussions often took place between young people and support workers who renegotiated the decision or diverted them to something that they felt was more manageable, realistic or reflective of young people’s views or the reality of the ward.

They also talked of the importance of time to explore and discuss their feelings, ‘symptoms’ and actions. They wanted to develop shared meaning about how and why they were feeling and how this affected them, rather than by only having observations. This included reflections about young people’s experience, responses, actions or choices. For example, young people wanted time with staff they trusted to explore and understand moments of distress, anger or frustration; to reflect on the reasons, causes and experience and how this had made them act, and the consequences; what they or staff could do differently; and to know that staff had heard and understood their feelings rather than their actions.
6.3.5 Summary

Young people were often unclear what, if any, power and influence they had. They felt outweighed by notes and documents describing help about them, rather than being developed and shared with them. Whilst decision-making was often regarded as being solely about medical or therapy ‘treatment’ options and occurring only on ward rounds, there were many other kinds of choices and decisions within young people’s care.

Young people were unclear about the level of influence (if any) they had. Furthermore, their experience of influence could be contradictory, with many things just happening to them without their involvement, positioning them as an object of care. As well as greater clarity about the types of decisions, it is also important to be clear about the level of influence of all parties (young people and the different staff groups) in the decisions.

As described earlier, at a minimum, young people wanted to know and understand the rationale and reasoning for how decisions had been reached, and to have the opportunity to express their opinions (to inform the decision or to express their disapproval). The distinction between decision-making as a process of deliberation and the decision itself needs to be clarified – even when young people are not the main decider, they can (and should) still be involved in the discussion and deliberation. Clarity is needed to clearly communicate:
• what decisions exist across the different domains
• what influence young people have in making each decision,
  who the main decider is and justification of why this is so.

Without clarity and transparency, young people’s ability to question or challenge decisions (or to even know what is or should be happening within their care) is absent.

6.4 Knowing: credibility, doubt and (mis)trust
Fricker (2007, p. 1) states that ‘conveying knowledge to others by telling them’ is a basic epistemic practice. SDM is based on bringing the knowledge and values of young people into decision-making. It therefore requires young people to share their views, knowledge, values, feelings, and opinions, and for these to influence the decision-making process. However, as described, many young people felt that they had little or no involvement in decision-making and their views (testimony) were often absent. When they were involved in decision-making, they often felt their views carried little weight or they just accepted the views and decisions of staff.

As discussed in Chapter 2, epistemic, and specifically testimonial, injustice, occurs when someone is wronged in their capacity as a knower, when the credibility of their testimony is given less weight (credibility deficit) because of identity prejudice on the part of the hearer (Fricker, 2007, p. 1). This section explores knowing and how the credibility of young people’s views and
knowledge were questioned due to their age and mental health. It also explores how the many constraints in the unit caused doubt or mistrust in young people’s views.

6.4.1 ‘They think that because you have a mental illness that you can’t make your decisions’

It’s not like we don’t know what we’re doing. We do, but we just can’t really cope, that’s more why we’re in here, rather than we don’t know what we’re doing.

Jimena, young person

Young people felt they were not believed owing to assumptions about the diagnostic label they had been given. Jaime and Emily both described how they often experienced their expressions, actions, or preferences being explained as a symptom of their eating disorder. In one example, Jaime asked to go outside into the courtyard because she was hot (the inpatient unit was very warm inside). She was told she was not allowed unless she put on a coat. The staff member felt that Jaime was asking to go outside in the cold as a way to lose weight. In another example, Emily, described how she had painful legs due to a physical health condition and was more comfortable when she sat with her legs raised. Yet staff told her she had to sit with her feet on the floor, as to do otherwise was because she was trying to affect her eating in some way. While Emily described understanding that there were ways in which her eating disorder could affect her thoughts and actions, she was also clear that this did not mean that this influenced everything they said or did:
I hate being told it's your illness talking, because I know it is. But sometimes I know it is definitely me talking

*Emily, young person*

Some staff provided clear descriptions of how their beliefs towards eating disorders affected how they perceived the credibility of young people. As Martha explained, she did not believe anything young people with eating disorders said because of:

the deviousness of the things that comes out with that illness, that particular illness, I struggle with that. So you are constantly watching them. I don’t trust them, at all. Because I don’t believe nothing they tell me.

*Martha, senior nurse*

This was similar for other diagnoses, such as borderline personality disorder (BPD), where some staff described doubting or disbelieving much of what young people said, as they thought this diagnosis equated to the person being manipulative or having ulterior motives. Certain diagnoses therefore equated young people’s views with untrustworthiness.

This caused them, and other young people with similar experiences, to feel angry, frustrated and, over time, despondent. They learnt that others would explain their thoughts and feelings as stemming from their diagnostic label, which made them feel that expressing their views was pointless.
6.4.2 ‘They’re just being a teenager’

Young people described how their views were also doubted or undermined if they did not agree with staff. Asif described how his refusal to take medication was seen as a refusal of help or as proof of his lack of capacity. Asif had strong views about medication. He expressed deep concerns about the impact on his body and wanted to know what impact medications would have. He was angry that he had been prescribed medication without discussion or explanation, firstly for depression (a diagnosis he did not agree with), which then changed to another medication when his diagnosis was altered (without discussion with him) to psychosis:

I didn’t wanna take it because I didn’t really believe in medication, ‘cause, because if I don’t have depression, I’m putting chemicals in my body which I don’t need and you can’t really see the short-term or long-term effects on what, what it will be.

Asif, young person

He was frustrated that he had not been given information about the side effects and the potentially harmful impact on his body. He said he was not refusing treatment, but he was resistant to taking medication, particularly without knowing what the side effects of this were:

Well I like, obviously the side effects is one of the things, another thing is, how it, how it changes your body for better or for worse, how it actually, how it actually transforms your chemicals in your brain sort of, or whatever problem you have. I would like, I would like to know more about it.

Asif, young person
However, he said his reasons for refusal were dismissed as being unfounded, as if he were being difficult and refusing treatment because he was too unwell to make a decision, rather than refusing a form of treatment. He was later sectioned and forced to take the medication. He was adamant he would stop taking it when he could.

This was among several examples in which young people’s values and preferences were given less weight than others’ views about what they needed, which were often justified as being evidence-based or in their best interests. Refusal was seen by some staff as being caused by young people’s lack of capacity, or having no basis, rather than being based on their legitimate values or preference. Young people’s views and values were therefore absent or undermined in comparison to a ‘medical’ viewpoint:

One of the common ones, they feel that there’s nothing wrong with them. So they don’t need the medication […] Another one is, some of them just don’t want to take the medication. They have no specific reason apart from they just don’t want to take it […] So, within the rights of the section, we are then able to restrain, and administer the medication via injection. And it’s from there that the mental state will improve, and their view on medication will change. Some will change, but some never change. And they will tell you that, ‘We’re not going to take it.’

Martha, senior nurse

6.4.3 ‘No one believes me’ – calmness as credibility

I’ve noticed that without my meds my moods have gone really like … High and low. So I get really angry and short tempered and then like, I cannot stop tears, which is really irritating … So like I’m trying to like give a speech of what I’m feeling and then I get really frustrated.
Jimena, young person

Jimena, like other young people, felt that her views were taken less seriously owing to the way in which she expressed them, as if distress or visible expressions of emotion made her views less real or reliable. They felt they were less likely to be believed as a result.

Because I feel sometimes the staff, like… I misbehave quite a lot, but then they don’t take me as seriously as they take some of the other people.

Louise, young person

Young people’s expressions of frustration or resistance were often explained away as expected teenage behaviour with the reasons for their actions overlooked or discounted. Matt described how he was using the phone in the unit when a member of staff asked him to end the call at 9pm as the phone was not allowed to be used after this time. Matt refused as he wanted to finish the call and the member of staff turned the phone off. Matt thought ‘that was a dickmove’ and he lashed out and retaliated. Matt felt ‘kick offs’ were often triggered by unfair moments or inconsistencies, yet he felt that even if he (or others) apologised, or had reacted in the way they had done as they were ‘not in control’ owing to their level of distress, their behaviour was seen as if they are doing it on purpose, or there was some ulterior motive. This meant he felt he ‘can never just be pissed off.’
Jodie, a support worker, described, young people’s resistance or refusal was often seen as just being ‘teenage defiance’ because they had been told ‘no’. This suggested that young people’s reasons for resistance were invalid or immature and they should just passively comply with adult authority. For example, they were often told ‘you have to understand …’. This led young people to feel dismissed, unheard or increasingly frustrated, which in turn affected how they acted and added further ‘proof’ of their ‘volatility’.

The differing feelings staff had towards young people affected how tolerant they were, which could then cause disagreements and split the team. Seb, a family therapist, described how one young woman got on well with some staff but was seen as more difficult by others. This affected how they viewed her, with some doubting her and thinking she was not trying hard enough, while others believed she was vulnerable and needed support. As Jenny, a senior nurse explained, how well staff got on with a young people also affected how tolerant staff were towards them.

Some staff saw the young people who were more outspoken as difficult rather than reasoned, which then affected how other staff heard them. Reputation had powerful effects on how young people were framed or perceived as credible or not. For example, some young people, particularly those who frequently questioned staff or expressed dissatisfaction, were sometimes seen as being volatile or difficult rather than expressing reasonable frustration. This positioned their emotions as lacking meaning.
Young people’s reputations were also affected by previous interactions with staff. As Abbie, senior nurse, described in the previous chapter, notes are not value-free factual accounts. If staff had been involved in a difficult interaction with young people, or were tired and stressed after a long or difficult shift, this could affect how they passed information to other staff about them. This could then affect how other staff perceived and reacted to these young people.

Whilst many staff experienced young people’s behaviour or expressions of distress as difficult, how they understood these expressions varied. Firstly, some understood distress or difficult behaviour as in some way intentional, for example, as attention-seeking or a way of manipulating others. Secondly, this could be seen as a sign or symptom of the mental illness. Therefore, whilst recognised as a need for reassurance, the distress was seen as equating with unreliability, or as symptom to be cured, rather than as a valid expression. Lastly, it was seen as a form of communication or understandable frustration, which should be explored and understood. However, while many staff tried to understand, they felt they lacked the time, reflection or knowledge to understand and interpret young people’s expressions.

Young people’s behaviour or distress therefore affected how far they were heard or believed. This left some feeling conflicted: they felt they needed to be calm or ‘act well’ to be heard, yet they were in the unit precisely because
they needed support to manage their difficult feelings, and/or their distress was a reaction to being in the unit.

6.4.4 Knowers and the known

If you say something and they don’t agree with you, that doesn’t mean they can’t help you in another way. But, but then they will say some, like ‘this isn’t a hotel, this is a hospital, just accept the treatment you’ve been given.’

*Asif, young person*

Some young people were aware that their views carried little weight in comparison to those of the staff. As Emily described, ‘If the voice is let in by the staff, you get it. If it’s let in by you, you don’t get it.’ They felt that the most effective way to get their voice heard was to talk to care and nursing staff they knew well about what they wanted. The care or nursing staff would then put this into young people’s notes, which would then be read by other staff and the doctors. They felt that this was more effective than them expressing their views directly.

Similarly, young people described how they felt they were more likely to be heard – for example, in ward rounds – if they had an advocate with them or a member of staff they knew well, who could support them to speak up for themselves. They felt heard, listened to and believed when an adult was with them or speaking for them, as if their own views were lacking in some way:

*Umm, my ward rounds are actually quite good, to be honest. Uh [I have an advocate and I think that helps, because I think if you don’t have an advocate they don’t listen as much.*
Some young people described how they felt disbelieved and felt that their views about how they were feeling were questioned or minimised. They described being told, ‘well you seem fine’ or ‘you look ok’. Dan described how, during a previous admission to a different unit, staff would disbelieve or belittle their expressions of distress and ‘would make snarky comments and stuff, or like, undermine how ill we were’. He spoke more positively of his relationships with staff in this unit, but his feelings of trust or being trusted were undermined and framed by his previous experiences.

Young people felt their expressions of their inner, unobservable feelings, or emotional states, and specifically their perceptions of their mental health, were not deemed to be as important as the observations of staff, or other ‘measurable’ markers, such as blood tests. For example, many young people described how the side effects of their medications made them very drowsy and caused them to sleep more. Yet when they struggled to get up in the morning, some staff interpreted this as expected teenage behaviour, despite their explanations to the contrary. Young people felt they were being forced to experience side effects and then additionally blamed for their effects.

To young people, their physical, as well as visceral and moral, feelings and emotions were significant. Yet they felt as if biochemical changes, or other assessments of the effects of medication, took precedence over their expression and experience of side effects or effectiveness:
I knew it wasn’t weed anyway that was making it [bad], I knew I’d been like this for years, I just used that to cope. But it was quite horrible having to wait that long for it all to get out of my system [to prove it], because it was seven weeks until they started properly listening to me. *Melissa, young person*

Therefore, to be heard or believed, young people’s views often needed to be ‘validated’ by other sources which were deemed to be more reliable, such as tests, observations, the testimony of staff, or getting staff to write their views in the notes.

Some of the staff viewed trust as being implicit in their knowledge as a professional, as if young people should accept their views, decisions and reasoning because of their positions and/or because of the professional patient relationship. Underlying this was the notion that their knowledge as a professional, including what was best for young people, was more credible than that of the young patients. Martha, senior nurse, explained:

> So, sometimes it's out of ignorance, why people don't agree. Because, if you're in a general hospital, most of the time when they come, the doctors come and said, ‘Oh, I'm going to give you some antibiotics …’ Nobody really make a big issue and say, 'No, we’re not having it.' Or, nobody does that. I've never seen anybody does that. *Martha, senior nurse*

This contradicts young people’s desire to develop trust through time and relationships, rather than abstract trust in the training or position of staff.
Some care and nursing staff described examples where staff who spent little time on the ward (management and medical staff) were less trusting of young people. For example, as Patsie explained, there were times when the nurses felt young people could be trusted to go on leave as they could see their progress, but the doctors would not agree ‘because they just get the snapshot’ of them. It was perhaps harder to trust and easier to doubt abstract ideas or distant knowledge about young people, rather than proximate knowledge of them. These were the staff who were distant, and who spent little time with young people but were informed about them by notes and the views of others, rather than the direct testimony or contact with young people themselves.

Young people trusted the staff with whom they spent time and who they could get to know, which made them feel able to share their thoughts and feelings with those staff. The staff closest to the young people also seemed to trust them the most as they were basing their judgements on proximate knowledge **formed with** them. They spent time with young people, saw them, talked to them, interacted and negotiated with them. Young people felt trust was reciprocated and these staff, as Asif said, ‘treat us more fairly’. Staff knew **them as people** rather than behaviours divorced from meaning.

They therefore felt known and heard by staff who had received knowledge from them, not about them. The staff young people trusted the most were therefore those who made clear and obvious efforts to understand their inner
world and this positioned young people as the reliable knower of their private internal world.

Where these practices were limited, and observations of young people’s external behaviours were a proxy for their inner thoughts and feelings or where they spent little or no time with staff, trust was undermined. Trust is formed through mutual interactions and understanding the innermost carings of the other (Wiesemann, 2016). Thus, how can young people trust those who doubt them; who don’t seek their knowledge; or spend time understanding what is most important to them? Trust is therefore not formed, or is undermined by, distant practices and relationships. When young people’s views or actions are separated from meaning, context, and reasons, this can cause mistrust and doubt. It is perhaps easier to doubt than trust from a distance.

6.4.5 ‘They just need to give me more chances to prove myself that I'm safe, but they just don't trust me’ – risk, past and possibilities

While many staff wanted to believe in and trust young people, their decision to trust (or how much to trust) young people’s views (or not) could have very real consequences and could entail high levels of risk, distress or harm. They were aware that the decisions they made, such as whether to let young people have their shoelaces or not, could have significant consequences.
They were therefore very vigilant about whether they could trust young people’s views and the weight of thinking ‘but what if...’ For example, staff described memories of young people harming themselves in the past, as well as anticipation of the possible harm to come if they trusted young people and got it wrong. Many staff described how, when considering a decision that would affect a young person, they would think about whether they could defend their decision in a court of law if someone came to harm. This could make staff err on the side of caution rather than trust young people.

A lack of time and trust also meant staff felt they were making decisions as lone individuals, who were solely responsible for their outcomes. In an environment with high levels of distress, this became incredibly difficult and made staff feel unsafe and isolated:

[Referring to a previous job] I didn’t ever feel concerned about the trust, you know, I felt quite confident in the decisions that I would make as part of the team and hadn’t experienced not being supported. But here, that [being undermined] did very much happen and that’s quite tough.

Abbie, senior nurse

Some staff therefore doubted young people’s views based on memories of previous harms or anticipation of future harms.

6.4.6 Summary

Young people’s credibility as knowers was undermined not only by assumptions about their psychiatric diagnosis but also because of mistrust in
their views and capacity as knowers. This mistrust was affected by the distance and lack of time to develop relationships between young people and key decision-makers; the possibility of risk and staff’s fear about the consequences of decisions; the reputation of young people and staff’s emotional reactions to young people. As (Origgi, 2012) suggests, the credibility judgement does not only rely on epistemic injustice based on identity prejudice but also on epistemic trust, as our belief in what someone says is based on our trust in the source of information.

If a young person (the known), who has a credibility deficit, disagrees with a professional (a knower) who has credibility, it can be interpreted as proof of the young person’s deficit as a knower. Decision-making is then affected by a balance of the perceived credibility of the knower. Young people are positioned according to their age, status as a patient and mental health difficulties, and through the many processes of observation within the unit as ‘the known’ – and the staff are positioned as the knowers. Therefore, any disagreement from the young person creates a contradiction and tension, not just about the decision at hand but about the status of the knowledge of young people and professionals. Alongside age and mental health, their knowledge and testimony are also given less credibility due to their status as a patient, in comparison to the knowledge and position of professionals.

While there may be times when young people’s distress affects them, making generalisations can be seen as an example of testimonial injustice as it assumes all of their testimony lacks credibility. Furthermore, while there may
be instances where young people may lack formal capacity to be the main decider in certain decisions, they still have views, values and opinions, which should be heard and respected. Even when a young people’s epistemic powers are impaired, their autonomy can still be acknowledged (Harcourt and Martin, In press) and they can still have a say, be heard, listened to and respected. When this is denied, it is an example of epistemic injustice.

At one end of the treatment spectrum there are life saving treatments which can be confidently recommended, and on the other, those which have uncertain benefit and strong side effects. Towards this end, mental health care is further complicated by uncertainties about the origins, nature and cure of mental illness, let alone about the optimal treatments. The benefits of therapy and medication widely used in mental health can be uncertain and partial, and the side effects can be very serious. These problems mean it is even more vital that young people are informed as much as possible about the different options. Whilst staff have a duty from preventing young people from self-harming decisions, it is vital that young people are as involved as possible in shared decision-making to understand the risks, harms and can decide which they are willing to accept and those which are unacceptable to them – something only they can know.

6.5 Doing: the effect of distant decisions

The relationships between nurses, support workers and young people were where most decisions were enacted and their effects realised. This seemed to be where discussions and decisions turned words into actions, became
real and had determinate effects. This section explores some of the constraints when decisions were enacted, the contradictions they created and the impact on young people, nurses and support workers.

6.5.1 (Re)negotiating decisions

As mentioned earlier, some nurses and most support workers described being absent from discussions and decision-making about young people’s care. They felt that decisions often lacked their close personal knowledge of young people, the realities of practice on the ward, as well as young people’s views. For them, this meant that they felt many decisions were partial because they did not take account of all relevant knowledge, or were unfeasible to put into practice because of the realities of the ward.

Being absent from the deliberation meant that young people, nurses and support workers said they did not understand the rationale for decisions. This meant that nurses and support workers and/or young people would renegotiate some decisions. Some staff felt the decisions were not feasible and therefore subtly adapted them or avoided them all together. For example, support workers described how they often felt young people could do less than decisions suggested and would break them down into more manageable chunks or avoid them all together. Decisions could therefore be renegotiated or resisted when they came onto the ward.
6.5.2 ‘One day there was another pill there’

I’ve seen a doctor that assessed me to see if I needed to be on one-to-one. And I did. So I was on that for a couple days. And then the doctors came in here umm, to... They basically took me off my section, without asking how I felt, like in the moment or what was going through my head.

*Dan, young person*

So, you might not even talk about anything that you would think suggests, oh you mean more medication, and then they could still come back with it.

*Siobhan, young person*

Several young people described times when aspects of their care would change without having been involved in the decision or being informed it had been made. For example, this included medication doses being changed and young people suddenly seeing an extra tablet or their calories being increased:

They don’t inform you. I had my calories upped. And found out later by saying, ‘Why have I got so much on my plate?’

*Emily, young person*

A lack of explanation or discussion therefore prevented young people from being able to disagree, question, or influence the decision. Real choice requires being involved in discussions and deliberations. This lack of discussion felt coercive for both the young people and also for the staff who had to implement the changes. It communicated to young people that they had little or no power and were expected to comply, and to staff that they were there to enact rather than understand. Some young people appeared to have become used to it or did not expect to be involved in discussions. Some
felt unsafe; for example, they did not know whether the change of dose was a mistake. Others felt deeply frustrated, angry and dismissed, and would question, ask for an explanation or refuse:

They’d be a lot more open to treatment, basically. A lot more accepting of treatment. If they feel more powerful than… if they’ve got more power to project their own views of what they think. I think, if they were given the floor to do that, then they’ll be more open to treatment they will receive from other people. Because they think things are happening without their will. Against their will, basically. That things are happening and they don’t really have much of a say in it, so they start thinking that people are working against them when… when the opposite is true.

*Hamza, young person*

It’s really disempowering because if they don’t understand why, then they’re just floating round in this system that’s telling them you can do this and you can’t do this and they don’t understand why.

*Jen, senior nurse*

Melissa felt strongly that even though she knew she had been very distressed at time, she thought things should be explained to her.

It’s obvious that you’re really struggling and, like, I was kicking and screaming and throwing things like three times a day, like… and it was just really bad, because I was a bit delusioned [sic] as well. But [they should] talk about it properly, rather than just do it.

*Melissa, young person*

Decisions without discussion or rationale become things just done to people as objects, and actions separated from reasons lack meaning. Young people would resist these moments or refuse, or there would be a conflict between
them and the staff. As Asif described, ‘it's not that I don't agree to it, it's just that I should have been involved whilst making that decision.’ He and others would describe the target of their resistance as the lack of involvement. Others felt questioning staff could be construed as difficult or antagonistic.

As described earlier, resistance was often described as non-compliance. Non-compliance seems to suggest that young people do not have a valid reason for their refusal or that they should passively comply with the decisions of others. Their refusal was seen as lacking meaning rather than reasoned resistance against a wrong or potential harm.

I think information, it's really important. Information of how the system works and stuff like that is really important because, then, you understand where things can go wrong. And then you can actually make an initiative then and actually try and project your voice in trying to fix that, that wrong, basically.

*Hamza, young person*

Not understanding how the decision had been reached made young people feel unsafe – how could they know that a decision was right and fully informed, if they had not been involved in the process of thinking, reasoning, deliberating and understanding what the best option for them was? How could they protect themselves from wrongs if they did not know what is expected? Resistance should be seen as a signal of an absence of something vital that needs to be addressed, rather than non-compliance, which is the end of the story.
6.5.3 The absence of the means to explain

I find it a bit uncomfortable when I’m trying to explain something to a young person, and I don’t know enough. You can just tell that [the young person is thinking], ‘What are you even saying?’

Patsie, nurse

Staff, especially support workers and some nurses, lacked information about how or why decisions were made. They were the staff having to implement decisions, and the staff who would be faced with young people who were, as Frankie, a support worker, said, ‘frustrated and annoyed, and upset’. When they then couldn’t explain a decision, as they had not been given the information or rationale, they felt stupid, undermined and unable to do their jobs properly. Some described feeling defensive. They did not want to say ‘I don’t know’, as this was embarrassing. They tried to give young people the best explanation they could, but this was often vague and could be interpreted by young people as being fobbed off. This could cause further tension and affect their relationships with young people and undermine trust.

Jen, a senior nurse, described that, without reason or rationale, young people would ‘get really frustrated and distressed’ because they would keep asking, yet not get an answer. This could escalate to a very ‘difficult situation where they get really angry, quite rightly so and then they’re going to take that out on themselves or others’. Therefore, the absence of involvement could have very real and serious effects. However, these effects were often distant from those who had made the decision.
6.5.4 Hollow care: doing without meaning

Short and sharp, ‘this is what you need to do’, no reason for it, no rationale, no evidence, no nothing. Its ‘this is what you’re here to do, this is what you’re doing’. It’s all about behaviour, what behaviours we stop and start, that’s all, there’s no theory behind it or understanding.

*Jess, support worker*

As Jess described, the ways in which decisions about young people’s care were communicated often lacked rationale or explanation. They were told what they needed to do but not why or, crucially, how. This meant staff often lacked the knowledge or understanding to enact decisions and care plans. As Catherine, a support worker, described, care plans were not detailed. They were developed by management who were ‘not going to know the specifics’ because they were ‘not down here doing the face-to-face interaction’.

As young people’s being was reduced to observations of their behaviour, some nurses and support workers felt they were reduced to a series of actions separated from their meaning. They often had to support young people who were very distressed. Staff were also distressed by not feeling they knew what to do or how to care. For example, Catherine, a support worker, described how a young woman with health anxiety would repeatedly ask her – ‘I want my obs done, I want my obs done’ or ‘oh my hearts, oh my heart’ – yet Catherine did not know how to respond. She desperately wanted to help, but she was unsure whether reassuring the young woman would be helpful or make things worse, yet ignoring her pleas made her feel cruel and
uncaring. If nurses or support workers lacked knowledge or rationale, they questioned how they could support a young person safely. They felt they would not be able to judge whether they were supporting young people properly or would not know if they were doing something wrong.

6.5.5 Doing without meaning: care or cruelty?

Rebecca, 17, came into the unit because she was struggling to overcome her compulsions. She had agreed to be admitted as she saw the unit and intensive therapy as her only hope. She had been involved in developing her care plan for exposure work, which involved gradually exposing her to the very things that caused her distress. Rebecca and her psychologist understood that this would cause her to become distressed, but that this was a necessary part of her therapy.

Rebecca was deeply frustrated during her interview with me, describing how her exposure work happened rarely. She was supposed to have it seven times per day, but she said it happened two to three times at most and, on some days, not at all. She said that when she raised this with the nursing or care staff:

They go, ‘Oh yeah, sorry. It’s been very busy.’ But it’s like I’m in hospital. That can’t be an excuse.

*Rebecca, young person*

When the staff did do her exposure work, she would become distressed and beg them to stop. Many staff would stop as soon as she became distressed,
even though this was a necessary part of her therapy. When this happened, Rebecca had immediate relief from distress, but she later became frustrated and, as Abbie, senior nurse, said, ‘she would then come and speak to me and say, they’re not doing it very well.’ Rebecca wanted and needed them to be able to work through her distress and make sure her exposure work happened. As Rebecca described:

Like there’s been times when I’ve actually asked, ‘Can I just discharge myself because this place isn’t helping?’ It’s just silly. They don’t stick to my care plan at all. We are involved in writing it but it’s just they don’t follow it at all. Like there’s not enough staff. I feel really unimportant; like they don’t do enough work with me because I have to do a lot of exposure work for my OCD.

Rebecca, young person

Rebecca would then share this frustration with her psychologist, who in turn felt frustrated. She had written the care plan with Rebecca and believed it was being enacted. She was dissatisfied that this was not happening. This then caused conflict between her and the care and nursing team as she assumed it was being done, yet no one had come to talk to her about why it was not happening or why the care plan was not being followed through. ‘I might write in the notes,’ she explained, ‘but I’m told that nurses don’t read them. The care I take in writing it is wasted, because they’re not receiving it’.

However, the nursing and care staff did not understand OCD and exposure work and, as such, did not fully understand the reasons for the distress it caused. Without this understanding, they perceived the distress they were causing as unnecessary. As Abbie, senior nurse, highlighted, this contrasted
with supporting young people with eating disorders, where support also caused high levels of distress, yet staff tolerated this and did not avoid it. It seemed that this distress was understood and tolerated by nursing and care staff as helping someone to eat fitted with their understanding of care and nursing, as food is a basic need and the young person was visibly underweight (although this is not the case for all types of eating disorders).

Additionally, supporting young people with low mood to get up in the morning and undertake daily living tasks could cause them distress, but these practices sat more comfortably with the nursing and care role and the staff understood the reasons for the distress. As Nelia, a psychologist, explained:

> Getting people up in the morning, making sure they self-care. Those are sort of things which fit more easily into, maybe a nursing role. Umm … If an eating disorder … I think, there’s no issue with somebody sitting with a young person with an eating disorder just while they eat.

*Nelia, psychologist*

Nursing and care staff could, therefore, understand the *rationale* for the young people’s distress and, while difficult, this still sat within their role. They could understand that, despite the distress, they were helping or caring. Therefore, as they did not understand OCD, this caused them deep conflict – they felt as if they were being asked to do things that unnecessarily distressed young people, and it felt cruel rather than caring. Since nursing is not meant to distress but rather to care and address needs, this went against
their core beliefs about their roles. When faced with the distress they acted to stop it, as this seemed the only right thing to do.

This raised conflicting feelings for nursing and care staff about what kind of practitioner they were, their roles and values. It put them in the challenging role of being asked to enact decisions that seemingly went against their morals and nursing practice:

I think it’s really difficult for a nursing group who are not all mental health nurses to withhold that kind of care and compassion and that wanting to make it easier for someone.

*Abbie, senior nurse*

Not having the rationale or understanding made them feel as if they were providing hollow care – a series of actions that were harming rather than helping; cruel rather than caring. This left them feeling distressed and like a ‘bad nurse’ because this contradicted their values about how a nurse should practise.

### 6.6 Summary

As shown in the previous chapter, young people’s being was collapsed into the staff’s knowledge of their being – their real thoughts and feelings into observations. There was also an epistemic distance between young people and many of the staff who were making decisions about their care. Observational knowledge took precedence, and there was an absence of young people’s testimony and knowledge. Where young people’s testimony was heard, it was often subject to testimonial injustice and epistemic
mistrust, which affected the credibility and influence of their views. The deliberations of professionals may have been highly informed medically but that they often did not appear to involve personal knowledge of the young person. When decisions are made about, rather than with, young people, these are not merely benign processes, without effect. Decisions are not just isolated moments, they are situated within relationships and when young people are excluded or overridden, it is not just the outcome of that decision that is affected: it is also the self that is being excluded and denied, and trust in themselves and others harmed.

Trust is key to young people’s autonomy and moral worth yet, as has been described, there were many ways in which this trust was absent or eroded. Trust is formed through interactions and understanding what is most important to young people (Wiesemann, 2016) but young people were often absent from deliberations and decision-making, or spent little time with key decision-makers. This undermined their ability to trust or be trusted.

Decision-making could be partial and decisions also partial in their implementation as (even when decisions were made with young people) staff lacked the knowledge and rationale, as they were distant from the discussions and deliberations.

Staff, on the whole, wanted to develop positive and empowering relationships with young people. However, they were often prevented from doing so by the
many constraints, processes, routines and systems within the units (this is explored further in the next chapter). They were alienated with a split between their ethics and the practical reality of their roles, which left them unable to care for, involve and engage young people in the way they believed they should. This left many feeling distressed and conflicted.
Chapter 7. Social systems that constrain and promote mistrust

7.1 Introduction

The third level of the four-planar social being is social relations and systems. This chapter explores how systems constrained or enabled decision-making and framed practice, possibilities and relations between staff and young people. CR aims to balance and examine interactions between structure and agency, yet psychiatry and psychology tend to concentrate on individuals rather than their contexts. These interactions are therefore important to explore, as the individual actions of staff and young people cannot be divorced from their context and the factors that influenced them to act. To do otherwise would judge individuals on their actions rather than the causes, meaning and motivations and/or the constraints of the service.

This chapter explores how young people often felt they were making decisions as individuals against a whole system; how the system undermined time and trust with young people; and the power and contradictions of rules and routines. It also examines how risk, distress and a lack of systemic support affected staff and their emotional capacity to give choice and control to young people; and how the systems are ingrained with doubt and anticipation of risk and mistrust.
7.2 Blame: individuals or the system?

I think for me, it’s about how the system … my impression is of an orchestra and if a bit of the section isn’t working, then everything falls down. If we can work together as a team, it works well but if it doesn’t it can be difficult.

_Seb, family therapist_

As described in chapter two, young people highly valued time with staff and normal human interactions and conversations, yet the inpatient unit systems and procedures prevented this as staff were very busy and lacked time. Many nurses, for example, described how they wanted to spend more time with young people, but spent so much time in the office doing paperwork or writing notes. Similarly, support workers described how they would like meaningful time with young people, but that this time was often structured by, for example, being on a one-to-one. They felt this prevented them from having the time to involve young people in meaningful conversations about their care.

Several staff saw it as their role to encourage young people to become involved in decisions; to enable young people to see themselves as decision-makers; and to enable them to develop the experience and confidence to do so. Staff saw this as one of the key aims of their role. They believed this would enable young people to feel valued and heard in the present and encourage them to develop their confidence and ability to make decisions in their future. They also believed this improved young people’s safety in times
of distress or at risk of harming themselves, as it gave them a sense of agency to feel more in control of their distress.

For these staff it was distressing to see young people being passive. They regarded empowering young people as a core, critical element of their care and recovery. They described feeling as if they were failing young people if they could not spend time with them. Their efforts were pitted against and outweighed by the constraints of the system.

In one unit, due to the staff shortage, there were high numbers of agency staff, which placed extra pressure on the other staff. They identified relationships with their colleagues as one of the most important factors to enable them to do their job well, to feel safe, feel able to be open and reflective and to feel confident to make decisions with young people. However, if there were many agency staff on a shift, it could make this challenging. A lack of consistency in how to support young people was often cited as an issue that caused conflict within teams. There were therefore a number of factors that undermined staff trust and confidence in each other.

A lack of time affected their ability to work as a team and feel supported. As Abbie, a senior nurse, said, when they had time they could support each other, get an acknowledgement that it’s ‘really hard isn’t it, but don’t worry, we’ll support you, everyone’s on board.’
Secondly, a lack of time affected the ability of staff to be consistent in maintaining boundaries with young people. Some staff felt that this made them look like ‘the bad one’. Other staff described how their efforts to be collaborative were undermined by other staff wanting to ‘be the one to make the rules’, be in control and assert authority. Similarly, some staff were more likely to hold boundaries with young people, even if this meant they might experience a difficult situation, whereas other staff would ‘give in’ more quickly, so that the young people liked them, or to avoid challenge. As Abbie explained:

I think what can be a bit of an issue here, especially with lots of new people and people that haven’t got that trust with each other yet, is that some of them might hold that position but they don’t know because the young people go and test everybody and someone might give. And then that person feels there’s a bit of betrayal in the team.  
*Abbie, senior nurse*

Trust was also undermined by lots of new staff or agency staff who had not yet come to know each other well or developed trust in each other. Trust was also exacerbated by a lack of time to be reflective, talk and think together as a team, which some staff explained meant individuals blamed each other rather than the system. As Nelia said, ‘reflective practice [could] be used more as a forum for exploring issues, particularly around splits’. When staff saw others not holding boundaries, they saw this as though the person was undermining them, rather than seeing it as being driven by the system, or a lack of time or confidence. Therefore, with time and reflection as a team, they were able to experience trust and support and, without time to reflect, this could feel like conflict and betrayal.
Staff wanted to care and to be seen as caring, yet the system undermined their relationships with young people. To compensate for this, some did things to be liked or were lenient; as Abbie, senior nurse, highlighted, they want ‘to be the one that’s liked,’ which could cause conflict in the team and a ‘good cop, bad cop situation’.

Like young people, staff recognised their own need for space and time to be reflective about their relationships, how they worked together, how they explored issues and reflected on different opinions, perspectives and resolved disagreements.

7.3 Young people v. the system: ‘I just felt like I’d walked into a big trap’

I know that I don’t push the boundaries as much as other people, because … I kind of shut down, and just kind of freeze. So even like little things that I do, I’m afraid that I will get put on section, just terrify me …

Jimena, young person

Decision-making is not just a discrete event or a one-off encounter between one young person and one professional. Young people are choosing and deciding within a system. They are faced with making choices where they see themselves as an isolated self versus the system and its many powerful constraints.
I was being told, like, “You’re under section,” but I didn’t really know what it was, like, for like a week or so. And the situation I’m in and what, what sectioned means and why I’m a patient here: what sort of illness I have and all that information empowers you, because you then understand your status here. You’re a patient.

Hamza, young person

Young people’s understanding of Mental Health Act legislation had a profound impact on their perception of their rights and power to be involved in decision-making. Being sectioned, or the knowledge of the possibility of being sectioned, significantly affected their actual or perceived sense of choice, agency and liberty. Being sectioned had implications for their freedom, but most of them did not understand these restrictions.

They didn’t tell me about the section and stuff, but, and when I first got here, I really, really thought I was only going to be here for like two weeks or like four weeks at the most, at the absolute max, I thought I was gonna be here. And then when I said I wanted to go and they said I couldn’t I was like, what? I thought I could, and then that was like horrible to suddenly feel like they’d just trapped me almost, like, I just felt like I’d walked into a big trap.

Jaime, young person

The anticipation of being sectioned also had powerful effects on young people. This made them cautious about expressing her/his views on other important decisions and silenced them.

One of the, doctors in the community team when I was put on the fluoxetine the first time round, mum was trying to, mum was asking her questions and then the doctor said to mum, and I wasn’t there but apparently said, ‘We’re not far from the Mental Health Act you know.’ Or something like that and, I think, mum, well she immediately stopped asking the question. Kind of a bit scary because I’m, and I’m
a bit scared about if there is something I don’t want, if it’s like, a big
decision on medication I’m much more kind of cautious about even
making my view clear.

_Siobhan, young person_

While young people (or their parents) could consent to be admitted to the unit
on an informal, voluntary basis, they could be prevented from leaving by
being sectioned. Being sectioned could have long-term consequences for
young people, which weighed on their minds. Dan described how this
knowledge made him feel powerless, as he knew he had no real choice.
This affected not only his admission or treatment, but framed his experience
or expectations of all other choices.

Like, me choosing to do it, or being forced […] [It was] hard, because
you feel like you don’t have, you don’t really have a say. Because they
can force you to do what they want if they think it’s the right thing to
do.

_Dan, young person_

This also made staff feel conflicted:

With things like informal statuses, well that you’re here informally but if
you want to leave then we have to have a discussion about whether or
not you’re allowed to leave. So, is that an informal admission? I had a
conversation with someone about their rights and she very fairly said,
‘Yes but if I wanted to leave you wouldn't let me, you’d put a section
on me.’ How do you have a conversation with someone about their
rights and say, ‘You’ve got the right to leave, but you’re right,
potentially we would stop you,’ and you know it’s maybe having a
conversation around why you would stop someone and it being about
wanting to keep them safe and wanting to support them. But umm I
don’t know if it’s necessarily always happened.

_Rivka, student nurse_
Many young people felt very overwhelmed by the knowledge of not being able to leave. They felt that while they were told they had the choice to leave, they knew staff could override this decision. Consequently, they felt this was not a choice at all – they agreed to stay or would be made to stay. They then felt this reflected other decision-making processes within the unit – which suggested individuals must agree to do something or be made to do something:

Yeah, it’s like, now, they said if I was to discharge myself, ‘cause I’m voluntary, that they would get me sectioned, I was like that’s a bit mean.
Rebecca, young person

Many young people did not understand the difference between being admitted voluntarily or formally sectioned, and the real implications of being sectioned, and for some young people this had profound consequences.

Um, I was sectioned when I got here. It was really weird, like, I said I wanted to go and I kicked off. So they talked to me and reviewed me for being sectioned and then they kind of went off and did it and came back for me and said ‘you’ve been sectioned’. I was just like, what? It was really weird. Just out of nowhere…because they said ‘oh, we’ve got to review you because you said you wanted to go’ but, obviously, I can’t actually go, I just said I wanted to. I thought if you do something bad or try and discharge yourself when you’re not ready, like, that might get me sectioned, but I didn’t know that, like kind of kicking and screaming a bit would make me get sectioned.
Melissa, young person

I said that I would stay informally and they still sectioned me anyway. But normally if you say that you’re gonna stay informally, they won’t
section you. I just felt like I really wasn’t included in that decision. They didn’t even … they literally, from the moment I walked in there, they said that that I was lucky not to be sectioned for this long. They said that they would have sectioned me at my last hospital, and like definitely because I’d done such a severe suicide attempt, they would have definitely sectioned me this time round. It really annoyed me because I could have stayed informally. They said that when I walked in, because of what they’d heard, they’d said that they already agreed to put me on section but they just had to hear what I’m saying because that’s part of the system.

Jelena, young person

For Sara, a psychiatrist, young people being sectioned meant SDM was not possible. She felt this shifted her role from that of offering advice, which young people were free to accept or not, to making decisions for young people about their medication and treatment:

Some patients will end up under the Mental Health Act. And that will be when these things [shared decision-making] don’t work. When these [shared decision-making] approaches don’t work ... Because people do have the right, not to accept our advice, unless they’re going to be detained.

Sara, psychiatrist

However, many young people on voluntary admission in each unit described being given medication with no discussion, involvement or opportunity to say no. They explained feeling as if their refusal would be seen as proof that they were too unwell to ‘make the right choice’ and believed they would just be given medication or sectioned.
The restrictions on young people’s freedom and the requirements to take medication made young people feel powerless and led them to believe they could not be involved in any decisions, even once their section had ended.

These restrictions also made staff feel powerless and frustrated:

Umm, yes, I mean, it can be really frustrating as, umm, a professional, and I think particularly as a nurse. You feel quite disempowered sometimes because, because I'm aware that this person is informal, for example, and they've chosen to be here and therefore, actually, it is their right to say I want to leave. And I want them to be able to take that decision if that’s what they want to do, but also, I don’t want them to go out and (laughs) do something and hurt themselves. Umm, and then … And I think, I think it can just be really confusing for the young person.

*Jen, senior nurse*

Young people were not making decisions in isolation and not just with individual members of staff (who they may trust) – they were making decisions within a system against which they felt overwhelmed by and powerless.

**7.4 Rules and routines ‘Staff just go, ‘It’s the rules.’”**

Some staff make us go to bed really early. At like half nine. And like my sister gets to bed later than that; she’s 10 …

*Louise, young person*

As described in section one, there were many restrictions in the units that prevented young people from doing many of the small, ordinary things that they take for granted in their lives. These restrictions make young people feel
constrained, powerless and led them to believe they have no choice in other decisions. Many rules, routines and regulations governed how young people and staff spent their time, their use of space and how they interacted. Young people understood the need for some rules to keep people safe, ensure they got the level of care they needed and to enable them to understand their rights. However, many aspects of the rules and routines felt overly constraining, restrictive or unclear. Rules could, therefore, provide clarity and boundaries, but could also feel coercive, oppressive and make staff and young people feel as if there was a rigid track governing the service, with little opportunity for influence or decision-making:

Some of their rules are just really ridiculous. Like we’re not allowed blankets … which is … I don’t really understand.

Louise, young person

While all young people understood that there were rules and routines in place, many were unaware of what the rules were. They also did not understand the reason or rationale for many of the rules or routines. This meant they had little understanding of the reasons for decisions and left them feeling uncertain and unable to exercise choice. Young people felt the rules were often about small, insignificant things, rather than those designed to keep them safe.

Robert described being told he was not allowed to use a blanket in the lounge area. This left him feeling frustrated as he could not see the reason or harm in having a blanket, as he and other young people would be able to do at home:
I'm not the type of person who gets angry. I don't know, I kind of just laugh it off. I just kind of think, ‘Well, it's not affecting anyone here. It's like not affecting anyone else. I don't understand like what the problem is’

Robert, young person

The lack of clarity about the rules, routines and the reasons for them made young people feel uncertain about what they should do, what the expectations of them were, making some feel unsafe and frustrated. Rules that seemed to be about insignificant things or that felt age inappropriate made young people feel overly restricted and patronised:

There are some rules that are so ridiculously stupid and there’s no reason for it so we don’t know what to do.

Rebecca, young person

Many staff, particularly nurses and support workers, also felt unclear about what the rules were or why they were in place. This particularly affected nurses who were newer or support workers. Like the young people, the majority of support workers felt unclear about what the rules were or why they were in place. This made them uncertain about what they were supposed to do, whether they were doing their job correctly and undermined how they interacted with young people:

We had, umm, an incident on nights, one of the nights that the young people wanted to stay up a little bit later. But the nurse in charge was like, ‘Well, bed time…’ Like, it wasn’t a school night so it was, umm, I think it was like, 11:00 maybe, which I think is a little bit later than the normal anyway. And the young people were like, ‘Well this particular nurse lets us.’ And, decided that they weren’t going to go to bed. So, that nurse in charge in this particular instance didn’t really have … kind of, the authority there. Or, I don’t like saying authority, because
that's not really the right word, but the power to say, 'Okay, well it’s bedtime. Umm, let's try and settle down a bit.' Because the response was, ‘Well, this nurse lets us do it, so why can’t you?’ We feel powerless then. We can’t run a secure, like, safe unit for people, if we don’t stick by the rules, really. Yeah.

*Frankie, support worker*

Young people felt that rules changed frequently and different staff had different rules, meaning there was little consistency. As Frankie (support worker) described, not having a clear understanding of the rules and routines meant she was unclear about what to do or whether she was doing the right thing. This left her frequently doubting and questioning her actions, decisions, and interactions with young people for fear she would do the wrong thing or get into trouble. She also described how this meant young people would choose which staff to ask as they knew who was stricter or who was uncertain. This left her feeling as if she and others could not run a safe unit and made her feel powerless.

The lack of consistency affected trust as it seemed as if there were different rules for different young people. As Jaime said, it took her time to build up trust in staff and the different rules and expectations of staff left her feeling uncertain. She found this:

> quite frustrating when you’ve been able to do it before and it’s been fine and then another person comes along and goes, you can’t do that, it’s like no, you can’t have one person telling you you’re doing something and the other not.

*Jaime, young person*
Support workers were therefore often the ones having to implement the rules and routines with young people, with little understanding of why. They felt as though they were in a conflict between pleasing the system and providing individual care for young people. As Iain explained, the rules of the unit and expectations of what decisions he should take were gradually learnt over time, as he came to understand what decisions senior staff would have expected him to make:

The longer you’re here, you actually know how the unit works and you know what decisions management or the MDT upstairs would have liked you to take.

Iain, nurse

As described in the previous chapter, support workers and some nurses described being doers, as if they were just there to implement a series of actions decided by others with little meaning or reason for them. This was exacerbated by the lack of clarity about the rules. They were at once the least likely to be involved in deciding the rules and the closest to the effects of putting unclear rules into practice. This affected their relationships with young people who were frustrated and wanted explanations that the support workers were unable to give, which caused conflict and frustrations between the two least powerful groups within the units – young people and support workers.

As Seb, a family therapist, described, this was further hampered by a lack of clear ethos and shared understanding within the different teams about what the unit was for and what it could do for young people:
I think what we lacked was an ethos and so how … you know, how do people change? Is it they come here to get fixed? Or is it just a minimum change to move forward or …?

*Seb, family therapist*

It was therefore hard for young people to exercise choice or influence decisions when they did not understand what the rules and routines were or why they were in place.

Whilst consistency was important to young people, they also needed flexibility. For young people, a consistent ethos and approach to rules, rather than blanket, one size fits all rules, were essential. They described consistency as understanding universal, shared principles; having a clear understanding of what the rules and boundaries were for them as an individual; understanding the reason why some rules might be different for other young people; understanding the reasons and rationale behind *why* rules, routines, and boundaries were in place and space to discuss these. Therefore, their understanding of consistency included a degree of flexibility to accommodate individual need and preference, not the application of fixed rules.

As Robert described, a lack of flexibility was perceived as mistrust in young people’s maturity and perceived as staff just wanting to exercise authority over young people:

Like last night, one of the people in here, it’s their mum’s birthday and they wanted to call their mum goodnight but the phone had been
switched off. So we’re not allowed and if you … if she … if a member of staff lets that person, then everyone will want to c-… phone it and we were all just kind of thinking, ‘We’re not like that immature that we need to be like, ‘Oh, well, it’s unfair.’ We’d just be like we understand it’s a one-off occasion. They obviously got quite upset, especially it’s their mum’s birthday and they only got to see them for a certain amount of time in the visiting. Um … yeah, they … like, fair play, like they normally are the type of people who get angry at … like scream and shout and staff that they kind of took their stuff away for the situation but … Like they are the type of person to normally scream and shout about it and make reaction but they, fair enough, they did like walk away. But then the staff member followed and … and it kind of like … sometimes it feels like they want a reaction just so they can use their authority in a sense.

*Robert, young person*

Choice for young people was constrained or swallowed by the routines and systems running the unit. As Sara, a psychiatrist, explained:

> On the floor [ward], the nurses need a system that actually works. [Young people] can’t have so much autonomy that [nurses] aren’t running a ward anymore. You know, that … They can’t have so many sort of diverse care plans that they can’t run it in unless they’ve got, I don’t know, double the amount of staff or something. You know, there are practicalities to it. So, I think … I think that’s, that’s potentially an issue. So, you know, potentially, I would say, well it’d be nice for the kids to be able to choose their bedtime a bit. But actually, that’s never gonna work, because it’s, it just doesn’t work in this, in the routine here. So the, the real things that are left for them to choose are quite, they’re quite few.

*Sara, psychiatrist*

These rules and routines also caused conflict between ‘caring for’ and ‘doing with’ as the systems supported practice that did ‘to’, rather than ‘with’ young
people. This thwarted the good intentions or efforts of some staff to involve young people as their efforts were overwhelmed or unsupported by the system.

Unclear rules and routines therefore systemically disempowered young people and support workers, who already felt powerless. It communicated to them all that they needed to follow the rules, rather than understand them, and that they could only follow hollow instructions.

7.5 Rules and routines – closed world to judge
The rules and routines of the unit provided an unclear and changing environment, and created expectations that framed the actions and interactions of young people and staff. This caused great frustration. Firstly, the lack of clarity, perceived fairness of the rules and inconsistency made young people feel frustrated and uncertain how to act. Yet, despite this lack of clarity they felt they were expected to follow the rules and comply with staff instructions, instilling a clear power differential between young people who felt as if they were expected to comply passively and staff who were expected to know and implement the rules (even though they often also did not understand them). Several young people said that if they questioned the rules, they were seen as being difficult.

This framed young people’s actions against the rules of the unit rather than what would be ‘normal’ outside the unit. They were expected to comply with
unclear rules for the proper running of the ward. Their frustrations or questioning were seen as incursions of the rules (which they often did not know about) rather than being understandable, and reflective of their uncertainty or of them wanting some freedom and choice.

7.6 The invisible weight of risk and distress: possibilities and anticipation – ‘I go home glad they’re all still alive’

The weight of risk constrained decision-making. Constraint was increased by a lack of time and support for staff. Perhaps one of the most common themes for staff was the level of risk many decisions carry and the emotional capacity of staff to manage this. As Nelia, a psychologist, described, the capacity to hold and carry the weight of risk affected how far staff felt able to involve young people in decision-making:

[There is often no right or wrong] I mean, I think there are decisions that people probably have to take a big breath and manage the risk. Because I think in the end, it becomes … You know, no matter how much training you have, and how much … Ultimately, it’s your own capacity to bear it, I think. I mean, I personally think so. I’m not sure everybody would necessarily agree. Umm, and there are some people who are more risk-averse. There definitely is [sic] some people who get … Who would just …? And I mean work with lots of different psychiatrists, and some psychiatrists who’d … Very, very able to manage risk. Very clear … Umm, and there are some who are very anxious, and would tend to keep people for longer or, get them to leave, and you know … Who’s to say who’s right and who’s wrong? Actually, because, you know … It’s risky! [Laughs].

Nelia, psychologist
As Sara, a psychiatrist, explained, perceptions of risk often outweighed young people’s views:

That’s influenced by risk. So uh, one of my patients today tried to umm, put a ligature round her neck on the weekend and she’s on one-to-one obs [observations] and when we saw her, actually she still thinks that she would umm, she’s thinking about suicidal thoughts all the time. But the thing is, I, it’s unfortunate when risk influences decision-making umm, rather than making decisions based on what the underlying condition is and what the correct treatment for that condition is. That’s the problem, when those two things are in conflict.

*Sara, psychiatrist*

Many staff said that they received little or no emotional support in their roles. This could cause them great distress and left many feeling extremely worried and anxious, doubting or worrying about the decisions they had made. This reduced their ability to involve young people in decision-making for fear of the greater uncertainty this entailed. They felt they were lone individuals carrying the risk of decisions, rather than supported by the system. For some, this meant they relied on the perceived reassurance and safety of policies, procedures and more restrictive practices towards young people. If they were not getting enough support to manage the emotional weight of their work and the decision, then reverting to process became a proxy safety net:

When people are more anxious, they’re more likely to make a decision for someone rather than sit with the un- … the unknown because that’s a grey area and, you know, um … perhaps a lot of the struggle of the young people we have is managing that grey area, you know, and, and I think professionals do it as well. [When they are anxious
they are more likely to] impose something … [rather than] allow something to unravel, if you like, yes.

Gail, art therapist

To care, staff need to develop caring relationships with young people, yet at the same time they might have to undertake or witness coercive or distressing acts (Goffman, 1961). As Jess explained:

There’s no review, there’s no debrief, there’s no, nothing. [It would help if] to get a debrief on this, we will explore what went wrong, how can we improve, you know, just being looked after, felt cared for by the like, senior, I guess … There’s nothing worse than restraining I think six times in a day and nobody checks, oh are you okay? Because … I’m tired, I’m frustrated, nothing seems to be working for this person and it’s like, okay, it will work, just give the medication time or something, no-one came up and said you know, what you’re doing is important, or, you know, and it just looks bad on them because you lose hope and then [the young people] can tell.

Jess, support worker

As a result, there was a tension. To care, staff needed to invest emotionally, but this could then cause them greater distress. If the staff themselves were not cared for or given emotional support then, in order to continue caring in some fashion, they need to withdraw emotionally from that same caring relationship. Absence has real, determinate effects (Bhaskar, 2008a). The absence of care and emotional support for staff had effects because their needs were overlooked and unsupported, causing them to distance themselves from young people. As shown in the previous chapters, young people were acutely aware of this distance, which was enacted through
observations rather than caring interactions, and hollow time when staff are there physically but did not connect or engage with young people.

Most staff described feeling anxious about their position in decision-making in some way, regardless of their role or seniority. Staff felt they were positioned in the system as strong, rational and able to cope. In some ways, the more senior or experienced staff were, the more they were expected to be (or felt they were expected to be), stronger and more resilient than junior staff. This carried great emotional weight. Many staff described, when making decisions, reflecting on whether they could defend their thinking in a court of law if something happened and someone came to harm.

Risk or the perception of risk is an invisible, but powerful mechanism that weighed down the ability of staff to involve young people in decisions about their care or determine courses of action within their roles. While visible in its effects, risk is an invisible weight that drags down the ability and capacity of staff. Thus, the emotional capacity of staff to care, bear risk and give choice and control to young people was constrained by systemic issues, which included a lack of time, care, and support.

7.7 Distressed systems and mistrust – time, power and change

I think most people on the, yeah, um … some people are more directive than other people, but it’s a shift because we had a previous
[hierarchal] ethos on the unit I think, and since myself and the other consultants have come it’s changing. But I think it takes time.  
*Lauren, psychiatrist*

Staff described several ways they had wanted to, or had tried to, make changes to improve the ways they engaged with young people, involve them in decision-making, and communicate decisions better to other staff. For example, Lauren, a psychiatrist, described running teaching sessions to help staff to understand certain mental health difficulties or to explore difficult scenarios. She had also developed a one-page plan for all young people so that any staff member could look at it and see what their care plan was. However, these (and other) efforts were overwhelmed by the rules, routines and physical reality of the setting.

Tension existed between the needs of the young people and the needs of staff. On the one hand, staff wanted to meet the individual needs of the young people and offer them more choice and freedom. However, this conflicted with their views on their desire for the perceived safety of routines. This therefore created conflict between procedures, and the preferences and autonomy of young people. Staff described how they would feel very out of control when young people had more freedom and choice, or when routines changed or stopped. Many felt that increased choice for young people reduced their control as staff. Some staff, therefore, equated routines as being in control and with safety – for themselves and for the young people.
Theresa, a nurse, felt the conflict between needing to keep everyone safe and not wanting the unit to feel like a prison. She felt that recently young people had far more freedom over their use of space. This meant young people were in many different areas at the same time, which to Theresa felt dangerous and distressing:

At the moment we’ve got people everywhere. This has got dangerous now. Because we don’t want the young people to feel that they’re in a prison, which when I first went there it was sort of a bit … and I did say, well [they’re not here] not because they’ve done wrong. And you know, you don’t want to run it like a military camp kind of thing, but I think at the moment, I feel that we’ve gone that bit too far the other way, and we need to just pull back a little bit. And that’s hard to do because obviously the young people are resistant of that. And to maintain that good working relationship with them. So, it is a, it’s a bit of a fine line that we tread, I think.

*Theresa, nurse*

The routines and rhythms of the unit also caused conflict between the needs of young people and the working patterns of staff. Shifts, time and actions were routinised to be able to let staff run the ward rather than adjusted to the personalised needs of young people. However, given the constraints on staff time and the number of staff in the unit, there appeared no other way. Many processes were designed to enable staff to manage *within* these constraints. Practice, at times, was given precedence over personalised care through the material reality of being in the unit. This caused a contradiction between what staff were able to do on a daily basis and how they wanted to be able to care for young people.
As shown in the last chapter, young people appeared subject to credibility deficits partly influenced by epistemic mistrust. Many of the rules and routines appeared to be driven by fear and mistrust. So much time was spent observing and recording, yet this contradicted the desire of many young people (and staff) for time and talk to feel known, heard, cared for and safe. There was a tension between the need for rules and routine and the individual views, needs and preferences of many young people living in one space. This tension, influenced by the heavy weight of perceptions of risk, reduced and restricted opportunities for young people to exercise choice and be involved in decision-making. Robert described how he understood the difficulty for staff who, to keep everyone safe, restricted young people’s use of space and therefore severely limited their choices: ‘I think they try their best to accommodate, but I think it’s just a bit hard just to keep people safe at the same time’.

Systems were therefore designed to monitor and observe, and seen as necessary on the grounds of safety and the prevention of harm. These systems and processes affected trust between young people and staff. Systems – and the reasons for rules, routines and rhythms of the unit – were often associated with and driven by the presence of the memories of past harm and anticipation of future harm. Several staff spoke of very distressing situations in which young people had harmed themselves, which made them fearful. Distress and the anticipation of harm affected the emotional capacity of staff to be able to risk giving greater choice to young people. The presence of harms from the past and anticipation of future risks therefore appeared to
outweigh the young people in the present. Decisions with young people were not discrete, they sat within a system. It was easier for some staff to err on the side of caution and mistrust young people than to risk trusting them and them coming to harm. They defaulted to the perceived safety of processes and procedures.

Whilst some staff could see the need for change, they could not see how this could be possible. For example, whilst they acknowledged that the environment young people were in was strange and disorientating (through being removed from friends, family, and known people and places) and that the units lacked many ordinary choices and freedoms (like not being able to access their bedrooms, or not being able to contribute to usual task of daily living, such as cooking), they just could not see any alternative. When describing these constraints, they frequently justified them as being necessary as the only way to keep young people safe from harm. Therefore, they felt in a no-win situation – whilst some could see the harms caused by restrictions, they could see no other way of preventing more serious harm. For some staff, the position of seeing no alternative reassured them they were doing what they could. Yet this distressed others because they wanted to be able to change and improve the way the unit ran, but could not see how. They therefore felt conflicted. On one hand rules and routines were seen as the only away of keeping young people safe and enabling staff to feel safe in their practice, yet these same processes also left them feel distressed and unable to care in the way they hoped for.
Erm, and then the older ones are just... Yeah...'This is the way we’ve done it for years and we’ll never change the way we do it.' But they tend to be like quite, 'We’re the oldest, we’ve been here for a long... Don’t you worry, you just do what we’ve told, what we’ve said, don’t worry’. Jess, support worker

The risk of risk of possible harm therefore outweighed the small daily incursions and harms to young people’s autonomy.

7.8 Summary
As has been shown in previous chapters, to trust and be trusted is vital for young people to feel known, heard and involved. Yet many of the rules, routines and rhythms in the units undermined time and trust between young people and staff. The system privileged rules and routines to run the ward over individual choice and autonomy. This placed processes and routines, which focused on the observation and protection of bodies, over young people’s views and knowledge, and the social and relational aspects of care and shared meaning-making. While young people and most staff valued meaning, relationships and time, systems and processes often prevented meaningful time together to develop trusting relationships. Many of the rules and routines facilitated practices, which undermined trust and the autonomy of young people and prevented staff from supporting young people in the way they believed they should.

Small events and interactions are not isolated and cannot be separated from the systems in which they happen (Archer, 1995). The system framed the
many practices identified in this and the previous two chapters, which undermined the autonomy and freedom of young people and staff. Systems create or sustain normative conditions (Bhaskar, 1998) which then frame the context for positive or constraining practices, actions of staff, and interactions between staff and young people. The rules and routines of the unit replicated normative adult/child, professional/patient relations. They also privileged cool, distant practices, which monitored, observed and recorded, over time, talk and meaningful interactions. The rules were driven, in part, by a powerful desire to prevent harm. Yet these practices, along with removing young people from known people and places, were constraining and frustrating the desire for safety through time, relationships and trust. Rules and routines become a proxy for safety, which could undermine choice, freedoms and the human and social interactions required to form trust.

Whilst most staff saw the need for change, those who were least powerful (young people and support workers) had the greatest urgency for change, as they were the ones who felt and experienced the implications of the system. Those who were most powerful in some respects (therapists and psychiatrists) were also the most distant – both from the effects of the system and decisions, but they also spent least time on the wards where much of the decisions were enacted.

The system undermined young people’s ability to be heard and for staff to hear them. Epistemic injustice cannot be placed on individual interactions.
alone; great change is needed at all levels to support practices that enhance
time and trust between young people and staff.

Chapter 8. Turning thinking into doing: reflexivity, alienation
and resistance

8.1 Introduction
This chapter explores the fourth plane of the four planar social-being – inner
being and subjective agency. It considers how young people and staff
reflected on and reacted to the many constraints of being in an inpatient unit,
and how these constraints affected how they saw themselves as decision-
makers.

During the analysis, a number of key themes emerged showing the differing
ways young people responded to the constraints of their environment, how
they viewed themselves as decision-makers, what they most valued within
the decision-making process, and the differing forms of resistance the
described. Similar themes also began to emerge when analysing the
accounts and experiences of staff. The differing groups appeared more
deeply connected to decision-making than just preference; it was core to who
they were and how they saw themselves as people in relation to decision-
making. I was keen to understand this in more depth and I found that
Margaret Archer's (2000; 2003) work on agency, reflexivity and internal
conversations enabled me to deepen my analysis.
Reflexivity explains how people reflect on their objective circumstances and mediate structures and constraints through their internal conversations (Archer, 2003). They talk their way through their goals, options, deliberations, plans and moves (Wiley, 2010) and the trajectory of internal conversations is therefore concerns ➔ projects ➔ practices (Archer, 2003)

People begin their decision-making with their main concerns and therefore, from who they are. As stated in Chapter 2 (p.64-65), our ultimate concerns (Archer, 2003) or carings (Jaworska, 2009; Wiesemann, 2016) are more than preferences or values – they are core to what and who people are, and reflect the self. People deliberate and exercise modes of reflexivity, based on who they are as a person. Our reflexivity, agency and autonomy are therefore expressions of the self.

The following sections explore reflexivity and how young people and staff saw themselves in relation to decision-making. This includes how they conceived of themselves as decision-makers; what was most important to them about decision-making; what caused them most distress; and the differing ways some exercised resistance.

8.2 Thinking separated from doing: I’m not a decision-maker
Several young people did not see themselves as decision-makers. Of these young people, all but one described examples from their lives to suggest they
had a higher sense of agency and involvement in decision-making before being admitted. However, in the unit, they did not see that they should.

Reflexivity can be fractured when people become passive because, for example, they are disorientated about their ultimate concerns, how best to act, or both (Archer, 2003). The following sections describe how young people’s agency and reflexivity were fractured, including how they saw themselves as passive in relation to their diagnosis or difficulties; how they saw themselves in relation to adults and professionals; and how their inner self and agency were undermined and restricted due to the many constraints of the inpatient environment, interactions, and routines, leading them to see themselves as powerless.

8.2.1 Self-doubt: ‘My illness decides’

I guess sometimes you don’t know what’s best for you, as I said, like, you can be in a bit of a haze.

Melissa, young person

A small number of young people felt their illness had more agency and influence over their thinking or actions than they did. They saw themselves

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6 It is important to note that it is not possible to determine whether, or to what extent, a young people’s reflexivity was fractured prior to admission into the unit. Similarly, fractured reflexivity does not necessarily mean they are unable to exercise reflexivity in other contexts (Flam, 2010). Therefore, this section is only in relation to young people’s reflexivity within the inpatient unit.
as powerless in comparison to their distress (or diagnosis) and felt this would ultimately influence any involvement in decision-making. Jaime felt that any talk of her preferences ‘would probably be the illness’ talking and so any expression of preference ‘wouldn’t be for the right reason.’ She therefore felt as though decisions about her treatment or care plan needed ‘to be decided by the doctors’. For her, others deciding for her reassured her that her illness would not influence or try to undermine her care.

Melissa described doubting her knowledge because ‘if you’re mentally ill, you don’t really know what’s going on around you.’ Her belief in the power of her illness over her caused her to believe that she was unable to make decisions. Other young people felt like their distress, or the side effects of the medications they were prescribed, prevented them from knowing what was best for them. They also described accepting decisions as, for example, they felt that professionals would not prescribe them medication unless they needed them.

I must be crazy if they’re giving me pills.
Robert, young person

Others felt so distressed, low, or tired from medications that decision-making just felt too overwhelming. They could not see themselves as having anything meaningful to contribute. They therefore felt that their parents or the staff must be better placed to make decisions for them.

7 It is important to note that there may well have been other young people whose distress may have severely impaired their ability to make decisions but who were not involved in an interview.
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8.2.2 Deference and assumed roles

‘You kind of have to trust the professionals a lot and you don’t really know them, obviously, but you have to put all your trust in them, just to make these choices about you, because you’re young’.

Melissa, young person

Some young people doubted their ability to make decisions owing to their age and/or position as a patient and believed they were too young to make decisions. They therefore felt that parents or professionals were the ones who should make decisions for them. Melissa, who was 17 years old, described how she did not feel she should make a decision ‘because when you’re under 18 you’re not really allowed to decide, are you?’ She went on to say she had to put her trust in her parents or staff to make choices ‘for you because you’re young’. Melissa described making choices in her life but juxtaposed this to being in the hospital where she did not think she should have choices because she was in a hospital but said ‘if I wasn’t in hospital then I should be able to have a say’. Some young people therefore believed that the staff or their parents should make decisions for them and saw no role for themselves.

Because the psychiatrist said it would be good and I was like, well they’re the professional.

Siobhan, young person

Young people were therefore passive (the often literal and expected role of a patient), as they had no belief or understanding that they should have any
involvement or influence over decisions that affected them. They were subject to the social norms of the doctor/patient relationship and compliance or deference to professional or adult knowledge and roles.

8.2.3 Becoming passive: being disorientated, displaced and restricted

For young people, the constraints of being placed (and therefore displaced) in a new, strange environment cannot be underestimated. The very experience of being in a strange and unfamiliar environment meant they just assumed they had no choice or control and should just go with the flow and do as they were told:

I do think we should have some say but I think sometimes … well, if I was out of hospital and I wasn’t there [in hospital], I think I would have more …

_Melissa, young person_

Being in such a strange environment meant young people were stripped of any points of reference. Everything was new and unknown, meaning they were completely displaced from being able to make any sense of their situation. For some young people, the process of admission and the subsequent loss of control over key aspects of their daily lives meant they learnt to ‘go with the flow’ and follow the explicit or implicit expected ways of being in the unit. They withdrew through uncertainty, disorientation or passive acceptance that this ‘must be the way things are’ and that they should ‘go with the flow’ rather than do anything that might look out of place. However strange the environment, they just wanted to know ‘how to fit in’
and were very conscious that they did not want to be embarrassed or ashamed by doing something out of turn. Therefore, they just went along with what was happening, as they did not know what to do otherwise.

I knew if I properly refused treatment, I'd just get sectioned.  
*Dan, young person*

There were many powerful practices within the units that communicated to young people that they had no role or influence in decision-making. As discussed in Chapter 5, young people described how their being, thoughts, feelings, and inner self, were reduced through observations to staff (mis)interpretations of their behaviour and visible actions. This communicated the power of staff over them and positioned young people as subject to the interpretations of others – the knowers and the known.

How they saw themselves in relation to decision-making was also affected by having little or no choice over their daily lives and use of space. If they could not choose to make a cup of tea when they wanted, or had to ask a member of staff for permission to go to their rooms or to use the toilet, they therefore also assumed they had no influence over decisions about their care or treatment. They felt physically constrained and lacking any form of autonomy, self-determination or freedom of action.

Being able to act, do, and exercise agency is pivotal to human being – who and what we are is emergent from our relations with reality (Archer, 2000).
Human beings are not meanings; they are ‘doings’ (ibid.). Restrictions and constraints on young people’s freedom, movements and daily routines are not just restrictions on actions or movements – they constrain the self. People develop embodied and practical knowledge through their interactions with reality (e.g. environment or interactions with others) and, therefore, the physical constraints on young people within inpatient units taught young people they were passive and powerless.

It made me feel, like, lonely, like no one understood me, no one cared. I felt like all the control was just gone, like it wasn’t in my hands. It was just like some person in an office making the decisions for me. 

Dan, young person

This passivity was reinforced by the many things that just happened – where decisions had been made without them even being informed, let alone involved. Many young people described learning their diagnosis had been changed, or only knowing their medication had been changed when they came to take it and it was different from before:

Just, like, why am I bothering. A lot of the time, like should I really bother even talking to them, because I know it’s up to them anyway.

Melissa, young person

These regular and repeated occurrences just increased young people’s disorientation and distress, and reinforced that others make decisions for them. This disorientation and distance from the decision-making process felt insurmountable. Where decisions were made about them, and changes to their care or treatment just happened without their prior knowledge or involvement, this demonstrated the significant imbalance of power in the
relations between staff and young people. They just followed instructions and deferred to actual or perceived authority:

They were speaking all the time and it felt like you could kind of hear them making decisions about, your life.

Siobhan, young person

Repeated experiences of not feeling heard, of the many restrictions and lack of choice over their daily lives disempowered young people and led some to stop seeing themselves as decision-makers:

Because they … just don’t care anymore because they have been, they’ve been pushed so much. Well they’re pushed they’ve been pushing so much to have some change and when that change don’t happen they … give up … It’s really frustrating because if, if you’ve taken the time and the energy to speak up and to fight your case and then nothing’s done about it, what’s the point, people just lose hope and then it’s like, people just lose hope. Do you know just what I’m saying, it’s, it’s no good.

Asif, young person

After repeated failed attempts of trying to influence decisions or the constant ordering of their space and time taking away control from even the most basic of acts, many withdrew and became passive. As a nurse, Mark, explained:

They don’t feel heard. What it means is they’re more likely to accept … things just going, ‘Yeah, well that’s the way it is. I’m going to have to do it. We’ll just see what happens.’ It could sometimes be frustrating when you’ve seen young people and they’re not interested in these decisions. And you think well what, why is that like? Is it because you’re unwell at the moment or is it because this has been your experience for years in services that, actually, people haven’t gone
through things with you … so you just sort of go along with things now?

Mark, nurse

Either young people felt their expressions were not welcomed and made things worse, or they felt there was no point. For them it was better to withdraw than experience the distress of repeatedly trying and failing. They believed it was either less distressing to be passive, or because they saw no other way.

Young people were epistemically disempowered and experienced or witnessed their own or other young people’s views holding less weight than those of the staff. Thus, they felt it was impossible that their views would be trusted or hold credibility over those of the staff or the system. This, combined with the social norms of complying with adult and professional authority, was silencing. They assumed that if they refused or became distressed, this could result in significant conflict, time off the ward or restraint – turning into a battle of will and values, which they knew they would lose. Consequently, they were resigned to passivity.

The many powerful constraints in the environment and use of space, relationships, and rules and routines of the unit therefore communicated to young people that they did not have a role in decision-making. Whilst several young people spoke of moments where staff tried to listen to them, they still felt unheard or powerless. These moments and the intentions of
staff were therefore overshadowed by the many other powerful messages young people received.

8.3 The importance of deliberating and deciding together – the self as a decision-maker with others

Young people, such as Emily and Darina, saw themselves as decision-makers if they could think, deliberate and decide with others. They did not like feeling as if they were making decisions alone or felt unable to without others. When they talked about decision-making, they spoke of how they valued time, discussion, and deliberation with others.

They particularly valued this when they had had a difficult day and to make sense of it. It was important for them to sit and think together with someone (either young people, staff or family) about what had been difficult, what they had tried, and what they could try next time. This helped them to feel less isolated and more in control. Even just knowing they would have the opportunity to talk to someone they trusted was reassuring.

I talk to my teddy [Eric] […] because nobody else will listen to me (Laughs). Nobody can give you like, advice, but I always find it really helpful when people ask you questions. I find it easier to talk about stuff, and umm, but Eric can’t ask me questions!

Darina, young person

They also valued time with staff they trusted to think together about how to put decisions into practice. For example, they valued time after ward rounds or following changes to their care plans to talk to nursing staff or support
workers about *how* they were going to put this into practice. They particularly valued support to break down actions into smaller, manageable steps; to get encouragement from staff; and to set goals with others to get the reassurance that they were manageable goals:

> Like ... I was trying ... I often set goals which aren’t achievable. And then that makes it not a good thing rather than a really helpful thing.

*Emily, young person*

They placed most importance on thinking, deciding and doing together with others. They therefore saw an important role for other young people, family or staff they trusted in the decision-making process as being alongside them and deciding together.

### 8.3.1 The distress of decision-making – being separated from trusted people

Being separated from the people they trusted, such as friends and family, caused significant distress, as they felt they needed others to feel able to make choices and decisions. This was compounded further if they did not feel there were staff they could trust or by not having time to talk and deliberate with others. Decision-making or the thought of decision-making, therefore, made them feel vulnerable, isolated and distressed if they did not have time to talk and deliberate with people they trusted. This distress was heightened by hollow relationships with staff and not having trust in those around them. Emily talked of the importance of being able to talk with staff and break things down into small goals or steps. She felt reassured and
more able when she could think, talk and plan with others. She and Darina saw time and deliberation as a core source of trust, reassurance and safety. Whilst other young people also valued these, for Emily and Darina, these were features of what they needed to see themselves as being decision-makers.

They found it particularly difficult when staff observed or just sat with them and did not talk or interact, as they saw interaction as support.

Yeah. Because it's supposed to be support. It's not supposed to be sit there, sort of ... And I need quite a lot of support, really.

Emily, young person

They found ward rounds and the resulting decisions particularly difficult as they had limited time to deliberate or they felt outnumbered and unable to speak up. Whilst time and trust were key to their reflexivity and sense of self as a decision-maker, the staff in the ward round were the people with whom they spent the least time, leaving them feeling uncertain or powerless. They described how they would then talk to support workers or other young people they trusted after the ward round; however, these people were also low down in the decision-making hierarchy. They found choice without talk uncertain and distressing.

When talking about decision-making, Emily and Darina described the distress and powerlessness of not having people to talk to:
A lot of [staff] just do it ‘cause they’re getting paid to do it. It doesn’t make you feel like you can talk to them ‘cause sometimes you feel like you’re wasting their time, and that’s not good.

*Darina, young person*

For them, this was more than about not being able to make isolated decisions. This was at the core of what they needed to feel as if they had any agency or control at all and being separated from this was one of the key ways their reflexivity was impeded. This made them feel unsafe, out of control and very vulnerable.

They did not see themselves as lone decision-makers and talked about searching for people to talk to or just closing down and withdrawing. They wanted people to talk to, but these people needed to actively seek them out rather than expect them to speak up or ask for staff time:

“So I think, if they offered to talk more about, and ask you what’s going on, then … Then it would be easier to go to them in the first place, ‘cause if I felt like I could go to them, then I wouldn’t have hit anything.”

*Darina, young person*

They wanted to trust others and know staff, feel known, and be reassured they could think, talk and decide with others.

### 8.3.2 Influencing not deciding

There were also staff who expressed a similar way of seeing themselves in relation to their roles or as decision-makers. Staff, such as Theresa and Catherine, similarly did not see themselves as lone decision-makers. Like
Emily and Darina, they saw talked of the importance of making decisions with others. They saw themselves as ‘doers’, which meant they were there to provide care for young people, rather than as lone decision-makers. They felt most comfortable in seeing their role as implementing the decisions, instructions and guidance of other, usually more senior, staff. They accepted the traditional hierarchy of decision-making and felt reassured that others held the responsibility for making decisions.

When asked what would improve decision-making, these staff described wanting clearer guidance or more specific advice on how to support young people, including, for example, more detailed care plans. They wanted time to reflect with others about how they should undertake their roles and implement decisions about young people’s care. For example, one of the support workers described how helpful she found regular, short meetings with her manager during the shift so she could check in about what she should do and how:

Um, telling us how to do all the things, I think, I think giving some specific examples of how to deal with things … Within the handover and in the care plans it’s, they just say um … such and such needs lots of encouragement to get up in the morning, um, encourage 15 minutes in the sensory room if requested before breakfast. They just say that, it doesn’t really say how to talk to them. But then I don’t know if that is because everybody has got their own methods of doing it or … Yeah, sometimes, sometimes I wish there was more to say about how to go about things, how to talk to people.

Catherine, support worker
Where they did feel they should be involved in decision-making processes, this was primarily to ensure that staff and young people’s views and needs were taken into account in decisions made by others and to ensure the decisions would be possible for them to implement practically within the unit. They distinguished clearly between wanting to influence the decision and being the decider. They felt reassured that others were the decision-makers, particularly where there was risk involved:

It’s quite stressful, actually [making decisions about risk and support]. I think well we’re working with adolescents, they are so, so much more unpredictable. So it, it, it is a massive responsibility. And I, I, I personally would prefer it that the doctor makes that decision [to reduce the level of risk observation]. But as I say, we do have influence, but it’s a, it’s a team influence as opposed to well actually I’m … I think you should take this person off one-to-one. It wouldn’t say that … I wouldn’t take that risk. I would say they have been behaving like this, so we haven’t seen any risky behaviours and then it will be up to the doctor to make the final decision.

Theresa, nurse

As well as clear communication about decisions regarding the care of individual young people, these staff also valued clear rules and boundaries in the unit to give them clear guidance on how to undertake their roles day to day. Where they did have to exercise choice or make decisions within their roles, they wanted to do so within the boundaries of pre-agreed rules. They equated rules and boundaries with safety and reassurance as they enabled them to know what to do, and made them feel as if they were implementing rules rather than making decisions.
8.3.2.1 The distress of uncertainty

Some staff described feeling unsafe and out of control and unsafe without rules or guidance. They felt anxious and uncertain when decisions had not been communicated clearly, meaning they did not know what to do or lacked guidance on how to do it. They felt distressed by uncertainty. Some nurses felt too much choice for young people was unsafe because it created a great deal of uncertainty and their ability to feel safe in their role came from having certainty, rules and guidance.

This was also the case when they did not have the time or opportunity to talk to and seek advice and guidance from colleagues. To feel confident in their work they needed to understand what they should do and how, and have space and time to talk with others. Making isolated decisions left them feeling very anxious:

One-to-one, um if they ask for your services, usually like new admissions if they are unknown, if their mental health really deteriorated and they ask for your help and then you go and do it, I know it is like common sense just like helping somebody but I don’t know it is still feels … It is so like personal, when it is like teenagers, it is not like they are an old person and they literally cannot do anything for themselves, you would know that you are not, you are within those right boundaries.

*Catherine, support worker*

They were therefore critical of poor communication about care plans or decisions. They felt frustrated at being told what to do, or what support young people needed but, without detail, guidance, or time to discuss how they should put it into practice:
Yeah, it does, I wouldn’t want to sit there in a reflection meeting with my manager and some other people and be like, ‘Yeah, I just didn’t know what to say to this patient, I was really struggling,’ ‘cause then I don’t want them to think that I can’t handle what I’m doing. Yeah, because I don’t want people to think that I can’t do my job.

*Catherine, support worker*

When they felt they did not have the guidance they needed they described how they would become avoidant. For example, if they were asked to make changes to young people’s care but they lacked the guidance to do so, they would continue with what they were doing before:

I just kind of, I just get on with it, and try and be involved as little as I can in those tasks.

*Catherine, support worker*

### 8.4 Decision-making and the primacy of the self

Rebecca, Jimena, Louise and Ikeoluwa, felt that they should be involved in decision-making. Core to their sense of self as a decision-maker was that they should be involved as only they knew what most important to them. For them, decision-making could only be right if it included and reflected what was most important to them - their inner self. They felt that only they could know this. Ikeoluwa strongly believed that no one could know young people better than they knew themselves:

So I know what works for me, but then I’ve been told that I have to take this medication and that medication. So I think every young person knows themselves best.

*Ikeoluwa, young person*
This was not about ‘getting their own way’ or just doing what they wanted. They needed to know the decision was strongly informed by or relevant to their values, goals, and concerns.

I don’t know it was quite pointless doing it [care plan], because it didn’t have anything that I thought would be like useful. [I should have been involved] because it would have been… it’s more relevant to me rather than just like a generalised thing.

Louise, young person

They wanted to be able to make choices and decisions for themselves as independently as possible. This did not mean they did not need or value the involvement of others in decision-making about their care and support.

Some spoke of finding it useful when staff could deliberate with them, based on what was important to them and who they were. Young people wanted to be as autonomous as possible, and where the staff were involved in the deliberation and negotiation phase, young people wanted to be the decider.

However, Matt did not see staff as helpful. He appeared to have the strongest sense that only he could know and understand what was right for him. He seemed to doubt that staff could be useful in any sense in knowing him or helping him, and was suspicious and doubtful of their actions. Matt described the efforts of staff to assess him:

They were very interesting but not very helpful, but I learned quite a lot from them. Fortunately I was able pick up what they were trying to do very quickly. They were trying to sit in different poses to see if I’d copy. They would try and put on yawns to see if involuntarily yawn as well. The surveys they give you, you can see very quickly what they’re for… depression, anxiety, anorexia, bipolar – differing ones.
Dependent on your answers they could get a rough idea of what you are. In my case it didn’t really help, because I sort of anticipated what they were going to do next.

*Matt, young person*

Therefore, these young people saw that they should be decision-makers and involved in decision-making because decision-making could only be right if it involved their core concerns, reflected who they were as people, which only they could truly know.

**8.4.1 The distress of decision-making and constraints on the freedom to be, do, and decide**

Whilst Rebecca, Jimena, Louise, and Ikeoluwa saw that they should be involved in decision-making they were deeply frustrated that they were not. Ikeoluwa felt staff decided everything for her because staff thought ‘they know what’s best’. She continued to explain that this made her feel sad.

It’s frustrating because we literally have no freedom here.

*Rebecca, young person*

The absence of freedom to exercise personal autonomy and make choices and decisions was the aspect deeply frustrating and distressing for these young people as it constrained their sense of self. They were very affected by the restrictions on their use of space and personal freedom, as well as not being involved in decisions about their care:

‘Well, this is the best option for you,’ and they [staff] do it when I’ve said no and, um, yeah. There’s not a lot. I don’t feel like really much freedom here, like, you know, you can’t … you know, there’s just so
many rules and … and, like, you can’t … you know. I don’t know, you can’t, can’t walk around the unit; you’ve got to stay in one room. You know, you can’t wear this, you can’t do that, you can’t … it’s just really restricting so you don’t really get much choice.

*Rebecca, young person*

Restrictions on their freedom of movement, to act and be, made them feel out of control, as if their very self was being restricted or denied. If they were excluded from decision-making, they did not trust the validity of those decisions because they had not taken account of whom they were.

Additionally, they found it particularly distressing when they were not believed, or their views about their feelings, situation or care were not taken into account. Jimena was genuinely frustrated that her views on her feelings and difficulties were not enough and needed other evidence to be believed:

> And like I went to Dr [psychiatrist], and I was like, ‘I’m struggling and I need to … I can’t get out of bed and…’ And she was like, ‘Well, I need evidence …’ Shouldn’t my word be enough? Like I’m … Why would I, why would I make up not being able to get out of bed? It’s not fun, it’s not cool …

*Jimena, young person*

The inpatient units were such alien environments. They were separated them from the knowledge, information and means to make decisions for themselves, which left them feeling distressed and out of control.
8.4.2 The distress of reliance on others

Like there’s been times when I’ve actually asked, ‘Can I just discharge myself because this place isn’t helping?’ It’s just silly. They don’t stick to my care plan at all.

Rebecca, young person

Young people also found it challenging to be reliant on others for the provision of care. This frustration was heightened for Rebecca when her care was not being provided as agreed in her care plan:

Like they don’t do enough work with me because I have to do a lot of exposure work for my OCD. Um … they just don’t remember to do it. They … you know, there’s been days where I’m meant to do about seven or more a day and I’ve done three, two or three.

Rebecca, young person

Rebecca’s ultimate concern was to get the help she had agreed in her care plan to enable her to manage her compulsions. She had been involved in developing her care plan but was frustrated at then being reliant on others to implement it. She knew that without her care plan being implemented, she would not be able to ‘get better’ and manage her compulsions. She was frightened about being discharged before she was ready. She was frustrated by the powerlessness of being reliant on others, as this overlooked and denied who she was. She knew what she wanted and needed but was unable to enact this without others:

It feels awful because I just feel so helpless and then they’re just going to discharge me because I’m not ready but they seem to think I am but I’m not. And my whole recovery revolves around that issue, like I’m
scared to try hard, I’m scared to show that I’m improving because they mostly look at the … like if you’re looking happy or not, like they don’t really look at that if you’re looking miserable and you’ll think all happy things and then, ‘Oh yeah, she’s ready,’ and they won’t consider the fact that, ‘Oh, she’s been also down here and there,’ but …  
Rebecca, young person

8.4.3 The separation of doing from caring

For staff, to feel able to do their jobs well, they wanted to understand the rationale for decisions, to determine whether the decision was right, and to give them the knowledge to be able to put this into practice. Like Rebecca, Jimena, Louise, and Ikeoluwa, their core focus on decision-making was on ensuring it reflected the self. Therefore, not being involved in the decision-making process and having to implement the decisions of others was challenging:

I think in hand over, the decision or, what we’re doing now is passed over. But often, the rationale is missed. Because of time constraints and, and if you’ve been out for three days and you’ve come back on shift, it’s just, ‘Okay so that’s what we’re doing now.’ Maybe I don’t have time to ask in hand over, ‘Why are we doing that?’ I think that’s difficult. You haven’t had the chance to understand why we’re doing them. I find […] it quite anxiety provoking as well. I think the nature of shift work, being in and out … affects the rhythm of your work but also affects your relationships with the young people, and it also affects the nitty gritty of, ‘Am I informed enough to be able to like make these decisions?’

Mark, nurse

Staff needed to understand the rationale to be able to feel in control and feel confident in how they cared for young people. Therefore, not feeling as if
they had all of the relevant knowledge, information and rationale to be able to act and make informed decisions compounded these feelings.

They also needed to understand the rationale so they could answer the questions from the young people and talk to them about their care. They were left feeling stupid, embarrassed and letting young people down when they were unable to explain:

I do, I find it a bit uncomfortable when I sit like maybe in this room and I’m trying to explain something to a young person, and like, and I don’t know enough, and that’s why it’s made me go and ask upstairs or whatever more, because I have sat in that before and then you can just tell that they’re like, ‘What are you even saying?’

Patsie, nurse

Being separated from being able to practise in the way they believed they should led staff to feel they were doing rather than caring. They felt conflicted, as they wanted to build good relationships with young people but were concerned they were letting them down, as they were not able to provide the care they believed they should. Not able to do their jobs or not able to do the jobs in the way they hoped led them to feel they were unable to care, which conflicted with how they saw the essence of their role:

And I know one of the new members of staff … is actually a newly qualified nurse that’s come to us straight from qualifying said … oh, she’s kind of over her little honeymoon period, really and sort of going, ‘This is not what I thought it was going to be like. I thought I was going to have time to sit with people and talk to people and do care plans with them and go out and do things and do kind of one-to-one therapeutic work and, you know, I just feel like I’m lucky if I get out at the end of the day and everyone’s alive.’ And I think a lot of people
feel a bit like that. It is ... it is really hard. It is really hard when you
have all of these skills and all these ideas about what you, you know,
you expect the role to be. And in a place like this, you are ... it’s kind
of an acute service where you are [in a] fire-fighting role.
Abbie, senior nurse

8.4.4 Resisting distant decisions

It hasn’t got my view, and it’s just kind of like their 2D view. So it’s like
kind of like flat and just the one thing that they’re focusing on.
Jimena, young person

Rebecca, Jimena, Louise, and Ikeoluwa described resisting decisions when
they were distant and did not appear to take account of their thoughts, values
and concerns. For them, decision-making simply could not be right if it had
not taken account of the inner-self. They therefore saw these processes and
decisions as being partial and described how they would resist, dismiss or
circumvent it.

Though sometimes it can be frustrating, because like being on the
ward so much, we see a lot more of just how they are like day-to-day,
whereas the doctors come down, and they do see them a lot, but it’s
like it is different, so sometimes that can be frustrating that ... 
Patsie, nurse

Nursing and care staff resisted on similar grounds as those with the real
proximate knowledge of the young people, their care, or their role in
providing that care – were not included in the decision-making process).
They felt that only they and those who were proximate to the site of the
decision could know what would work on the ward and what worked for
young people. Consequently, they resisted decision that lacked this knowledge because they *could not* be right or best if they had not involved their proximate knowledge and/or that of the young people concerned.

**8.4.5 Resistance as being and tactical agency**

I just spat it [medication] out because I didn’t want to have it.

*Louise, young person*

Young people resisted as a way of expressing some personal autonomy when everything seemed to be happening around them or to them. They were strategic in their resistance and engaged in small, subtle and hidden acts of resistance. For example, they would go to therapy groups, passively comply with staff requests, or go with the flow and follow the routines of the day, but would then resist subtly by not listening, pretending to listen and to ‘go along with things’ outwardly, but then not do it or ‘switch off’ internally. Louise described how she would go along to therapy sessions but would disengage by not being fully honest or restricting what she shared with her therapist.

*I wasn’t really very honest so… Because I just didn’t really tell her anything…because I didn’t want to.*

*Louise, young person*

They therefore engaged interpersonally but disengaged and resisted intrapersonally. This withdrawal was a form of resistance as this was their only way of expressing any sense of personal autonomy and control. It did not seem important that many of the acts went unnoticed by staff. The acts of
resistance were for themselves primarily. They could not affect or exert
control over their objective circumstances in any meaningful sense, but they
could refuse to engage as a reminder that they were still a person with some,
albeit very minimal, control. However, they were keen not to be seen as
‘difficult’ as they did not want to harm their already fragile autonomy.

Rather than challenge outwardly and risk being seen as difficult or
challenging, young people and staff were more tactical. They knew or had
learnt through experience that being too assertive was misread as being
difficult or their views did not hold the weight of others. They believed that
they were expected to be passive, compliant and do as they were told and
that acting otherwise could be detrimental. They were conscious of their
agency and its limitations and so were strategic in finding ways to navigate
constraints and use enablements. To convey their views they used the
agency and epistemic powers of others.

Jimena used her dad to raise issues with staff in the unit as she felt this was
a better way of getting her views across covertly:

So he like talks to the doctors and like therapists and everything, and I
tell him what he should say and then he does it in a better way …

Jimena, young person

Similarly, young people described talking to nursing and care staff they
trusted, as they felt that if these staff wrote their request in their notes, it
would be more likely to be successful than if they asked directly. They knew
that a request coming from a staff member carried more weight than if they
made the request themselves. Like young people, nursing and care staff also exercised tactical autonomy. Staff who felt lower down in the hierarchy or who had experienced not being heard exercised their agency by using the perceived status of other staff. For example, some support workers described how they knew they would not be believed if they spoke to a doctor directly, so, like the young people, they talked to a nurse they trusted who then spoke to the doctor or other senior staff.

8.5 Decision-making and respect for the self through fair and ethical processes

Asif, Jelena, and Hamza felt they should be involved because it was their right to be. The decision affected their lives and care, and therefore they should be involved. It was not acceptable to them that others decided for them without any involvement or influence. They saw this not only in relation to themselves but also spoke strongly about the rights of all young people to be involved in decision-making. Therefore, they saw themselves in relation to decision-making as it being a fundamental right. They placed most emphasis on the process being fair and ethical rather than the outcome of the decision - the outcome of decision-making just could not be right if the right process was not followed.

Asif, Jelena, and Hamza therefore focused importance on the process and therefore the right to information, to weigh up risks and benefits, as it was
their body these would affect; it was therefore only right that they understood and decided what they were willing to trade off:

If it’s a medication which you need and she’s not really giving you any information about it, or she may have forgotten to give you information about it, it’s really harmful to your health, do you understand what I’m saying? I think that young people should actually have the right to know what the medication is, and how it affects the body.  
*Asif, young person*

They felt that, above all, decision-making should be open, transparent and fair. Young people understood they could not always be the main decider, but felt they should always be involved and that it was crucial to know and understand the options, have information about risks, transparency, understand the rationale, have the opportunity to express their views and know they had been taken into account.

Decision-making was about power, and they equated transparency and information with rights and protection. Asif was very critical about the lack of involvement of himself and other young people in decisions. He felt this was fundamental to rights and protection:

Well, the thing about young people is, if you’re trying to protect them you should tell them what the side effects are, that way they can they know what the side effects are, that way they can go to go and speak to the doctors about the side effects. That, that’s how you’re going to affect, that’s how you’re going to protect them. Because, if for example they start showing symptoms of side effects or something that’s really dangerous, and then err you don’t tell them that it is side effect therefore maybe it’s just, they, maybe it’s just something else and then they start getting these side effects and then you, the only person that truly knows who is having these side effects is the person, young
person themselves. So then they go speak to the doctor, but if you
don’t tell them if you don’t give them that option then you’re put,
basically putting them at risk.
_Arif, young person_

They felt their inner selves and those of other young people were being
disrespected if decision-making did not follow a fair and just process.

Transparency was also key for staff; this equated open, transparent decision-
making with ethical practice:

_I think it’s about how you do it [involve young people]. I think that we
have to be open, and like, I just don’t think that’s ethical, otherwise._
_Saanvi, student nurse_

They saw it as their ethical responsibility to improve young people’s
knowledge of their rights and be open and transparent in decision-making.

They therefore believed that it was not if, but how you involved young people.
They felt it was a professional responsibility to be transparent and honest
because of, not despite, the potential risks or consequences. They felt as if
there were no clear-cut right or wrong answers for the majority of decisions,
and it could only be young people who could decide what risks and benefits
they were willing to accept or trade off:

_If you, you want this young person to ... who’s been admitted to open
up and trust you and be honest, why not be the same?_
_Iain, nurse_

They saw empowering young people through involving them in decisions as
the core purpose of their role and saw themselves as advocates to enable
young people to see themselves as decision-makers and to develop the experience and confidence to do so. They felt that, over time, involving young people in transparent decision-making, discussion and deliberation would enable young people to gradually learn and internalise how to make decisions and a sense of agency as a decision-maker:

Okay. Err it’s, I, I’m not here to make someone else’s decisions for them I’m how, here to help them, umm, achieve what they want to achieve within the capacity that I can.

*Rivka, student nurse*

This was why they did their jobs and, as Rivka described, not involving young people in decisions ‘makes nursing pretty pointless. Umm. Full stop.’ This did not mean that other staff did not believe in young people’s rights, but that for these staff, it was the core feature of their role and of ethical care for young people.

**8.5.1 The distress of decision-making**

For Asif, Jelena, and Hamza involvement was a right and they therefore found it frustrating and disrespectful to them as people when this right was not respected, when decisions were made about them, or when they were not given access to the resources, to enable them to make decisions.

The distress and frustration they experienced was due to not believing the process was right or fair. They spoke with deep frustration at not being involved in decision-making and of not being heard, as it was, to them, their
fundamental right. They particularly highlighted how wrong it was that they were not involved, due to assumptions about their age or mental health:

And I think that’s, that’s, that’s one characteristic of young people is that, sometimes, they do get belittled and they don’t really get, umm, the attention they deserve, sometimes. Because they are still considered to be young people, and some of the stuff they might think … are considered to be insignificant sometimes. But, I think that’s, that’s, that’s quite wrong, actually and that, sometimes, young people can say things that are proper and only someone who’s there to listen and actually … like will actually know what they’re saying.

Hamza, young person

Asif described being sectioned for refusing to take medication. He described how his diagnosis had been changed from depression to psychosis and they were changing his medication to treat psychosis. He had wanted to know why his diagnosis had changed and what the side effects of the medication were. He said he asked doctors why his medication and diagnosis had changed and was told he was showing signs of psychosis. He said he had asked them to tell him what these signs were, but did not feel he was given a satisfactory answer.

Asif saw it as his right to question the decision about his changed diagnosis and the medication he had been prescribed as a result. He said he accepted he needed treatment, but that he wanted to try other approaches, such as talking therapy, before medication. He described how his refusal was seen as an inability to make an informed choice and proof of incapacity. He
therefore felt that he was not refusing treatment – he was refusing to take medication:

Just because I was closed off to the medication they couldn’t help me with talking therapy or something like that.

_Asif, young person_

He described repeatedly asking for, but not receiving, information about why his diagnoses had changed and also asked for information about the side effects of the medication. When he got the information, he said it was for the wrong medication:

They haven’t given me any examples, and all the examples they gave me were either vague or not to the point where I understood, do you understand what I’m saying?

_Asif, young person_

It is not possible to comment on whether or not Asif did indeed have capacity or not to be the main decider. However, what is important is that to him, and other young people, this was almost irrelevant – he was frustrated because he believed he had not been involved and it was his right to know and understand his diagnosis. To him, the process was unfair and violated his rights, which was the primary reason he was distressed and frustrated. He had been disrespected by an unfair process:

It made me feel quite frustrated because if it’s up to the point where I don’t understand, I normally understand quite a lot of things, and if it’s up to the point where I don’t understand, then there’s, then obviously there must be something wrong with it, do you understand what I’m saying?

_Asif, young person_
Their distress and frustration were grounded in their rights, and therefore their dignity as people, not being respected. Regardless of whether or not Asif had the capacity to make an informed decision, he felt that he and other young people should be involved in decision-making and be given information in order for the process to be transparent, and for them to be able to understand the risks and benefits of potential options. They were left feeling anger towards the process, rather than the outcome. They were frustrated by the injustice of not being involved in decisions, which made them feel undermined, devalued, and angry for themselves and for others.

The frustrations of nurses and support workers centred on being prevented from practising in a way they believed was right. They wanted to involve young people in decisions as for them, this was core to ethical practice and they were therefore deeply frustrated when they could see decisions being made about young people. Rivka, a student nurse, was very conscious of the power imbalances in the unit and questioned whether SDM was even possible in a system designed to make young people do what the system wants them to do.

8.5.2 Resistance and rights
Asif, Jelena, and Hamza exercised resistance because decision-making processes were perceived to be unfair and therefore their rights were not being respected. Their resistance was direct and visible, and on the basis of what they saw as a breach of their right or those of others. Young people
would outwardly express their frustration to the staff, ask for information or criticise the decision-making process.

These young people challenged openly, despite knowing this may further harm their chances of being involved in decision-making. Jelena, in particular, was seen as challenging and outspoken. She was regularly in conflict with staff where she confronted them on what was unfair for her and other young people, but was seen by some to be angry or difficult.

As Hamza describes, he was striving to learn more, to enable him to change the system:

Information, information. Information. Information of the place I'm in now. Umm, I think it's mostly information. A lot more transparency in what goes on. I think if it was there, it would be a lot more empowering. So it's just, generally, I think information, it's really important. Information of how the system works and stuff like that is really important because, then, you understand where things can go wrong. And then you can actually make an initiative then and actually try and project your voice in trying to fix that, that wrong, basically. Umm, umm, no, not really. I don't think there is much … because confidence will just come after, after you know your stuff. Once you know your stuff, I think, it's … it's sort of easy after that. You, you can … you know what to say then and your say would have more an effect then, because it will maybe of substance.

*Hamza, young person*

Both staff and young people described resisting on the grounds of having a lack of rationale for why decisions had been made. They needed to understand because it was their right, but also because this knowledge
enables them to determine if the right process had been followed and, therefore, whether it was a good decision.

Young people felt decisions were meaningless if they did not understand the rationale. They saw it as their right to understand the reasoning and would, therefore, resist or refuse:

Yeah, you can't do nothing like they're just restricting you on everything. It’s not even like they’re trying to get you out of one bad habit and try to controlling like control you to put you in like a different state of mind; it’s just they’re just controlling you for no reason, and it’s just a bit ridiculous.

*Jelena, young person*

Staff similarly described examples of resisting because they did not understand the rationale. For them, a lack of rationale made them feel unable to practice ethically, because they needed to understand, not just be expected to do:

Short … Short and sharp, it’s, this is what you need to do, no reason for it, no rationale, no evidence, no nothing, it’s … this is what you’re here to do, this is what you’re doing. It’s all about behaviour, what we have to … behaviours we stop and start, that’s all, there’s no theory behind it or understanding of why we’re stopping that.

*Jess, support worker*

They described significant self-reflection about what was right and gained confidence in *how* they had reached a decision. They needed to be able to justify why they had acted in the way they had:

I tell everyone that I've got … what I do is before I make any decision – it sounds really weird – what I do is actually I picture myself … if it's a
diff... difficult decision and I know it's positive risk-taking that's called for, I know that potentially, there's, there's risks associated with the decision, I always picture myself in court answering to a judge. So the judge says to me, ‘Right, can you explain this decision?’ If I can say, ‘No, I'll hold my hands up, the decision was wrong but the reasons as to why I chose the decision was in the best interest of the young person’ then there’s nothing... I can't get into trouble for that.

Iain, nurse

Iain experienced a situation where he was criticised for his decision-making about a young woman’s care:

I suppose an example that comes to mind was we had somebody who had an eating disorder and she was refusing to come out of her room in the mornings to have breakfast. I felt as though it wasn't necessary to actually restrain the patient to get her out to the breakfast, which has happened previously. I just didn’t think it was beneficial for the relationship between us. One day, I left her to sleep in the morning and on the Monday I was questioned as to why I did that. I was told that I should have restrained her and taken her out. And I was like, ‘Well, if you could put that in her care plan,’ because it wasn't in her care plan, ‘if you can inform the parents and let them know that this, this is what we're going to be doing, you've made that decision but I'm not happy to put my hands on a 16-year-old, drag her out of her room to breakfast. It's not beneficial for anyone.' So that was, I had a bit of a disagreement and I just got really angry.

Iain, nurse

For Iain, a man restraining a young woman was just not justifiable. He reflected that she was young, and physically weak, but also perhaps not refusing to eat or engage in treatment, but just a teenager who wanted to sleep late. Despite being severely criticised by more senior staff, he felt the way he had reached the decision was right and that he had acted in an ethical, and therefore justifiable, way.
Saanvi, a student nurse, challenged a psychiatrist and a senior nurse who did not want to tell a young man about the side effects of the medication and prolactin. Prolactin can cause males to grow breast tissue. Her primary reason for rejecting this was that it was not right or ethical to withhold information from him about the side effects. She felt strongly that even if he did refuse to take medication, it was his right to know the risk and to refuse. To her, the risk to him of being excluded from the discussion, not knowing the side effects and then suddenly growing breast tissue without understanding why was far more significant. She was frustrated as the refusal to share information with him was to coerce him into agreeing to take the medication and to prevent him from refusing. To her, the role of professionals was to be transparent and accept that young people will not always do what others believe is best:

I think it’s important for them to be aware of the pros and cons of anything, really … [starting taking medication] And then one day he finds that he’s got these boobs, ‘Where have they come from? What’s that?’ You know? Whereas, for him to have these pros and cons, it gives him a bit more control, a bit more empowerment. And he knows why he’s made that decision …

*Saanvi, student nurse*

She challenged this, as she believed it was his right and that not sharing the information with him was more about adults retaining control:

Well, I guess this is it, it’s about the risk and it’s about, you know, kind of, do we want to give them…? I think it’s very interesting. Because I think, do we want to give them all the information? Because we’re scared, really, about them having all the information, and then we’re
not able to kind of, you know, we’re not able to … we have no control, then do we? Because, if they have it all, they might not … especially with someone that isn’t complying, and they might not comply and there’s nothing we can do about it. Not me, but I think that there’s a very interesting dynamic about why we might not, umm, and it’s whether, you know, it’s about, kind of … to give us a little bit more of an edge, or not.

_Saanvi, student nurse_

### 8.6 Summary – displaced and disconnected from the means to make decisions

We are at the same time free and constrained, and have some awareness of it as reflexive human and social beings (Archer, 1995, p. 2)

Young people and staff saw themselves in differing ways in relation to decision-making. The powerful constraints on young people’s bodies and inner selves from being in the unit, as well as being separated from known people and places affected their sense of self as a decision-maker. They did not know that they could or even should be involved in decisions and were disconnected from the means to make decisions. They perceived that they were making decisions with the setting in its entirety, with its powerful systems and structures, not just with individual staff, and therefore felt overwhelmed and powerless. They could not see how they could have any influence on what was happening around them. Their self-image was one of passivity and powerlessness, and they were resigned to not being involved in
decisions or discussions that affected them, in the face of the many constraints of their environment.

Reflexivity is fractured when the process of concerns ➔ projects ➔ practices is disrupted by external assaults upon a person’s ultimate concerns (Archer, 2003). Whilst human agency is ontologically inviolable and core to being human, reflexivity, and people’s personal and social identities are epistemologically vulnerable (Archer, 2000). Fricker (2007) describes situated hermeneutical inequality where there is dissonance between how a person sees the self in relation to their context and which can lead to epistemic harm. People’s sense of self as decision-makers is therefore affected by what others see and think of them as this affects their self-image (Flam, 2010). Young people were separated from the means to know how to act, be, or influence decisions. Some felt they could only agree and passively accept what was happening around them. They could not make sense of their own experiences, due to a position of disempowerment by being excluded from meaning making practices and decisions about the care, being displaced or disorientated, and through the overwhelming constraints on their bodies and freedoms. Hermeneutical inequality occurs when a person is unable to make sense of their own situation (Fricker, 2007) and this, along with the constraints and restrictions on young people’s bodies, privacy, freedoms, and autonomy therefore fractured their reflexivity and agency.
How young people saw themselves as decision-makers was therefore relative, changing, and influenced not only by how others saw them, but also by the constraints at the levels of the natural, practical, and social. It was not just that young people were prevented from doing the things that they wanted to; harm was done to their identity as a moral being. It was their self that was constrained, not just their actions.

Agency and self-determination are the core of who we are as humans (Bhaskar, 1998). Both young people and staff faced significant restrictions and constraints on their agency and freedom to be and to act. For some young people, these constraints and harms to their moral identities were so overwhelming that their reflexivity was fractured and consequently their ability to act or feel any sense of control over their bodies and selves.

Understanding how young people’s reflexivity becomes fractured is important for several reasons. Firstly, it is important to avoid a reductionist account of young people’s lack of agency and reflexivity being due to age, mental health problems or both. Secondly, it is important to avoid assumptions that staff merely did not bother or try hard enough to involve young people in decision-making. Several staff spoke of the desire to involve young people in decision-making, but were constrained and prevented from engaging with young people in the way they wanted to. This was also therefore difficult and frustrating for the staff who were trying to involve young people in decisions. Finally, it is critical to understand that the displacement of young people from surroundings and people they knew and trusted, along with the many
constraints on their bodies, use of space, and daily freedoms, had a significant impact on how they saw themselves as powerless and passive.

It is also critical to recognise that whilst other young people saw that they should be involved in decision-making, few felt able to have any influence. They felt frustrated and distressed at not being involved for differing reasons dependent on how they saw themselves in relation to decision-making. It is therefore important to recognise the differing ways young people saw themselves as decision-makers and what they placed the most importance on. This should enable us to more fully understand the differing ways they could be involved in decision-making.

Some young people saw themselves as decision-makers in relation to others. They most valued space and time to talk and deliberate and decide with others. They found isolated decision-making difficult or distressing and therefore needed to make decisions with other people who they trusted.

For other young people, decision-making could only be right if it reflected their inner self. They needed to have their knowledge of themselves respected and at the fore of decision-making, as only they could know what was right or best for them. Decisions made about them were rejected and resisted, as, in their eyes, if decisions did not take account of their knowledge or involve people with proximate knowledge of them, then the decision could not be right. The self, the outcome, and being the main decider were therefore the most important.
Finally, for other young people the most important aspect of decision-making and was a fair and just process. It was the process of decision-making that was pivotal to whether they regarded it as a ‘good’ decision. The process needed to be fair and respect their and others’ rights. In their eyes, decisions could not be right if the process was not fair or ethical.

Our emotions are a reaction to physical, practical and discursive order – and the physical, the performative, or self-worth (Archer, 2000). Therefore resistance, distress, or passivity may be reasoned responses to the significant constraints on young people’s ability to be and do. Resistance or passivity should be seen as visible signs and valid communications of a breach of their freedom and self-determination, an alienation of their autonomy, and a way reclaiming some sense of being a person.
Chapter 9. Conclusions

SDM means bringing the knowledge, values and expertise of young people into decision-making processes, alongside professional knowledge and evidence. This, therefore, requires that the person and their testimony – their inner self – is heard, involved and influential. However, these are the very things that are constrained or denied in many ways within the material environment, systems and routines in inpatient units.

This study has shown how shared decision-making was significantly undermined and constrained in inpatient units by the dominance of psychiatric positivism and risk.

Firstly, most of the young people felt they had no real choice about being admitted to the units and were admitted primarily on the concerns of others about the risks they posed rather than through an expectation of therapy or improved mental health. Those who did agree to being admitted did so through a last resort based on an expectation of intensive therapy – yet were deeply let down when their expectations were not met. The inner selves of young people in mental health institutions were constrained through being removed from known people and places, and placed into new, unknown and unfamiliar environment, with strange people, routines and restrictions. They were separated from people they knew and trusted, and were therefore separated from the support, care and advocacy of parents, family and friends. This added to their distress and uncertainty. This displacement meant they were unable to know how to be, act or do. Their inner selves were further constrained through body-environment relations and the many restrictions on their use of space and usual freedoms.
This was deepened when their inner thoughts and feelings (being) were reduced to (mis)interpretations of staff through observations (knowing). The inpatient units were dominated by the management of risk, and practices and processes designed to monitor and observe decontextualized actions and behaviours, and to assess the risks young people were deemed to pose or potentially pose. This privileged distant processes over those which supported time and trust and affected how young people could know and trust and be trusted and known, which resulted in their testimony being doubted and their credibility undermined. This was in strong contradiction to the things young people (and many of the staff) valued and hoped for, such as time, trust and normal human interactions. time and deliberation to enable them to feel known, heard, trusted and trusting.

This caused deep contradictions between young people's expressed needs and their needs as determined by others. Inpatient admissions were a reactive, individualised response of containment, observation and risk management, rather than therapy or improvement of mental health or addressing real, multifactorial causes of distress, troubled or troubling behaviour which led to their admittance into the units. These contradictions deeply undermined trust and any form of choice or control for young people, which significantly undermined shared decision-making. Young people could not make engage in decision-making or make informed decisions when reductionist, psychiatric diagnoses reduced their complex past into symptoms and did not account for their views, thoughts and expressions of their experiences, in favour of privileging observations of professionals. Similarly, their understandable frustrations and expressions of frustration in reaction to the constraints were medicalised.
decontextualizing their expressions of distress caused by being in the unit. Young people experienced deeply unequal power relations which meant they had no opportunity to counter the power of others over them. These constraints in turn taught young people, through their bodies and interactions, that they either could not or should not be decision-makers. Others expressed resistance as a way of reclaiming the self or as an exercise of moral agency.

Within this study, I have drawn on an original combination of philosophical and sociological theories in the planning, design, data collection and analysis. I used a number of concepts from critical realism and employed the four-planar social being to structure my analysis, which enabled me to identify constraints on decision-making, spanning the planes of being and body-environment relations; knowing, doing and interpersonal relationships; systems and structures; and inner being and reflexivity. This enabled me to contextualise decision-making and understand some of the factors constraining young people’s involvement in decision-making, and staff’s efforts to involve them.

Just describing all the factors I had identified in this study could have appeared as a number of disparate or disconnected events. Yet, when I examined the underlying causes and reasons, strong themes and connections emerged throughout the chapters to show how young people, staff and decision-making are constrained. What is clear is that SDM – and whether young people feel heard, listened to and able to influence decisions – does not rest just on isolated decision points or the actions of individual staff. Young people are in a relationship with, and therefore
make decisions in relation to, their whole environment. They feel heard or unheard not just in moments of decision-making, but through the restrictions on their bodies, actions and interactions at each level of the physical, interpersonal, systems, and inner being. Great change is therefore needed at all levels to enhance young people’s freedoms, autonomy and choice.

The following sections firstly explore the limitations of this study. The concluding sections then suggest the need for a broader conception of epistemic injustice to understand how young people can be denied in their capacity as knowers through constraints at each level of the four-planar social being. They highlight a new contribution to the understanding of the differing ways young people exercise reflexivity, see themselves as decision-makers and what they therefore regard as most important within decision-making processes. This includes understanding the differing ways young people are negotiating constraints, exercising agency, and reclaiming the self, and exercising moral agency through resistance.

The conclusion then explores the importance of deliberation as being more than conversation, but also as a means of respecting the ontology of the self and trust. Finally, it offers additional elements to be considered in the concept of SDM.

9.1 Strength and Limitations
A limitation of this study was undertaking the research in only two services. Whilst the research has identified some of the underlying, unseen constraints on decision-making, these will not be exhaustive and cannot claim to be fully representative of all
inpatient services. However, as the research aimed to understand the underlying constraints and influences rather than just describe experiences, it will provide a good foundation to explore if and how these (and other) constraints exist in other services.

Within this study, I decided to focus on exploring the experiences of young people (who are so seldom heard) and staff in inpatient units. I did not, therefore interview parents or carers who can be important advocates for young people. I decided not to also include parents owing to the limitations on my capacity undertaking the study part-time. However, the experiences of parents, how involved they feel in decisions about their child’s care, along with how their views and knowledge are valued or devalued, are important topics for further research I hope to undertake.

As discussed in the methodology (section 3.6.5), one of the limitations of this study was that I did not observe ward rounds or make other formal observations. This was partly due to the sensitivity of balancing relationships with the staff, but also because the young people described how overwhelmed and outnumbered they felt in these meetings or how they constantly felt observed rather than heard and believed. As also shown earlier, in section 3.2.2, the position of this research is that decision-making is not an isolated event. So, given the sensitive dynamics of balancing trust with both young people and staff, and owing to young people and staff’s remarkably consistent accounts of their experiences of ward rounds and of the issues that constrained decision-making within the units, I decided not to pursue formal observations. I wanted to respond clearly and adapt my practice to what I was hearing from young people and to place primacy on hearing their voices, rather than
risk their seeing me as needing to ‘validate’ their expressions by seeing things for
myself. The strength, therefore, was that I established trust, meaning the interviews
were more fruitful and participants were perhaps more open and frank than they
might otherwise have been.

I see this study as the beginning of further research and public engagement, in order
to seek to make changes to experience, practice and policy. If observations are used
in future studies, I will be able to use the findings from this research to demonstrate
my aims and intentions of what observations are for. I will also be able to use
collaborative approaches to illustrate that I aim to observe and make shared
meaning with young people and staff, rather than of them. A key strength was
therefore understanding the context because of my professional experience, as this
helped me to be thoughtful and sensitive in the execution of this research, as well as
insightful into how the findings might be useful to young people, practitioners and
policy makers.

The following sections explore how the findings from this research can support and
enhance our understanding of SDM, and how to engage young people more
meaningfully in decisions about their care.

9.2 The absence of the self

As has been shown, at each level there were constraints on, or an absence of,
young people’s inner selves and being – the very things that were so important for
SDM. The structures and systems in the wards, and the prescribed regimes based
on psychiatric positivism were counterproductive in how they overlooked or constrained the social and relational aspects of being, care, relationships, meaning-making, and decision-making.

Whilst it may seem odd, for example, to explore body-environment relations when researching decision-making, this thesis has showed how constraining young people’s bodies, significantly restricted their agency and very being. Young people were physically dislocated from known people and places. They were in unknown environments, with people they did not know and subject to processes, rules and routines, which were strange and unfamiliar. They were physically restricted in their use of space and in the day-to-day choices that most teenagers (or people of most ages) take for granted. This restricted not only their privacy and physical bodies but also their autonomy and personhood. These constraints on their autonomy told them, through their bodies, that they had little, or no, choice or control. They were displaced and uncertain how to act or be, let alone how to influence anything that happened around them.

The self was further denied through observations, which privileged observations of bodies and behaviours over the views and internal worlds of young people. Their real being and private inner self were reduced to other people’s perceptions. Observations and restrictive physical practices not only constrained movements and bodies, but also restricted the self. These restrictions communicated to young people that they had little or no role, or power, in giving knowledge or in decision-making.
These constraints on the self and the primacy of the biological over the social were evident and played out in relationships between young people and staff (see Chapter 5 *Knowing and Doing: Distant Decisions*). Whilst young people (and most staff) valued time and talk to know and trust staff, and to feel trusted and known (all of which were vital for being and feeling heard and involved), this was undermined in many ways. The young people were distant from decision-makers and decision-making. The knowledge of staff had an epistemic privilege and young people’s knowledge and testimony was either absent, was conveyed through staff observations and interpretations or subject to credibility deficit (as were young people themselves), owing to prejudice, doubt or mistrust.

Young people were distant and often excluded from meaning-making which prevented them from making meaning. It prevented them from knowing and trusting, and being trusted and known. Absence of involvement in decision-making (through actual lack of presence, lack of power or lack of epistemic trust) is an absence of the self and undermines young people’s moral agency, autonomy and identity as decision-makers.

These constraints were not due to the isolated actions or lack of care by the staff (as shown in Chapter 6) – they were framed and constrained by mistrusting, distant and depersonalised processes and systems. This was, in part, caused or exacerbated by a lack of resources and staffing. Staff were prevented from spending time with young people in the ways they wanted. Mistrust, inscribed in systems and processes, privileged distant, cool processes, rules and the routines and running of the ward, over choice, time, trust and autonomy. The system therefore prioritised the
observation and care of the person as an object of care, over time, trust and meaning with the person, as a knowing agent. Systems also gave professionals and inpatient services significant power over young people and their time, use of space, routines, information, decisions and freedoms. Therefore, there was a significant asymmetry of power invested in services and professionals over that invested in young people.

These constraints on, and absence of, young people’s bodies and selves affected their reflexivity and agency and sent strong messages to young people, leading them to believe they could not or should not be involved in decision-making. They came to be people to whom things happened. Others were disempowered because they were separated from the means to make decisions and they became distressed, frustrated or resistant. As shown in Chapter 8, and explored further later in this chapter, whilst young people exercised differing ways of seeing themselves in relation to decision-making, there was a common theme. Doing is core to being a person and our ultimate concerns are a reflection of who we are, of the self (Archer, 2000; 2003). When autonomy is constrained, the self is absent from important discussions and meaning-making activities, or things are done to us, and this causes epistemic harm to the moral worth of young people as knowers, decision-makers, and as people.

9.3 Reflexivity and the self as a decision-maker

As shown in Chapter 8, young people reacted in varying ways to the many constraints on decision-making and on being a decision-maker. They exercised reflexivity in different ways which reflected how they saw themselves as people in
relation to decision-making, and which aspects of decision-making were therefore most important to them. For some young people, the many constraints on the self fractured their reflexivity. This resigned them to passivity, because they believed they should not be involved in decision-making.

It is important to recognise the different modes of reflexivity young people exercise. As described earlier (see Section 3.2.3), understanding how structure and agency interact is vital, because to focus only on one or the other would be to constrain (Archer, 2000). For example, to show only the constraints would be deterministic, as this would assume that young people or staff were solely influenced by social powers and not able to exercise agency. Similarly, to focus only on agency would reduce decision-making to individuals’ actions. A lack of involvement or influence may be reduced to the lack of ability of young people or the lack of effort of staff, rather than due to the social powers of their circumstances. Exploring reflexivity (see Chapter 8) importantly showed how systems, interactions, processes and places in inpatient units constrained the agency of young people and staff, but critically also showed how they navigated these and expressed or exercised agency even in very constrained circumstances.

Whilst the agency or ability of some young people was fractured, others found ways to navigate or challenge these constraints. Understanding the four ways (although there may be more yet to identify) young people understood the self in relation to decision-making is critical in developing a more nuanced understanding of how young people navigate constraints on their agency, autonomy and decision-making. This also offers new ways of understanding which aspects of decision-making young
people valued the most owing to how they saw themselves as decision-makers. This was more than mere preferences – it reflected who they were as people.

Furthermore, understanding reflexivity offers ways of understanding distress and resistance. Young people talked of resistance not as a frivolous act, but as a reaction to their autonomy and inner being was being denied or constrained. Distress and resistance can be seen (amongst other things) as a sign of constraints on the moral agency and autonomy of young people. Normal, self-preserving resistance to oppression is often taken to be irrational and a sign of illness, reinforcing professional assumptions of inability or incompetence. However, resistance can be a response to the self being denied or constrained through a lack of autonomy, lack of understanding, or of involvement in important decisions and discussions. Understandings of resistance therefore need to include that it can be an expression of moral agency as a way reclaiming the self or of resisting wrongs.

9.4 Bringing the self in: talk, dignity and trust

As shown in the previous section, it is important to recognise that young people exercise differing forms of reflexivity and placed stronger value on differing aspects of decision-making. The common theme from the ways young people exercised reflexivity and saw themselves as decision-makers, was the importance of time, talk and deliberation in order to be known by others, to trust and to be trusted.

When young people talked about the importance of SDM, they talked of being heard, being listened to. The emphasis here, perhaps, is on being – the core theme that
emerged throughout each chapter was young people’s *being* and the absence, denial or constraints of the *self*. Young people valued being heard and being involved in choices and decisions about not only their treatment, but of their bodies, use of space and interactions. This was critical given their removal and displacement from places and people they knew and trusted, and subject to disorienting and restrictive people, places and practices. This was not merely in order to get the outcome they wanted, but because it conveyed that they were a person who was seen, valued and trusted by others. They craved familiarity and control, to feel like a person.

A common theme for all young people was the importance of thinking, talking and deliberating with people they trusted and who trusted them. This is not to say the outcomes of decisions were unimportant, but deliberation (thinking together) signified they were known and trusted; could know and trust others; and could trust in the process of decision-making. Deliberation was core to trust, which allowed young people to be known, and to trust that others knew them as people. Thus, deliberation was a vital practice to validate and respect the self. Deliberation and negotiation are crucial as they form trust, and show respect for young people’s being and moral worth as ‘only via this process can one empathically discern the inner life’ of another person (Wiesemann, 2016, p. 3209).

Being listened to and involved means more than the act of hearing words; it is ontological in recognising and respecting the dignity of the self. As shown, excluding young people from important discussions and decisions about them harms their moral agency, reflexivity and identity as decision-makers. Involving young people is
therefore imperative. If a key element of SDM is bringing the knowledge and values of a person into decision-making, then a central component of this needs to be building the trust (Sutcliffe, 2010; Wiesemann, 2016), confidence and self-identity of young people to see themselves as knowers and decision-makers. A key focus for SDM must, therefore, be to encourage young people through deliberation, thinking together, to build trust in the self and others. Being heard, deliberating, and shaping the decisions that affect us is core to who we are as moral beings.

Furthermore, dignity is a real (ontological) defining feature of being a person, not an added extra or social construction (Smith, 2010). It signals the inherent worth of people and the ‘ontology of personhood makes it morally true that persons are creatures worthy of being treated with respect’ (ibid. p.435). Concerns reflect the self (Archer, 2000) and seeking these concerns and deliberating with young people respects their moral worth and dignity. This reinforces the need to understand the different stages of decision-making of deliberating, deciding, and doing. Decision-making is not just about reaching the outcome. The process is just as, if not more so, important (Entwistle and Watt, 2006; Montori, Gafni and Charles, 2006). As a bare minimum, all young people should be given the opportunity to be involved in decision-making and deliberation.

Decision-making is not a technical process devoid of emotion (Alderson, 1993; Archer, 2000; Archer, 2003; Entwistle and Watt, 2006). Perhaps if people did make decisions wholly technically (where weighing up information free from emotion determines the best outcome), then people would be happier to hand this weighty task to others, yet they are not. Emotions and the self are central to reasoned,
shared decision-making. Young people and their inner selves and concerns, are what determined and guided decision-making. How they saw themselves as decision-makers guided which aspects of decision-making were most important to them – because of how they saw this as valuing, validating and respecting (or not) who they were as people. The self is the beginning of, and central to, deliberating and deciding. Young people talked of the importance not just for the outcome, but also for the recognition of who they were. Deliberation and deciding start with who we are and what is most important to us.

It is therefore vital to recognise how unique each person is. This is even more important in decisions related to someone’s experience of mental distress. As discussed earlier (see Section 2.5.1), the causes of mental distress are multifactorial (Pilgrim, 2015) and it is therefore critical to understand from the person her/himself about their experiences, understanding and meaning. Each person contains universal and unique aspects (concrete universal and concrete singular) (Bhaskar, Danermark and Price, 2018). Take, for example, a young woman experiencing distress:

1. She will be universal. By virtue of experiencing distress, she will share universal characteristics with other people experiencing distressing compulsions and with other women. She will also share universal features in how she exercises reflexivity with other people.

2. Each young woman experiencing distress is also a mediated person. She will have specificities (mediations) meaning that she will share some but not all characteristics with other people experiencing compulsions. She will equally
share some, but not all, ways in which she sees herself in relation to the constraints around her and in how she sees herself as a decision-maker.

3. Each person has a geo-historical trajectory – we are all born in different places and times, which shape who we are and our trajectories. Every young woman will have had different experiences, influences and events, which have shaped who they are and their experiences of distress. They will also see themselves differently in relation to decision-making and react in different ways to the constraints of their material circumstances.

4. Thus, each person is also a unique individual (concrete individual). Even those with exactly the same diagnostic label, age, gender, faith, and place will still be individuals with irreducible uniqueness. The causes of their distress, their understanding of it, and relationship with it, and their beliefs and attitudes about help, their subjective agency and how they see themselves as decision-makers will all be uniquely different.

It is this irreducible uniqueness of people and their core concerns and inner being that must be sought and respected. 'Rational' possibilities do not take account of the mediated, singular young person – of their circumstances or experiences which have shaped their experience of distress, or of their values about help and support. Therefore, whilst there may be many reasonable, universal options for help and support (possibilities), which will be most important for individual young people cannot be determined by others without involving young people themselves. If they are choosing an option (particularly those not preferred by adults), this does not necessarily mean they are being foolish, immature or unreasonable. What will work for one will not be right for another and it is crucial to understand that preference for
an option is more than a whim to be overridden. They are a core sense and reflection of the self.

9.5 Shared decision-making as stratified
As has been shown, the constraints on decision-making span all four levels of the four-planar social being, meaning it is crucial to have a broad, situated concept of SDM, which sees it as a complex, stratified social event.

Decision-making is not a technical series of isolated events, actions or concepts. SDM is an event, a process, and a series of practices and interactions in its enactment. To reduce SDM to an event obscures the many factors that influence and constrain decision-making and overlooks the vital importance of deliberation to develop trust, shared meaning-making and showing respect for the dignity of the self. To reduce SDM to a process of deliberation overlooks the actual decision and who wields the power to make the decision. It is therefore important for SDM to recognise the importance of the process of decision-making and event of signifying the decision. Similarly, attention should be paid to how decisions are enacted and how young people can shape, influence, and review decisions in their implementation and effects.

Young people also had a broader understanding of the range of decisions. SDM should incorporate more than narrow treatment decisions on medication or type of therapy, for example. As young people in inpatient units experience the whole environment, it is important to understand the importance of a wider range of choices
and decisions (as outlined in Section 6.3.4.2). The ones which were the most important or keenly felt were the ones which were the most proximate to the young people’s daily experiences – decisions about their use of space, ordinary freedoms of daily living, negotiations about living as a group, reflections on distressing experiences or situations, or the enactment of decisions and practices of support. They also wanted a shared understanding of the aims or goals of their support and an understanding of how they could get there. 

SDM is also temporal in two senses. Decision-making is influenced by experiences of the past (for example, of young people feeling previously unheard and consequently assuming they have no influence) or anticipation of the future (for example, anticipating the possible risks of the outcome of the decision). Furthermore, it has a temporal element in relation to ‘about when’ the decision is being made. For example, SDM is often discussed as future oriented – as focusing on making a decision yet to come (e.g. which medication). However, young people talked of a broader understanding. This included reflection on past actions or experiences to weigh up what had happened, what other possibilities there could have been and using this to inform their future actions or support. There were also decisions that were more future oriented – about aims or goals of support, or of planning what they would want to happen if certain situations arose. 

SDM should therefore be situated in the planes of the physical, interpersonal, systems and subjective agency, as outlined in Table 9 below, which summarises the key enablements and constraints to consider at each level. 

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Furthermore, SDM needs to include the following domains:

- **The self**: SDM should start from, be guided by, and continually refer back to what is most important to young people, their inner carings and ultimate concerns.
- **About what**: a broad range of choices and decisions (more than narrow decisions about medication or ‘treatment’) as outlined.
- **About when**: an understanding of the temporal focus of the decision being made, and influences from past experiences and anticipation of future possibilities (or risk).
• How: understanding the differing ways young people see themselves in relation to SDM and which aspects of SDM they regard as most important.

• Deliberation: deliberation as a core minimum, and recognition of the primacy of deliberation as respecting the ontology of the self, developing trust, and shared meaning-making. This should include a clear focus on the epistemic privilege of each actor involved in decision-making to give greater weight to the views and expertise of young people.

• Deciding: clarity about power and influence in making the decision. As much influence as possible should go to young people, depending on their preferences and mode of reflexivity.

• Doing: influencing how the decision will be enacted, reflecting on the experience of this, and refining future practices.

Young people should know and be helped to understand as far as possible what decisions are being made, why, and how much influence they have. This should be supported by visible tools and processes to develop shared meaning, deliberation, deciding, and enacting decisions. These visible, tangible practices should communicate the intention to hear, listen and involve using more than words. The practices should be more explicit and include tangible, physical elements including shared plans, goals, and shared records, which enhance shared meaning and shared information, but also signify a shift from words to reality, the intention to involve, and togetherness.

Opportunities for real SDM are overshadowed by constraints on young people’s bodies and inner selves at each level of the four-planar social being. Young people
felt heard or unheard not just in isolated moments of decision-making, but in their relationships with the whole environment and context they were living in. SDM and seeking and hearing the views, experience and expertise of young people, and thinking and deciding together, is therefore about recognising them as people, not objects, and bringing the self back in. For this to be a reality, change should happen at all levels. Restricting young people’s bodies restricts the self – they feel heard or unheard through embodied practices and interactions. Therefore, attention needs to be paid to their everyday, small choices and freedoms. Respecting bodily autonomy, day-to-day choices and freedoms, and keeping young people in places that are known and familiar, are likely to enhance their autonomy, and sense of self as people and decision-makers.

Relationships, interactions and practices should also enhance trust between young people and staff. Those who spend the most time with young people, particularly support workers, should be empowered and able to support and advocate for young people within decision-making processes. There should also be greater proximity to and time with members of staff who have the most power within decision-making, to enhance epistemic trust both ways, so that young people are able to know others and be known. These changes should be prioritised and supported at a systemic level, to ensure process and routines encourage and enhance time, trust and proximity, and support shared meaning-making – and doing ‘with’ rather than ‘to’ or ‘for’.

SDM should be situated in an understanding of epistemic injustice and justice.
Young people’s credibility as decision-makers is not just constrained by prejudice.
due to age or distress. There are many constraints or exclusions of the self at each level of the four-planar social being, all of which constrain how young people see themselves as decision-makers and how they are known and trusted as givers of knowledge, meaning-makers and decision-makers. The factors which influence epistemic injustice (testimonial and hermeneutical) therefore need to be seen as stratified – how young people’s views, knowledge and testimony are heard, believed and valued, what affects how staff form views about young people as decision-makers, and how young people see themselves as decision-makers in relation to their context (hermeneutical inequality). These are all affected by constraints at each level of the four-planar social being.

At the core of decision-making is a simplicity. It respects the dignity of children and young people as moral beings – because time, deliberations and negotiations seek what is most important to them based on who they are. In doing so, we respect young people’s being and self, their dignity and moral worth. Being known develops the crucial element of trust. Young people can be harmed in their capacity as knowers even if they are lacking capacity to be the main decider. Even when young people cannot be the main decider, they can and should still be involved in discussions, deliberations and in knowing and understanding care and treatment to respect their moral worth. Attention needs to be paid to how young people can inform decision-making even when they are experiencing high levels of distress or delusions and to how their expressed feelings and values can be clearly used to inform decision-making; how this can be communicated to young people; and how, when more complex decisions are being made for them by others, opportunities for choice and control in their daily lives can be enhanced.
There should be greater focus on the harms of not involving young people. It is core to ethical practice of how we engage with and relate to others and show respect for their being and moral worth as a person rather than an object of care. We therefore should shift the focus to justify why we should not involve or restrict young people’s influence rather than justify whether we should.

Finally, and perhaps most critically, we need to examine the harms caused by removing young people from known people and places and of the restrictive practices, and depersonalising spaces, which deny their privacy, freedom of movement, and autonomy. Making decisions for, rather than with, is not a benign practice. It is a moral and epistemic harm, which affects the inner being, agency and reflexivity of young people. The focus of practices should be on respecting the core concerns and inner selves of young people, and the places, people and relationships they know and trust. This should not just be in moments of decision-making, but in all interactions, practices and systems within mental health care and support.

Perhaps what is most challenging is how systems (and adults) can adapt and change to enhance young people’s freedom and moral agency, and relationships, systems and processes that support SDM in the very constrained circumstances of inpatient units – or indeed, in how we as a society determine whether inpatient units should be places for people experiencing distress.
9.6 Summary

SDM is constrained by many powerful influences at each plane of reality. This study has offered a deeper understanding of the factors that enable or constrain SDM within inpatient units. It also offers a new understanding of how young people exercise different modes of reflexivity – and how they see the self in relation to decision-making.

The aim of this study was to identify a broad range of constraints that affect shared decision-making in inpatient units as the basis for further work to explore the identified constraints in more depth. Further analysis of the data is planned to include a deeper analysis of the ways in which young people responded to and resisted the constraints on their autonomy and epistemic (and in particular hermeneutical) injustice. These include how the structures and unequal power relations prevent many young people in inpatient units from being able to make sense of their situations, to have confidence in their own knowledge, and to ‘dissent from distorted understandings of their social experience’ (Fricker, 2006, p.96).

Further research is needed to understand how best to achieve the great changes needed at each plane and to understand the impact they have. This could include exploring the impact that removing the constraints identified in this study would have on the trust, agency and reflexivity of young people and those who work with them. There is an ‘epistemic privilege’ in the position of the powerless (Fricker, 1999, pp. 209-10) and therefore further research of inpatient mental health should be co-produced with young people with lived experience to ensure their expertise and insight is central.
Whilst it remains to be seen whether SDM is fully possible given the many constraints in inpatient units, there are many ways in which young people could be more involved and heard within decision-making processes. It is vital we seek to find the best ways to enhance trust and autonomy, and young people’s sense of self, confidence, and moral worth as decision-makers.
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Appendices
Appendix 1: Information sheet for young people and parents

Hello, my name is Kate.

Please will you help me with my research?

- This leaflet gives you some information about my research project.
- This is so that you can find out more and think about whether you would like to take part.
- This leaflet:
  - Tells you more about the project.
  - Tells you more about me.
  - Answers some questions that you might have.

Study No: 14/0846

This research study has been reviewed by the National Research Ethics Service Committee
London Stanmore.
What is the research project about?
• There is very little research about young people's experiences of making choices and decisions about their mental health care.
• I am talking to young people and staff in mental health services.
• I am trying to learn how young people would like to be involved in decisions about their care, treatment and support.

What questions will I ask people?
I will be asking people questions like:
• Do you think young people should be involved in decision-making?
• What kind of decisions is it important for young people to be involved in?
• What are some of the difficulties about making decisions?
• What do you think helps young people to be involved in decision-making?

Who will be involved the project?
I will be talking to 40 young people aged 13-17 years old 20 staff, from 4 different mental health services.

About me
My name is Kate Martin. I'm studying at university in London and this project is the main piece of work I will do to get a PhD qualification. As well as being a student, I work with children and young people to understand their views and experiences of using physical and mental health services. I use young people's views to train staff and to make services for young people better.

Please get in touch with me if you have any questions or if you would like to get involved with the project.

Kate Martin, kmartin@ioe.ac.uk, UCL Institute of Education, 18 Woburn Square, London, WC1H ONG
Information to help you decide if you want to take part.

Here is some more information to help you to think about whether you want to take part.

Do you have to take part?
It is your decision if you want to take part or not. Even if you say ‘yes’ and agree to take part, you can change your mind and drop out at any time. If you decide to get involved:
• I am interested in your views and ideas, so you only have to answer the questions you want to.
• If you don’t want to answer a question that’s ok, just say ‘pass’ or ‘I don’t know’.
• You don’t have to explain why you want to stop or why you don’t want to answer a question.
• You can tell me if you want to stop or take a break.
• You can decide to stop being involved in the research project at any time. You do not have to give me a reason why. This will not affect your support and treatment from the mental health service in any way.

What will happen if you take part?
• I will be coming to spend time in the service.
• This is so I can see the different ways decisions are made with young people.
• I will spend time observing what happens.
• You can ask me questions about who I am, what I am doing and why at any time.
• If you do not want me to observe or take notes about things that involve you, then that is OK. Just let me or a member of staff know and I will stop.
• I also want to learn from young people’s views about decision-making. I will be asking young people if I can ask them about their views in an interview.

If you agree to take part in an interview:
• I will arrange a time for us to meet up.
• I would like to ask you some questions to understand your views. This should last for about 30-60 minutes and will take place in a private room.
• I would like to audio record our conversation so that I don’t forget what we talked about.
• There are no right or wrong answers. I am interested in your views.
Could there be any problems for you if you take part? 
· I hope that you will enjoy talking to me. 
· ... complaints 
mechanisms are available to you. Please ask your researcher if you would like more 
information on this.
Insurance
University College London holds insurance against claims from participants for harm caused by their participation in this study. Participants may be able to claim compensation if they can prove the UCL has been negligent. However, if this study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the study. University College London does not accept liability for any breach in the hospital’s duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

Record retention
In accordance with the UCL Records Retention Policy, research data are retained by UCL in their capacity as research sponsor for 20 years after the research study has ended. Data is then securely destroyed.
Appendix 2: Parent consent form

Parent/guardian consent form

Young people’s views on choice and decision-making in mental health care

- Before your child can get involved in the research project we need to ask you for your consent.
- Giving your consent means you agree for your child to be involved in the research project.
- Don’t forget, even if you give your consent, you can change your mind at any time and withdraw your child from being involved. Your child can also choose to stop being involved at anytime.
- You or your child do not have to give a reason for withdrawing from the study and withdrawing will not affect your child’s standard care in any way.

I have read the information sheet for this research [14/0846]. I have had time to think about the information, ask questions, and I am happy with the answers.

I understand that involvement in the research is voluntary. This means I am free to choose to stop my child being involved at any time. I understand that I don’t have to give a reason for this and that my child’s care won’t be affected if I do.

________________________________________
Name of child/young person

________________________________________
Name of parent/guardian

Date

Signature

________________________________________
Name of person taking consent

Date

Signature
Appendix 3: Young people’s assent form

Young person’s assent form

Young people’s views on choice and decision-making in mental health care

- Before you get involved in the research project we need to ask you for your assent.
- Giving your assent means you agree to be involved in the research project.
- Don’t forget, even if you give your assent, you can change your mind at any time and choose to stop being involved. You do not have to give a reason for why you want to stop being involved and this will not affect the care you receive from the service in anyway.
- If you are under 18, we also need to ask for the consent of your parent or guardian.

Please tick the box if you agree:

I have read the information sheet for this research [14/0846]. I have had time to think about the information, ask questions, and I am happy with the answers.

I understand that being involved in the research is voluntary. This means I am free to choose to stop being involved at any time. I understand that I don’t have to give a reason to stop and that my care won’t be affected if I do.

Name of Participant __________________________ Date ______ Signature __________________________

Name of Person taking consent __________________________ Date ______ Signature __________________________
Appendix 4: NHS REC Application
Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

**Please enter a short title for this project** *(maximum 70 characters)*

Shared decision making with young people in mental health care

<table>
<thead>
<tr>
<th>1. Is your project research?</th>
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<tbody>
<tr>
<td>☐ Yes ☐ No</td>
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<tr>
<th>2. Select one category from the list below:</th>
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</thead>
<tbody>
<tr>
<td>☐ Clinical trial of an investigational medicinal product</td>
</tr>
<tr>
<td>☐ Clinical investigation or other study of a medical device</td>
</tr>
<tr>
<td>☐ Combined trial of an investigational medicinal product and an investigational medical device</td>
</tr>
<tr>
<td>☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice</td>
</tr>
<tr>
<td>☐ Basic science study involving procedures with human participants</td>
</tr>
<tr>
<td>☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology</td>
</tr>
<tr>
<td>☐ Study involving qualitative methods only</td>
</tr>
<tr>
<td>☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)</td>
</tr>
<tr>
<td>☐ Study limited to working with data (specific project only)</td>
</tr>
<tr>
<td>☐ Research tissue bank</td>
</tr>
<tr>
<td>☐ Research database</td>
</tr>
</tbody>
</table>

If your work does not fit any of these categories, select the option below:

| ☐ Other study |

<table>
<thead>
<tr>
<th>2a. Please answer the following question(s):</th>
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<tbody>
<tr>
<td>a) Does the study involve the use of any ionising radiation? ☐ Yes ☐ No</td>
</tr>
<tr>
<td>b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☐ No</td>
</tr>
<tr>
<td>c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☐ No</td>
</tr>
</tbody>
</table>

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<tr>
<th>3. In which countries of the UK will the research sites be located? <em>(Tick all that apply)</em></th>
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</thead>
<tbody>
<tr>
<td>☑ England</td>
</tr>
<tr>
<td>☐ Scotland</td>
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<tr>
<td>☐ Wales</td>
</tr>
<tr>
<td>☐ Northern Ireland</td>
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</tbody>
</table>

3a. In which country of the UK will the lead NHS R&D office be located:

Date: 12/02/2015
4. Which review bodies are you applying to?

- [x] NHS/HSC Research and Development offices
- [ ] Social Care Research Ethics Committee
- [x] Research Ethics Committee
- [ ] National Information Governance Board for Health and Social Care (NIGB)
- [ ] National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- [ ] Yes
- [x] No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- [ ] Yes
- [x] No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- [ ] Yes
- [x] No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

- [ ] Yes
- [x] No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- [ ] Yes
- [x] No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Date: 12/02/2015

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9. Is the study or any part of it being undertaken as an educational project?
   Yes  No

Please describe briefly the involvement of the student(s):
The project is for PHD research and is therefore led by the student, under the supervision of 2 PhD Supervisors

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?
   Yes  No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?
    Yes  No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?
    Yes  No

Date: 12/02/2015
Integrated Research Application System
Application Form for Research involving qualitative methods only

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Shared decision making with young people in mental health care

Please complete these details after you have booked the REC application for review.

REC Name:
NRES Committee London - Stanmore

REC Reference Number: 15/LO/0377
Submission date: 12/02/2015

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:
Shared decision-making with young people in mental health care

A2-1. Educational projects
Name and contact details of student(s):

<table>
<thead>
<tr>
<th>Student 1</th>
</tr>
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<tbody>
<tr>
<td>Title:</td>
</tr>
<tr>
<td>Ms</td>
</tr>
</tbody>
</table>

Address

Post Code
E-mail
Telephone
Fax

Give details of the educational course or degree for which this research is being undertaken:

Date: 12/02/2015
Name and level of course/degree:
PhD

Name of educational establishment:
Institute of Education, University of London

Name and contact details of academic supervisor(s):

<table>
<thead>
<tr>
<th>Academic supervisor 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title</strong></td>
</tr>
<tr>
<td>Professor</td>
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<tr>
<td><strong>Address</strong></td>
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<td><strong>Fax</strong></td>
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<table>
<thead>
<tr>
<th>Academic supervisor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title</strong></td>
</tr>
<tr>
<td>Dr</td>
</tr>
<tr>
<td><strong>Address</strong></td>
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Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly:

<table>
<thead>
<tr>
<th>Student(s)</th>
<th>Academic supervisor(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student 1</td>
<td>Ms Kate Martin</td>
</tr>
<tr>
<td></td>
<td>✔ Professor Priscilla Alderson</td>
</tr>
<tr>
<td></td>
<td>✔ Dr Katy Sutcliffe</td>
</tr>
</tbody>
</table>

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- [ ] Student
- [x] Academic supervisor
- [ ] Other

A3-1. Chief Investigator:

<table>
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<tr>
<th>Date: 12/02/2015</th>
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<td></td>
<td>145177/737728/1/922</td>
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</table>
A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project? This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

Title: Forename/Initials Surname

Address

Post Code

E-mail

Telephone

Fax

A5.1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available): NA

Sponsor's/protocol number: 14/0846

Protocol Version: NA

Protocol Date:

Funder's reference number: NA

Project website: NA

Additional reference number(s):

<table>
<thead>
<tr>
<th>Ref Number Description</th>
<th>Reference Number</th>
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open...
A5-2. Is this application linked to a previous study or another current application?

☐ Yes  ☐ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

This research is exploring shared decision-making (SDM) in young people’s mental health care.

In long term physical healthcare and adult mental health care, shared decision-making is increasingly being advocated as a key way of enabling people to be more involved in decisions about their care, treatment and support. The concept of SDM is very new in young people’s mental health care and there is very little research or published literature on SDM or any form of decision making in young people’s mental health care.

Young people report a lack of involvement in decision making about their mental health care. However, some of the key benefits of SDM include that it can increase adherence, improve quality of care and improve outcomes (Richardson, McCauley and Katon, 2009). In a small study, young people reported that involvement in decision-making improved their adherence to treatment, and increased their safety, autonomy and empowerment (Simmons, Heitkox and Jorm, 2011). There are also many challenges to SDM in practice including questions about young people’s competence to engage in healthcare decisions (Day, 2008) or the complicated decision-making relationship between the young person, parent and therapist (Paul, 2004). Whilst many professionals support the concept of SDM, they also have very real concerns about time and risk.

The research will explore:
• how do young people and practitioners understand and experience shared decision-making?
• what are the key factors and challenges that affect decision-making? How do relationships, structures, routines, interactions affect decision-making?
• what can be done to increase and support shared decision-making in young people’s mental health care?

This qualitative research will employ an ethnographic research methodology and use a range of data collection methods, including interviews with <40 young people aged 13-17 and <20 staff in community and inpatient mental health services, and with <10 policymakers; observation in 2 community CAMHs and 2 inpatient CAMHs.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

The research questions have emerged directly from the researcher’s work with young people and professionals in mental health care.

Young people report a lack of involvement in decisions about their mental health care. Mental health professionals often support the concept of shared decision-making, but they experience challenges to this in practice and have concerns about issues such as time and risk.

Date: 12/02/2015

7

145177/737728/1/922
Given the lack of research in this area, the study is undertaking research across four settings to explore and identify the common legal, ethical and social themes that affect decision-making in young people’s mental health care.

Ethnography with semi-structured interviews and observations is the chosen methodology as the research seeks to identify the factors and mechanisms that serve to enable and constrain young people’s involvement in decision-making. Ethnography will enable the researcher to explore the research questions through multiple lenses, such as: observations of interactions between staff and young people; the views of young people; and the views of different types of practitioners. This will enable the research to explore
- how decision-making happens in practice
- how young people and staff experience decision-making
- how the social and legal context, setting, staff, young people and relationships interact and affect decision-making
- what helps to facilitate and increase opportunities for decision-making

Risks, burdens and benefits
• Young people may be anxious that involvement in the research could impact on their immediate care, treatment, and relationships with other young people and staff in the setting. Concerns will be discussed during the consent process and before/during interviews.
• Interviews or conversations may raise difficult or upsetting issues for young people, who may then experience distress afterwards. Whilst this research is exploring young people’s experience of decision-making and not their experience of mental health difficulties, it is likely that they may choose to share experiences that have been distressing. The researcher will aim to be objective but also sensitive, and offer to pause or end sessions if this seems appropriate.
• The researcher will liaise with a named member of the staff for the young people know who is willing to offer support after research interviews to anyone who has difficult feelings or distress.

Recruitment
The research will take an opt-in approach for interviews in community CAMHS services.
Recruitment in community CAMHS services:
• There will be a poster on the wall in reception/waiting room with the researcher’s name, photo and an outline of the research.
• The researcher will spend time in the waiting room and give young people information leaflets about the research, give an introduction and explanation about the research, and invite them to let her know if they wish to opt in to participate in an interview. The researcher will wear an ID badge as a clear identity.
• CAMHS staff will offer information leaflets to young people during regular sessions/meetings to explain the research and ask young people if they would like to participate in an interview.

Recruitment in inpatient services:
• I will ask for formal written consent to interviews and clinical consultations. I hope that the REC and the staff will allow me to conduct informal observations and conversations with patients and staff without prior need for consent forms. In order to ensure that everyone is informed about the research, and can ask, or even hint, when they wish me to leave I will be careful to do the following:
• I will give out information leaflets to everyone, and to all new contacts during the observation period, whether they are directly involved in my research or not.
• I will ask permission to put up a poster with my photo, briefly explaining the research and inviting inquiries.
• I will ask people, when I first meet them, and each time they arrive, if they mind me being there observing.
• I will be as tactful and unobtrusive as possible, and be alert to unspoken cues that people might wish me to leave.
• I will have informal conversations with young people about the research, give an introduction and explanation about the research, and invite them to let her know if they wish to opt in to participate in an interview.

Gaining consent:
Informed consent will be sought from each young person and their parent (where they are under 18).

To ensure young people are able to give their informed consent the following will be undertaken:
- Young people will be given an accessible information leaflet
- Young people will be invited for informal conversations about the research
- A topic guide containing example interview questions will be given to young people, to assist their choice about being interviewed
- During conversations about consent, the researcher will check young people’s understanding by asking for examples, or by asking them how they would explain this to another young person
- Young people will be informed of their right to give or refuse their consent to participate and their right to withdraw at anytime

Date: 12/02/2015
Confidentiality and anonymity

- Collection and processing of participants' personal data will be limited to what is necessary for the study.
- Information about confidentiality will be contained in the information leaflet. It is important that young people understand the boundaries of confidentiality and that disclosures about current serious self-harm, suicidal intention, risk of significant harm to themselves or others, may have to be disclosed to staff at the service.
- To ensure anonymity, young people will be asked to choose a pseudonym. Other identifying features, such as names of other children, staff, family members or certain places such as their home address will be anonymised during transcription.
- Interviews will be held in a quiet, private room. It is necessary to use a quiet private room to avoid interruptions and to help participants to relax and not worry about being overheard by others, so that they may then talk with more confidence, and their privacy is respected.
- Transcripts will be held securely on a password protected file on the researcher's computer and will be anonymised at the point of transcription.
- Analysis of anonymised information may be presented at conferences, in the PhD thesis and publications.

Data will be stored in line with the requirements of the Data Protection Act 1998. This will include:
- Data will be stored securely and password protected. Interview audio recordings will be held securely on a password protected file. They will be held until the end of the researcher's PhD and then deleted after two years.
- Data will be anonymised for storage on a computer or other such equipment
- A register of data will be stored and maintained. This will be anonymised.
- Personal details of participants will be stored separately from other data.

Safeguarding issues:
The researcher has an enhanced CRB disclosure and has significant experience in developing and managing safeguarding procedures in mental health contexts.
The researcher will:
- Identify and make contact with the lead safeguarding officer in each research site
- get access to and clarify the site specific safeguarding procedures, to report any concerns in the event they may arise during the course of the research.

A6.3. Proportionate review of REC application  The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6.2, you consider there are ethical issues that require consideration at a full REC meeting.

- [ ] Yes - proportionate review  [ ] No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- [ ] Case series/ case note review
- [ ] Case control
- [ ] Cohort observation
- [ ] Controlled trial without randomisation
- [ ] Cross-sectional study
- [ ] Database analysis
- [ ] Epidemiology
- [ ] Feasibility/ pilot study

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A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

How do young people and staff understand and experience shared decision-making in mental health care?

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

What are the key factors and challenges that affect decision-making?
How do relationships, structures, routines and interactions affect decision-making?
What can be done to increase and support shared decision-making in young people’s mental health care?

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

In healthcare and adult mental health care, shared decision-making is increasingly being advocated as a key way of enabling people to be more involved in decisions about their care, treatment and support. However, this is relatively new in children and young people’s mental health care, with little research or literature available.

Some of the key benefits of SDM in young people’s mental health care include that it can increase adherence, improve quality of care and improve outcomes (Richardson, McAuley and Katon, 2009). Young people report that involvement in decision-making has improved their adherence to treatment, and increased their safety, autonomy and empowerment (Simmons, Hetrick and Jorm, 2011). Young people have specific expertise about their lives and bodies (O’Brien et al., 2011) and involvement in decision-making “may enable clinicians and parents to acquire a better appreciation of children and young people’s needs and experiences, identify distinct treatment expectations as well as increase the likelihood of negotiating genuinely shared intervention goals” (Day, 2008).

SDM may help to reduce risk incidents, with young people reporting that SDM improved the delivery of their care and enabled them to take more responsibility for their actions (CAMHS EBPU, 2014).

Many young people want collaborative involvement in their mental health treatment and care, especially in the analytical stages of decision-making and weighing up the benefits and risks of treatment options, but often experience limited involvement in decision-making (Simmons, Hetrick and Jorm, 2011). Lack of involvement in decision-making can affect young people’s willingness to seek treatment or make it difficult to agree with decisions (ibid.) There is evidence of premature disengagement with 30-40% dropping out of services where there is non-collaborative decision-making, which is a key influence on non-attendance (Allergoa, 2008; Mitchell and Selmes 2007).

Challenges to SDM in practice including questions about young people’s competence to engage in decisions (Day, 2006) or in the complicated decision-making relationship between the young person, parent and therapist (Paul, 2004).

There is little research into experiences of young people in acute inpatient care (Stenhouse, 2011). An ethnographic study in young people’s inpatient care (Le François, 2007), found that young people felt their views were only encouraged when they were deemed appropriate or not risky, and they had little or no choice about treatment (LeFrançois, 2008).

SDM has the potential for significant benefits for young people in mental health care, yet there is limited research in this area. This study aims to explore and identify the advantages and possible disadvantages, the barriers and challenges to SDM in young people’s mental health care and identify how problems can be overcome and advantages promoted.
A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

Context
The study will take place in four services (two inpatient and two community CAMHS services) across two mental health trusts (one inpatient and one community CAMHS in each trust)

Ethnography
An ethnographic research methodology has been chosen as the research seeks to identify the real causes, mechanisms and structures that serve to enable and constrain young people's involvement in decision-making. Ethnographers can observe how events develop over time, and how values, beliefs or behaviours interact (Bryman, 2008). This will involve interviews and observations to enable the researcher to explore the research questions through multiple lenses, such as: observations of interactions between staff and young people; the views of young people; the views of different types of practitioners; the medical, social, legal and ethical literature and guidance and how this interacts with practice. This will enable the research to deepen understanding beyond the views of staff and young people about decision-making to also explore:
- how decision-making happens in practice
- how young people and staff experience decision-making
- how the social, legal and ethical context, the setting, staff, young people and relationships interact and affect young people's involvement in decision-making
- what helps to facilitate and increase opportunities for decision-making

Sampling
The research will take place in two inpatient services and two community CAMHS services and will purposively sample:
- <40 young people aged 13-17 years
- <20 staff

<10 local and national policymakers will also be purposively sampled for interviews.

Interviewees will be selected to cover both sexes, and a range of ages, class and ethnic groups, and mental health problems. The diagnoses to be selected have not yet been decided. As this small study progresses it may be found to be best to concentrate on two or three conditions.

Procedure
- Obtain permission from the authorities and named consultants.
- Display posters in the reception/waiting room and unit entrances with the researchers' name, photo and an outline of the research

For community interviews:
- The researcher will spend time in the waiting room and give young people information leaflets about the research, give an introduction and explanation about the research, and invite them to let her know if they wish to participate in an interview. The researcher will wear an ID badge to clearly identify them as a researcher. The researcher will note interest and contact details of young people who are interested.
- CAMHS staff will be asked to offer information leaflets to young people during regular sessions / meetings to explain the research and ask young people if they would like to participate in an interview. The staff member will inform the researcher of young people who are interested and with their permission will pass on their and their parents' contact details to the researcher.
- The researcher will then contact the young person and their parent to discuss any questions they may have
- If they agree to be involved in an interview they will be asked to sign a consent form and to arrange a time for the interview
- Interviews will take place in the CAMHS service or hospital premises

Procedure for inpatient services
- Staff will be asked to give out information leaflets the day before the researcher is due to come to the service. This will explain who the researcher is, include a photo and information about the research and encourage young people to discuss the research and ask questions when the researcher arrives.

Observations
- The information will clearly explain young people's right to opt out of the research process and to inform a member of staff if they wish to do so. The researcher will check with staff who does not wish to take part. Details of any observations involving those young people will not be recorded or included in the research, and the researcher will
take care not to go near them.

Interviews
• I will start with general observations and get to know the young people. I will then approach individuals and ask if they are willing to be interviewed. (See attached consent forms for young people and parents.) If parents are unlikely to visit I will post the form to them with a SAE or I will ask for permission to email them.

Procedure for Staff
Observations
• Information sheets will be given to all staff
• The researcher will explain the research to staff during team meetings or other appropriate meetings

Interviews
• The researcher will talk to staff (face-to-face or telephone) who express interest in being interviewed to answer any questions they have
• If they consent to an interview, a consent form will be provided and a time arranged for the interview Busy staff may need to be interviewed in two short sessions.

Procedure for local and national policymakers
• Policymakers will be contacted by phone or email to explain the research and to answer any questions they may have
• If they express interest in participating they will be sent information and consent form and they will be contacted to arrange the interview

Time frame
Interviews and observations will take place over a period of 12 months

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.
The questions and basis for this research have emerged directly from the researcher’s participation work with children and young people in mental health care.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Inclusion criteria for involvement in the research:
a) Young people aged 13-17 years old who are accessing the community or inpatient services
b) Young people who have given their consent. The consent of the young person’s parent/legal guardian will also be required if they are under 18 years old

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Exclusion criteria:
a) Young people who are not current patients in the services
b) are under 13 years old or over 17 years old

Date: 12/02/2015
A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:
1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days).
4. Details of who will conduct the intervention/procedure, and where it will take place.

<table>
<thead>
<tr>
<th>Intervention or procedure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking informed consent for interviews</td>
<td>1</td>
<td>20 minutes</td>
<td>Upon being supplied with contact details of a potential participant by a staff member, the researcher will seek written consent from the young person (and their parent/carer if they under 18). Consent will be sought immediately prior to the interview taking place and will involve a verbal discussion of the research and information in the information sheet.</td>
<td></td>
</tr>
<tr>
<td>and parental consent (where the young person is under 16)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interviews with young people</td>
<td>1</td>
<td>1 hour</td>
<td>Interviews will take place in the community or inpatient services</td>
<td></td>
</tr>
<tr>
<td>Observations in inpatient services</td>
<td>1</td>
<td>2 weeks</td>
<td>The researcher will undertake observations in each inpatient service over a period of 2 weeks.</td>
<td></td>
</tr>
</tbody>
</table>

A21. How long do you expect each participant to be in the study in total?

The study will take place over a period of 12 months, however for most young people their involvement would be approximately four months for young people in both inpatient and community CAMHs. This is to allow time to:
- gain consent from the young person and their parent(s);
- arrange and undertake the interview;
- follow up their treatment and experiences through observations and informal interviews.

In terms of the active participation of young people in the research:
- observations will take place intermittently over the four months
- interviews will last approximately one hour

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

• Young people may be anxious that involvement in the research could impact on their immediate care, treatment, and relationships with other young people and staff in the setting. The researcher will give young people time to discuss any concerns or potential concerns they have before they agree to participate, and also during sessions as they arise.

• Interviews will take place in private spaces to ensure young people can speak freely and not be concerned they will overhear. Procedures for confidentiality, anonymity and safeguarding will be discussed with all participants when gaining consent and again at the start of interviews.

• Interviews or conversations may raise difficult or upsetting issues for young people, who may then experience distress afterwards. Whilst this research is exploring young people's experience of decision-making and not their experience of mental health difficulties, it is likely that they may choose to share experiences that have been distressing. Thus, it will be important to ensure young people know whom they can speak to if they have difficult feelings or distress.

• The researcher will be spending time in inpatient mental health services. These are highly personal spaces for young people, where they do not only support therapeutically, but they are spending a significant period of time. The researcher is entering their space and must do so in a respectful way. There will be limitations to the level of participation of the researcher (for example, not to engage in therapeutic activity or provide direct support to young...
people with their distress. However, it would therefore be unethical and inappropriate to enter their environments and be a wholly detached observer. Rather, being in the space ethically, sensitively and in a way that engenders mutual respect and trust requires some level of involvement and interaction, with their daily lives and routines. The researcher will constantly be self-critically aware of how to maintain this complex balance.

A23. Will interviews/questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☐ Yes  ☐ No

If Yes, please give details of procedures in place to deal with these issues:

Interviews or conversations may raise difficult or upsetting issues for young people, who may then experience distress afterwards. Whilst this research is exploring young people’s experience of decision-making and not their experience of mental health difficulties, it is likely that they may choose to share experiences that have been distressing. Thus, it will be important to ensure young people know whom they can speak to if they have difficult feelings or distress including the pre-arranged member of staff, Childline, the Samaritans or other members of their mental health team.

Where there are concerns about risk of serious harm to a young person, the relevant safeguarding procedures will be followed. Safeguarding is included in the participant information sheet and will be discussed during the consent process and again at the beginning of interviews.

A24. What is the potential for benefit to research participants?

The research may also have positive effects. These may include an increased awareness for individuals of their decision-making rights; the sense that they may make possible later benefits for other young people, or future changes to the service or relationships with staff. The researcher has committed to offering two feedback and development sessions to each service involved, to enable them to learn from the research findings.

A26. What are the potential risks for the researchers themselves? (If any)

Having worked for years in this area, the researcher is aware of the risks of feeling very distressed about the young people’s problems and perhaps over-involved with them. Care will be taken to avoid these problems and to discuss the work, while respecting anonymity and privacy, with the supervisors.

**RECRUITMENT AND INFORMED CONSENT**

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Participants will include:
All young people aged 13-17 in the in-patient and CAMHS settings observed, except those who have said they do not wish to take part.
Young people among these groups, selected by the researcher or recommended by the staff, who will be invited to take part in interviews.

No medical records will be examined.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes  ☐ No

Date: 12/02/2015
Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?
- Yes ☐ No ☐
  If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).
  Posters and leaflets will be used during recruitment, but not advertisements or websites.

A29. How and by whom will potential participants first be approached?
- Inpatient services: young people will first be informed about the research by staff at the service.
- Community CAMHS: young people will first be approached by either:
  - a member of staff from the service who will inform the young person about the research and give them an information sheet.
  - the researcher in the waiting room of the service, who will give the young person an information leaflet.

A30. Will you obtain informed consent from or on behalf of research participants?
- Yes ☐ No ☐
  If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material).
  Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.
  If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.
  Yes, from both young people and their parents.
  If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?
- Yes ☐ No ☐

A31. How long will you allow potential participants to decide whether or not to take part?
As long as they require within the time period of the research.

A33. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)
Ideally the research would be inclusive. However, it is a self-funded PhD and will have to rely on young people and staff with an adequate understanding of English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.
- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

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The participant would continue to be included in the study.
Not applicable – informed consent will not be sought from any participants in this research.
Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:
Given the short length of active involvement in the study (approximately one hour for interviews), loss of capacity within this time frame is unlikely.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? [Tick as appropriate]

- Access to medical records by those outside the direct healthcare team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
  - Manual files including X-rays
  - NHS computers
  - Home or other personal computers
  - University computers
  - Private company computers
  - Laptop computers

Further details:
The use of personal data (emails and telephone numbers) will be necessary to arrange interviews with participants. Such data will only be gathered where this has been provided to the researcher by potential participants with the intention of being contacted for an interview. Details will be deleted if people refuse or withdraw.

Use of audio recording device: Yes with permission
Storage of personal data: Yes with permission.

A38. How will you ensure the confidentiality of personal data? [Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.]

As soon as participants have agreed to take part in the research, they will be asked to choose a pseudonym and will allocated a unique code.

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From this point on, the individual will be known to the researcher with that code and all data collected from interviews or observations will bear the participants’ code.

Personal information, such as contact details, will only be used to contact the young person and/or their parent to gain consent or arrange interviews and will be stored separately from the research data. All electronic data will be held anonymously.

Other identifying features, such as names of other children, staff, family members or certain places such as their home address will be anonymised during transcription.

**A40. Who will have access to participants’ personal data during the study?** Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Access to the participants’ personal data will be limited to the researcher and the researcher’s PhD supervisors.

**Storage and use of data after the end of the study**

**A43. How long will personal data be stored or accessed after the study has ended?**

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

*If longer than 12 months, please justify.*

In accordance with the UCL Records Retention Policy, research data are retained by UCL in their capacity as sponsor for 20 years after the research study has ended. Data is then securely destroyed.

**INCENTIVES AND PAYMENTS**

**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- Yes
- No

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

- Yes
- No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

- Yes
- No

**NOTIFICATION OF OTHER PROFESSIONALS**

**A49.1. Will you inform the participants’ General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

Date: 12/02/2015
A50. Will the research be registered on a public database?

☐ Yes  ☐ No

Please give details, or justify if not registering the research. The research qualitative and not a clinical trial and therefore does not require registration.

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

☑ Peer reviewed scientific journals
☐ Internal report
☐ Conference presentation
☐ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
☐ No plans to report or disseminate the results
☑ Other (please specify)

Feedback workshops to each service involved in the research.
Accessible report for young people (including young people involved in the study and young people more widely)

A53. Will you inform participants of the results?

☐ Yes  ☐ No

Please give details of how you will inform participants or justify if not doing so.
An accessible young people's report will be produced and sent to all young people involved in the research and to the research sites.

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

☐ Independent external review
☐ Review within a company
☐ Review within a multi-centre research group
☐ Review within the Chief Investigator’s institution or host organisation
☐ Review within the research team
☑ Review by educational supervisor
☐ Other

Date: 12/02/2015
Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, provide details of the body which has undertaken the review:
The researcher wrote a 24,000 word report of the literature review, research theories and methods for an upgrade examination, to move from MPhil to PhD level. The upgrade was approved in September 2014 by Professors Berry Mayall and Chris Bonell. They have extensive research experience in healthcare setting and with young people.

The researcher has two supervisors (Prof. Priscilla Alderson and Dr. Katy Sutcliffe), who both have extensive research experience in healthcare settings with young people.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

### A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total?

If there is more than one group, please give further details below.

<table>
<thead>
<tr>
<th>Total UK sample size:</th>
<th>70</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total international sample size (including UK):</td>
<td></td>
</tr>
<tr>
<td>Total in European Economic Area:</td>
<td></td>
</tr>
</tbody>
</table>

**Further details:**
- <40 young people aged 13-17 years
- <20 staff
- <10 local and national policymakers will also be purposively sampled for interviews.

### A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

The research will take place in two inpatient services and two community CAMH services and will purposively sample
- <40 young people aged 13-17 years
- <20 staff
- <10 local and national policymakers will also be purposively sampled for interviews.

**Young people:**
Interviewees will be selected to cover both sexes, and a range of ages, class and ethnic groups, and mental health problems. The diagnoses to be selected have not yet been decided. As this small study progresses it may be found to be best to concentrate on two or three conditions.

**Staff:**
Interviewees will be selected to cover both sexes and a range of professional roles within the services.

### A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Qualitative data will be coded using the following process:
- transcriptions and detailed field notes will be read and reread, searching for significant themes
- themes are likely to include types of decisions made, methods and types of sharing, enablers and obstacles, types of young people’s and staff preferences and priorities, sharing of information and control.

Data will analysed using NVivo qualitative data analysis software.

### 6. MANAGEMENT OF THE RESEARCH

<table>
<thead>
<tr>
<th>Date:</th>
<th>12/02/2015</th>
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<tbody>
<tr>
<td>19</td>
<td>145177/737728/1/922</td>
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</table>
A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

A64. Details of research sponsor(s)

<table>
<thead>
<tr>
<th>Lead Sponsor</th>
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<tbody>
<tr>
<td><strong>Status:</strong></td>
</tr>
<tr>
<td>- NHS or HSC care organisation</td>
</tr>
<tr>
<td>- Academic</td>
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<tr>
<td>- Pharmaceutical industry</td>
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<tr>
<td>- Medical device industry</td>
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<tr>
<td>- Local Authority</td>
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<tr>
<td>- Other social care provider (including voluntary sector or private organisation)</td>
</tr>
<tr>
<td>- Other</td>
</tr>
<tr>
<td><strong>Commercial status:</strong> Non-Commercial</td>
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<table>
<thead>
<tr>
<th>Contact person</th>
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<tbody>
<tr>
<td>Name of organisation: UCL Joint Research Office</td>
</tr>
<tr>
<td>Given name:</td>
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<tr>
<td>Family name:</td>
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<td>Address:</td>
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<tr>
<th>Is the sponsor based outside the UK?</th>
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<tbody>
<tr>
<td>- Yes</td>
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<tr>
<td>- No</td>
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</table>

*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

A65. Has external funding for the research been secured?

- [ ] Funding secured from one or more funders
- [ ] External funding application to one or more funders in progress
- [x] No application for external funding will be made

What type of research project is this?

- [ ] Standalone project

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A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

☐ Yes ☐ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Organisation
Address
Post Code
Work Email
Telephone
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/03/2015
Planned end date: 31/03/2016
Total duration:
Years: 1 Months: 0 Days: 31

A71-2. Where will the research take place? (Tick as appropriate)

☑ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 4

Does this trial involve countries outside the EU?

☐ Yes ☐ No

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A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS organisations in England</td>
<td>4</td>
</tr>
<tr>
<td>NHS organisations in Wales</td>
<td></td>
</tr>
<tr>
<td>NHS organisations in Scotland</td>
<td></td>
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<tr>
<td>HSC organisations in Northern Ireland</td>
<td></td>
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<tr>
<td>GP practices in England</td>
<td></td>
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<tr>
<td>GP practices in Wales</td>
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<tr>
<td>GP practices in Scotland</td>
<td></td>
</tr>
<tr>
<td>GP practices in Northern Ireland</td>
<td></td>
</tr>
<tr>
<td>Social care organisations</td>
<td></td>
</tr>
<tr>
<td>Phase 1 trial units</td>
<td></td>
</tr>
<tr>
<td>Prison establishments</td>
<td></td>
</tr>
<tr>
<td>Probation areas</td>
<td></td>
</tr>
<tr>
<td>Independent hospitals</td>
<td></td>
</tr>
<tr>
<td>Educational establishments</td>
<td></td>
</tr>
<tr>
<td>Independent research units</td>
<td></td>
</tr>
<tr>
<td>Other (give details)</td>
<td></td>
</tr>
</tbody>
</table>

Total UK sites in study: 4

A76. Insurance/ indemnity to meet potential legal liabilities

Note: In this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
- Other insurance or indemnity arrangements will apply (give details below)

The management of the research will be covered by UCL Insurance for negligent harm

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

Date: 12/02/2015
A76.3. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/indemnity arrangements for these sites below)

UCL insurance provides cover for negligent harm arising from the design of the research.

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

The age range of children under 16 will be from 13-15. This is due to the average age range of young people accessing CAMHS and inpatient services.

Although SDM is increasingly used with adult patients and in physical health care, young people in this research have the double disadvantage of being legal minors and having mental health problems. These may directly impair their decision making, or the problems may be assumed by the caring adults to impair all decision making, even if this may not be wholly or partially the case. The research is designed to examine these complex legal and practical problems. The aim is to provide insights to benefit mental health services and young people who use them in future.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

No children will be recruited as controls.

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

Gaining consent:
Informed consent will be sought from each young person and their parent (where they are under 18).

For community interviews:
- The researcher will spend time in the waiting room and give young people information leaflets about the research, give an introduction and explanation about the research, and invite them to let her know if they wish to participate in an interview. The researcher will wear an ID badge to clearly identify them as a researcher. The researcher will note interest and contact details of young people who are interested.
- CAMHS staff will be asked to offer information leaflets to young people during regular sessions/meetings to explain the research and ask young people if they would like to participate in an interview. The staff member will inform the researcher of young people who are interested and with their permission will pass on their and their parents contact details to the researcher.
- The researcher will then contact the young person and their parent to discuss any questions they may have
- If they agree to be involved in an interview the parent and young person will be asked to sign a consent form and a time for the interview will be arranged.
- Interviews will take place in the CAMHS service or hospital premises

Procedure for inpatient services
- Staff will be asked to give out information leaflets the day before the researcher is due to come to the service. This

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will explain who the researcher is, include a photo and information about the research and encourage young people to discuss the research and ask questions when the researcher arrives.

Observations
• The information will clearly explain young people’s right to opt out of the research process and to inform a member of staff if they wish to do so. The researcher will check with staff who do not wish to take part. Details of any observations involving those young people will not be recorded or included in the research, and the researcher will take care not to go near them.

Interviews
• I will start with general observations and get to know the young people. I will then approach individuals and ask if they are willing to be interviewed. (See attached consent forms for young people and parents.) If parents are unlikely to visit I will post the form to them with a SAE or I will ask for permission to email them.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

Written and spoken information will be expressed as clearly as possible. Young people’s questions will be discussed and extra care will be taken with those who may have limited literacy or whose first language is not English.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.
PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

<table>
<thead>
<tr>
<th>Research site</th>
<th>Investigator/ Collaborator/ Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution name</td>
<td>Department name</td>
</tr>
<tr>
<td>Street address</td>
<td>Town/city</td>
</tr>
<tr>
<td>Post Code</td>
<td></td>
</tr>
<tr>
<td>Institution name</td>
<td>Department name</td>
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<tr>
<td>Post Code</td>
<td></td>
</tr>
</tbody>
</table>

Date: 12/02/2015
D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

   - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
   - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
   - May be seen by auditors appointed to undertake accreditation of REC's (where applicable).
   - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
   - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee’s final opinion or the withdrawal of the application.

Contact point for publication (Not applicable for R&D Forms)

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- □ Chief Investigator
- □ Sponsor

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NHS REC Form

Reference: 15/LO/0377
IRAS Version 3.5

☐ Study co-ordinator
☐ Student
☐ Other – please give details
☐ None

**Access to application for training purposes (Not applicable for R&D Forms)**

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Professor Priscilla Alderson on 12/02/2015 09:13.

Job Title/Post: Professor
Organisation: UCL IOE
Email: p.alderson@ioe.ac.uk

Date: 12/02/2015
D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named as 64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question 476, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by [Name Redacted] 12/02/2015 11:11.

Job Title/Post: [Redacted]

Organisation: [Redacted]

Email: [Redacted]
D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

**Academic supervisor 1**

This section was signed electronically by Katy Sutcliffe on 12/02/2015 09:06.

- **Job Title/Post:** Academic Supervisor
- **Organisation:** Social Science Research Unit, Institute of Education, University College London
- **Email:** k.sutcliffe@ioe.ac.uk

**Academic supervisor 2**

This section was signed electronically by Professor Priscilla Alderson on 12/02/2015 09:16.

- **Job Title/Post:** professor
- **Organisation:** UCL IOE
- **Email:** p.alderson

Date: 12/02/2015