Exploring Human Rights in the Context of a Young People's Psychiatric Inpatient Service

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A thesis submitted in partial fulfilment of the requirements
of the University of East London for the degree of
Professional Doctorate in Clinical Psychology

May 2019

ABSTRACT

This study was an exploration, from a human rights perspective, of the experiences and views of young people in an inpatient psychiatric unit. The starting point was that young people's views and perspectives on human rights issues in their mental health care are important to understand, in order to better inform practices within mental health services. The key research questions of the study were:

(a) How do young service users understand human rights in the context of a young people's psychiatric inpatient unit?
(b) What do they experience as 'human rights issues'?

A critical realist epistemological stance was taken in the research, and the qualitative study design involved individual interviews with eight young people in an inpatient mental health unit specifically for young people. A thematic analysis yielded six key themes and a number of sub-themes. The key emerging themes identified were:

Theme 1: "I don't know anything about it": Explicit and implicit understanding of human rights
Theme 2: "Lost in the world": Connection and relationships
Theme 3: "I'm just told what to do": Heard and involved
Theme 4: Equality and protection from discrimination
Theme 5: Harm and iatrogenic effects
Theme 6: Balancing safety and restriction

In seeking to understand young people's views on human rights, this study has explored the breadth of care practices that could be experienced as harmful, disrespectful, discriminatory and diminishing of young people's dignity, privacy, and opportunity to exercise autonomy and build connections with others. Further, this study has highlighted the enormous complexity, and urgency, of developing mental health services which enable young people's views and wishes to be respected - as human beings with human rights.

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ACKNOWLEDGMENTS

Firstly, my upmost thanks go to the young people who participated in the study. You gave your time and energy to share your immense knowledge, so that other young people may have the opportunity for a better experience in the future.

To the staff at the service who helped introduce me to the ward and young people - thank you for facilitating this study. The pressure that you are under is palpable, and I am incredibly grateful for your time.

I cannot quite express how thankful I am to my supervisor, Nimisha Patel, whose wealth of knowledge is, in my view, unmatched, but whose kindness is also.

Similarly, to my personal tutor, Rachel Smith – thank you for always checking in, even when I was not the easiest to get hold of!

To both Nimisha and Rachel – you are the kind of person I want to be for others in the future.

Finally, to my friends Kate and Scarlet – thank you for letting me crash with you when I didn't think I could do it by myself. And thanks, Kate, for stealing my phone from me so I would actually do some writing.

1. INTRODUCTION

In this chapter, the literature search strategy is outlined, key definitions are presented and relevant histories are summarised. There is a particular focus on the definitions of ‘human rights’ and ‘human rights principles’, and of the developing history of ‘children’s rights’ and their relevance to mental health. This chapter is an argument and justification for the current study and, as such, ends with the study’s research questions.

The author takes the position that, for every definition, description of context, or historical summary, there is a multitude of other positions that could have been taken. The descriptions given here are a result of the articles I have read and my own approach to understanding, which has been influenced, in turn, by my own history and context. Thus, this chapter is an act of transparency and a clarification of my position, allowing the reader to progress through this thesis with an awareness of how I have understood each key term, and of the context in which this thesis sits.

1.1. Reflexivity and Situating the Research

Owning one’s own position is a key marker of the quality of qualitative research (Elliot et al., 1999). My decision to focus this research on the topic of ‘human rights’ was a direct result of my personal and professional experience. This personal context cannot be separated from the research, nor should it have to be for the research to be of worth. I acknowledge my role in constructing, not simply reflecting, a reality (Stanley & Wise, 2002). In line with this, I have chosen to write in the first person.

In the pursuit of transparency, I will share enough of this context to explain my position on the topic. In a past professional role, before this doctorate degree, I worked in an inpatient mental health unit. At the time, I observed several events that left me deeply uncomfortable, but which appeared to be in accordance with the policy of the unit. I felt as though I had no language to explain *why* I felt these events were ‘wrong’, and little power to effect change.

I also felt substantial guilt at my own involvement. It was only when I heard the language of human rights that I began to understand my reaction and how an argument could be made for change. Thus, it is my position that the language of human rights holds power, and that this power can be used to change policy and practice.

My decision to focus on children's human rights was also deeply personal and a consequence of my own experiences. I will not disclose these experiences here, but it is enough to say that I strongly believe that adults hold a "dangerous and debilitating power" over children (Scraton, 1997, p. 186), and that it is our moral duty to protect young people from the injustice that we, as adults, can cause.

1.2. Literature Search Strategy

The literature search included two stages. First, a literature search was undertaken to establish key legal documentation, grey literature and related academic literature that explore the concepts of human rights in relation to mental health and children's mental health more specifically.

Second, a literature search of relevant academic databases using the search terms 'human rights', 'children' and 'mental health' yielded over 600,000 results. Yet, a brief overview of these results suggests a prevalence of studies on the impact of war or refugee status on mental health, with seemingly little on the relationship between human rights in a UK mental health context and, even less on the topic of human rights in the context of children's mental health services. After attempting numerous different search strings, a pragmatic decision was made to focus the required formal literature search on children's *understanding* of human rights.

1.3. Defining 'Human Rights'

Broadly speaking, human rights are moral claims established as legal norms in international and national laws for the protection of all human beings. Historical sources of rights are thought to date back to the Magna Carta

(1215), with other significant sources including the English Bill of Rights (1689), as well as the French Declaration of the Rights of Man and the Citizen (1789), and the Bill of Rights in the United States Constitution (1791). However, modern human rights, as reflected in the current understanding of human rights, are derived from the Universal Declaration of Human Rights (United Nations, 1948), and the subsequent documents and treaties that have followed on from this, at international, regional, and domestic levels. International laws relevant to mental health include the United Nations (UN) Convention on the Rights of Persons with Disabilities (UN, 2006), the UN Convention on the Rights of the Child (CRC, 1989), and the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1987). At a regional level, the European Convention on Human Rights (1953) is a key document. At the domestic level, relevant documentation includes the Human Rights Act (1998), which brings the European Convention directly into our national law, as well as the Equalities Act (2010) and some elements of the Children's Act (1989, revised 2004), the Mental Capacity Act (2005), and the Mental Health Act (1983). This is a non-exhaustive list.

Whilst human rights can exist as norms of international and national law, if one only considered human rights to exist because of their enactment in law, then their existence is contingent on decision-making and political developments. Theorists of human rights have attempted to seek out support for the idea that human rights can exist in some deeper, more independent form: innately in human beings (see Morsink, 2009), as basic moral norms or as justified moral outlooks (Nickel, 2019). Note, though, that there are a number of philosophical, political, and other challenges to human rights, with critics as early as Bentham describing natural rights as "nonsense upon stilts" (Bentham, 1983). Further, Bobbio (1996) argues that human rights have emerged through history and are a product of human struggle; as such, they cannot be viewed as set in stone, but are susceptible to transformation.

The philosophy of human rights is rich in history and complex, and reflections on the nature, content, justification, universality and legal status of human rights is an entire sub-field of political and legal philosophy. A full exploration of this field is far beyond the remit of this thesis, but some of the key features are plurality, universality, and high importance. Human rights are plural in that they address a variety of problems, including the right to a fair trial, education, and freedom from slavery and genocide. Human rights are seen to have key features, including that they are universal; they apply to all living persons, regardless of whether they are enacted in practice. Finally, human rights are of “paramount importance” (Cranston, 1967), and must be so in order to compete with other significant considerations, such as national security.

For the purposes of this thesis, the complexity of human rights is acknowledged but, for pragmatic purposes, the term human rights is used to refer to legal norms, which set out fundamental, minimum freedoms for the protection of all humans.

1.4. Human Rights Principles

The introduction of the Human Rights Act (1998) has not resulted in an understanding of human rights in the healthcare profession, at the level of the patient, carer, healthcare professional, or organisation (Curtice & Exworthy, 2010). One response to this has been the promotion of a ‘human rights-based approach to healthcare’ (DoH, 2007) based on concepts said to underpin the Human Rights Act (1998); this avoids the need for technical legal knowledge (Curtice & Exworthy, 2010). This approach aims to enable staff to strive for better practice, not just ensure minimal standards; it aims for the ceiling, not the floor.

The human rights framework relevant to psychology and mental health has been outlined by others (Patel, 2019) and a number of human rights principles have been advanced as relevant to healthcare (e.g. Curtice and Exworthy, 2010; Patel, 2019). The ‘FREDA’ values (Curtice and Exworthy, 2010) include fairness respect, equality, dignity, and autonomy, and the ‘PANEL’ principles, proposed in Scotland, include participation, accountability, non-discrimination, empowerment, and legality (Cross Party Group on Alzheimer’s, 2009). Other lists have also included universality, inalienability, indivisibility, and inter-dependence as key principles (UNFPA, 2005). This multiplicity of lists appears to imply that these ‘key principles’ are constructed, rather than emerging from human rights law in some natural, inevitable way.

I will define each of the ‘FREDA’ principles here, based on the definitions of Curtice and Exworthy (2010), as these definitions will be of use for later chapters. Briefly, ‘fairness’ requires that a person is afforded due consideration of their opinion, and the opportunity to have that view heard and weighed alongside other relevant factors in any decision-making. Respect is the unbiased and objective consideration of the values, rights, beliefs, property of others. The principle of equality is multi-faceted, with non-discrimination as a key component. Dignity can be considered a state or manner worthy of respect and, by extension, self-respect. Finally, autonomy is the principle of self-determination, and it speaks to the freedom of a person to choose what happens to them. These principles are inter-related and inter-dependent (UNFPA, 2005). More detailed definitions are in Appendix A.

1.5. On ‘Children’s Rights’

The concept of ‘children’s rights’ is a relatively new phenomenon. Some argue that the idea of ‘children’s rights’ took hold in public discourse largely within the last 50 to 100 years (Kosher, Ben-Arieh, & Hendelsman, 2016), apparently prior to the conception of human rights. A brief foray into the history of children’s rights provides insight into some of the current debates, including the tension between paternalistic notions of protection and the drive to allow independence and self-determination. When reviewing this history, the ‘3P model’ is commonly used as a guiding framework (Toope, 1996; UNICEF, 2007); rights are said to prioritise ‘protection’, ‘provision’, or ‘participation’. In a very similar vein, several authors have made the distinction between ‘nurturance rights’ and ‘self-determination rights’ (Baumrind, 1978; Hart, 1982; Wrightsman, Rogers, & Percy, 1975 – all in Ruck), where the former refers to the right to protection and care, and the latter to some measure of control, autonomy, and participation.

1.5.1. A Brief History

From a Eurocentric perspective, before the 16th century, ‘childhood’ was not considered a separate life stage, with those over the age of six seen as small adults. Children were not a separate class from adults, and children were thought of, both legally and socially, as the property of their parents (Hart, 1991). Child labour was the norm and schooling was, for the most part, non-existent (Hart, 1991). At this time, children had very few, if any, legal rights (Stier, 1978).

The industrial revolution brought with it changes to child labour, with industrial settings that were often farther from home and with adult non-relatives. The recognition of children as endangered, from both the workplace and from adult strangers, has been linked to one of the main developments in children’s rights in the ‘Western world’: the notion of children as vulnerable beings in need of adult protection (Alaimo, 2002).

The child labour reform movement brought about a successful campaign of regulation and then elimination of industrial child labour, alongside a discussion of the meaning of childhood as a time of physical, intellectual, moral and social development (Alaimo, 2002). As schooling became more common and, later, compulsory, the notion of protection was joined by the notion of provision; attention was given not only to their safety but also to their basic needs, including schooling and healthcare (Archard, 1993; Brandon et al., 1998). However, there remained limited recognition of their freedoms and self-determination (Alaimo, 2002; Kosher, Ben-Arieh, & Hendelsman, 2016).

Only in the latter half of the 20th century was there was a noticeable shift towards acknowledgment of a child’s autonomy. Whilst the UN’s 1959 Declaration of the Rights of the Child held a predominantly protection-provision view (Cohen, 2002), the next few decades were key to the development of participation rights. The U.S. Supreme Court, for example, made a series of landmark decisions (re Gault, 1967; Tinker v des Moines Independent Community School District, 1967; Planned Parenthood v

Danforth, 1976) that reflected a developing recognition of children as "persons" entitled to many of the same rights as adults.

In 1989, the UN General Assembly adopted the Convention on the Rights of the Child (CRC). This record-breaking Convention, the most ratified of all human rights treaties (Cohen, 2002), crucially highlights that the child is an individual with a voice and developing autonomy (Alaimo, 2002), who should be respected as an individual with their own perspective and intentions (Krappmann, 2010).

1.5.2. Where History Has Left Us: Contemporary Views of Children's Rights

Though it could be argued that the rights of children are better detailed and implemented, globally and locally, than ever before (Kosher, Ben-Arieh, & Hendelsman, 2016), it is not the case that children's rights mirror the rights of adults (Hart, 1991). There is not the same focus on dignity or integrity that is afforded to adults, and rights can be indirect via a parent or guardian (Kosher, Ben-Arieh, & Hendelsman, 2016). Under the CRC, children's rights are viewed as different to those of adults; whilst they have adult-like rights, they require special protections (Goodwin-De Faria & Marinos, 2012). In the preamble of the CRC, it is stated that the child requires special safeguards "by reason of his physical and mental immaturity" (Preamble, UN, 1989); the CRC constructs children as 'rights-bearing citizens', who, by way of their age and maturity, are considered in a state of 'diminished responsibility' (Goodwin-De Faria & Marinos, 2012). Perhaps conflictingly, almost one-quarter of the Convention's article are related to self-determination (Hart, 1991), which seemingly implies a growing belief in a child's right to active participation (Quennerstedt, 2016). This debate has great relevance to this thesis, as it is this tension between protection and autonomy that, whilst relevant to mental health care more generally, is perhaps an integral feature of children's mental health care.

1.5.3. Critiquing the Concepts of 'Childhood' and 'Children's Rights'

The view of a child as a citizen with diminished responsibility can be critiqued. Leading child sociologists have argued that contemporary views of children as objects for development or socialisation, as ‘adults in the making’, diminish the human value that a child holds in the present (James, Jenks and Prout, 1998; James and James, 2004). These authors consider biological immaturity to be a universal feature of life, not restricted to childhood (James & Prout, 2003), and reject the view of a child as lacking competence or rationality. Instead, they view children as active social agents that are not only shaped by others, but actively shape their surrounding society (James, Jenks and Prout, 1998; James and James, 2004). As contributors to society, they hold knowledge of their own (Corsaro, 2005), and this knowledge is a source from which we, as ‘adults’, can learn a great deal (Quennerstedt, 2016).

The concept of ‘children’s rights’ is also not without criticism, with some philosophers going as far as to argue that children are volatile and unreliable and, as a result, cannot be trusted to exercise their rights (Brighouse, 2000). Other critics are less concerned about whether a young person can be ‘trusted’ with these rights but, instead, propose that affording greater self-determination rights might actually conflict with a child’s right to be cared for and nurtured (Baumrind, 1978).

Further, the legal system has been challenged, with barrister and judge, Christina Lyon (2007) calling the CRC international rights ‘toothless tigers’ without the ‘bite’ of national law. The dependence on age and stage could also be regarded as undermining of the principles of human rights as equal and inalienable for all. Further, international children’s rights have been criticised as individualistic, ‘post-colonial’ and ‘Western’, imposing their authority on the poorer majority without consideration of local needs or cultures (Imoh & Ame, 2012; Balagopalan, 2014).

Acknowledging these critiques and debates, I take the position that human rights apply to *all*. This, of course, includes children. Whilst a child’s vulnerability evokes the need for additional protection, this protection can prevent self-determination and can discount the important perspective that every young person brings to an issue. Thus, with any vulnerable group and with young people in particular, we must hold in mind the delicate balance of protection and autonomy.

1.6. Relevance of Human Rights to Psychology/ Mental Health

According to the foreword of the ‘Human Rights in Healthcare’ framework (DoH, 2007), “healthcare and human rights are dependent upon each other. Quite simply, we cannot provide good care without respect for human rights” (p.2). Whilst the author agrees with this position, it is worth exploring further the relationship between human rights and healthcare, psychology, mental health, and the mental health of young people in particular.

1.6.1. Relevance to Clinical Psychology

Firstly, human rights violations have a causal effect on distress (e.g. Johnson et al., 2010; Neufeldt, 1995; Steel et al., 2009), and a core purpose of the profession is to reduce distress (DCP, 2010). Secondly, mental health practices are known to infringe human rights principles (Cady, 2010; Gostin & Gable, 2004; UN Human Rights Council, 2013) and psychologists may be complicit (Patel, 2003). Thirdly, the NHS, as a public authority, and its staff are duty-bearers under the Human Rights Act (1998) and must comply with all human rights obligations. Thus, understanding human rights is a vital part of the role of psychologists in the NHS, from both an ethical and legal standpoint and Patel (2019) argues that a human rights-based approach to psychological practice demands a respect for human rights principles, alongside ethical obligations, in all aspects of psychological practice, services, clinical supervision and team discussions.

1.6.2. Relevance to Mental Health

In a review of basic patient rights in psychiatric care, Cady (2010) stressed the relevance of human rights issues from the moment a person is admitted to hospital, if not well before. In the process of admission, the person likely loses a number of freedoms that most take for granted: the ability to leave with ease, to schedule one’s time, and to choose activities. Under certain conditions of ‘capacity’, a person may also lose the ability to manage their own finances and legal affairs, or make other important decisions. This restriction of everyday activities inevitably raises human rights issues. If mishandled, mental healthcare-specific procedures can raise further issues, for example around confidentiality, informed consent, and the right to have the least restrictive care possible. Further, Cady (2010) argues that psychiatric care can be “more coercive and less open to public awareness and accountability than the treatment of patients with other medical conditions” (p.117). These, in combination, prime the context for a powerful concoction of human rights issues.

In recent years, these human rights issues have been put under the spotlight in the international arena (United Nations, 2017a; UN, 2017b; UN, 2017c). For example, the documentation from the Human Rights Council Resolution on Mental Health and Human Rights (UN, 2017a) states that the council are:

> *“Deeply concerned* that persons with mental health conditions or psychosocial disabilities, in particular persons using mental health services, may be subject to, inter alia, widespread discrimination, stigma, prejudice, violence, abuse, social exclusion and segregation, unlawful or arbitrary institutionalization, overmedicalization and treatment practices that fail to respect their autonomy, will and preferences […] sometimes amounting to torture or other cruel, inhuman, or degrading treatment or punishment” (p.2, italics in original text)

On the domestic stage, a 2018 report by the government-requested Independent Review of the Mental Health Act (“Modernising the Mental Health Act”, 2018) acknowledged the difficulty of circumstances where rights appear to conflict, such as the right to liberty versus the right to life in the case of potential significant self-harm or suicide. The authors called upon the principle of proportionality, and stressed that the least invasive action be taken that still enables the state to fulfil its duties. Furthermore, the Chair of the review spoke expressly to the complexity of balancing a person’s autonomy with the State’s duty to protect the vulnerable. This balance of protection and autonomy mirrors the aforementioned discourse of nurturance versus self-determination in the children's rights literature. The authors describe autonomy versus protection as a fundamental tension that "no amount of legislation, recommendations, reports or inquiries can ever solve" (p.16), but nevertheless express the need to rebalance the system to be more in favour of the preferences of the patient. Crucially, the report stresses the importance of a rights-based approach, with a focus on improving respect and dignity, in order to redress this balance.

1.7. Human Rights and Children's Mental Healthcare

Much of the above applies to young people's mental health services as well as to the adult sector. Young people still stand to lose freedoms upon admission to a ward, human rights principles are still relevant to numerous aspects of their care, protection still needs to be balanced with autonomy, and incidents of abuse are known to have occurred in Child and Adolescent Mental Health (CAMHS) settings just as they are known to have occurred in adult wards. However, whilst this may be the case, there is very little, if any, literature that explores the relationship between human rights and children's mental health. What follows is a summary of the grey literature on the key issues for children's inpatient mental health services. Human rights are rarely, if ever, mentioned explicitly in these reports, but their findings can be interpreted through a human rights lens, much in the same way that human rights principles have been shown to be relevant to mental healthcare more generally (Curtice & Exworthy, 2010).

1.7.1. CAMHS Inpatient Mental Health Units: Current Concerns

A report from the Education Policy Institute (Frith, 2017) explored the inpatient provision for children and young people in England, analysing data from the NHS national datasets, NHS Digital and NHS Five Year Forward View for Mental Health Dashboard, as well as information from existing literature. The report highlighted a significant number of concerns, including problems accessing beds and subsequent admission of young people into adult wards, a dearth of community care, workforce shortages, and concerns around the quality of care. As part of their assessment on the quality of care, the report specified concerns around restraint and seclusion, with 15% of units unable to provide information on the frequency of restraints used on young people, and 21% without a policy on the use of seclusion. Further, there were ten deaths of young people under the age of 18, from the years 2013 to 2017, who were under the responsibility of inpatient services. A report from the House of Commons Health Committee highlighted similar concerns (HCHC, 2015).

These reports can certainly be interpreted through a human rights lens, for example in their relationship to the right to life, the right to health, and the right to freedom from torture or cruel, inhuman, or degrading treatment, amongst others. However, these reports provide an understanding of some of the human rights issues in CAMHS inpatient units, but less indication of how we might put human rights principles into practice.

1.7.2. Young People's Experiences of Psychiatric Inpatient Units

It proved difficult to examine the literature on young people's experiences of inpatient units. Though there are studies focusing on outcome data, such as clinician ratings or 'symptom change', comparatively little is known about young people's subjective views of their care. Of the few studies available, some focused on a specific aspect of inpatient care, for example the transition into adult services (Gill, Butler, & Pistrang, 2016), the experiences of those with a particular diagnostic label (e.g. Offord, Turner & Cooper, 2006), or the challenges faced by those with a particular identity (e.g. sexuality; LeFrançois, 2011). These studies are of use and relevance and, together, can provide valuable insight, but the breadth of the topic does not easily lend itself to a brief review.

To give an example of specificity, LeFrançois (2011) explored heteronormative practices within one UK inpatient CAMHS unit, using grounded theory to examine "heterosexist-infused power relations" (LeFrançois, 2011, p. 1). The specificity of this study is not a criticism; the study makes important points about how we should be examining our practice. The study gave many examples of heteronormativity in mental healthcare, where ‘heteronormativity’ refers to the inherent ways in which those who do not conform to dominant norms around sexuality are “rendered as abnormal and subjected to intense scrutiny and control” (LeFrançois, 2011, p.2). Such examples include staff’s reaction to same-gendered hand-holding, monitoring of young people’s sexualities, and individualizing a ‘queer’ young person’s distress rather than viewing it as a reaction to societal oppression. Whilst specific to sexuality, the experiences described by the young people in this study appear to relate to issues of equality and non-discrimination more widely.

Other studies took a broader stance, exploring general issues faced by young people in inpatient wards. Whilst these studies are also of interest and value, they can be limited in their depth of exploration of the perspectives and meaning-making of the young people involved. For example, the Charity YoungMinds conducted a series of studies into CAMHS inpatient experiences (Street, 2004; Street & Svanberg, 2003; Svanberg & Street, 2003). The findings highlighted a number of important concerns around information sharing, limited bed numbers, and out-of-area placements. There was also some attempt to explore the subjective experiences of young people, with mention of feeling left out of decision-making, and worries around privacy, boredom, lack of connection with the ‘outside’, and the effects of limited physical activity. However, it could be argued that these studies did not explore the meaning of these experiences for the young people in depth. As an example, the researchers quote one young person, who stated “I thought I was going to be locked in a bed. I was pleased once I got in and found out what it was like. … it wasn’t as bad as I thought…” (Street, 2004, p.116) and summarise this as a concern about a “lack of information”, rather than, say, an expression of fear or anxiety around restrictions to freedom and autonomy.

One study that did explore the experiences of young people in more depth was that of Offord and colleagues (2006) who examined the retrospective views of young people with a diagnosis of anorexia nervosa (Offord, Turner & Cooper, 2006). The researchers conducted semi-structured interviews with seven young people placed in general inpatient psychiatric wards; thus, whilst the choice of interviewees was diagnosis-specific, the context was similar to that of the current study. Using Interpretative Phenomenological Analysis, the researchers proposed four themes: removal from normality versus connecting with the outside world; treated as another anorexic versus a unique individual in distress; control and collaboration; and the importance of peer relationships. The findings emphasized how services, in their current approach, often almost completely separate a young person from the 'outside'. The participants also spoke of staff's assumptions based on diagnostic labelling, as well as to issues around control and powerlessness under the guise of protection, and active discouragement of connections with other service users. Note, though the authors did not explicitly consider these experiences from a human rights perspective.

Polvere (2010) also conducted interviews with twelve adolescents and young adults with multiple experiences of 'out-of-home placements' in the United States, including juvenile detention and foster care. All participants had some experience of a mental health inpatient placement, and the focus of the study was on their experience of this in particular. The study shed light on the "dehumanizing and traumatic experience" of physical restraint (Polvere, 2010, p. 326), the disappointing lack of therapeutic intervention and poor discharge planning, as well as the effects of conflict with staff, conflict with other service users, and stigma, shame and alienation as a result of diagnostic labelling and placement. This study is an important yet distressing read, and is not the only call for awareness of the negative effects of intensive inpatient mental health care (e.g. McNeal et al., 2006).

Finally, media articles can also shed some light on the experiences of young people in inpatient units. One example is comedian Fern Brady's exploration of the iatrogenic effects of her past experience in a CAMHS day-unit. In her article, she describes how she felt "pathologised and treated suspiciously", and describes very little formal psychological support, poor information-sharing between services, and little to no follow-up or transition (Brady, 2015). Though this is a retrospective description of one person's experience, it raises concerns that other young people may still relate to today, and may also be interpreted through a human rights lens, for example with reference to the principles of respect, non-discrimination, fairness and inclusion.

Thus, whilst the pool of research into subjective experiences of inpatient mental healthcare is limited, it nevertheless raises significant and multiple concerns. What appears to be missing is an in-depth consideration of the experiences of young people that prioritises their perspectives and delves into how these experiences can be understood through a human rights lens. The current study is one attempt at beginning to meet this need.

1.8. Exploring Human Rights Understanding in Young People

A glaring gap in much of the documents and literature considered thus far is the perspectives of young people themselves.

1.8.1. The Importance of the Young Person's Perspective

From a human rights perspective, research that focuses on the young person's perspective indicates respect for their views (Melton & Limber, 1992) and allows them the autonomy to speak for themselves in a context where their views are often ignored (Goodwin-De Faria & Marinos, 2012). This avenue also has the potential to protect young people from further harm (Peterson-Badali, Morine, Ruck, & Slonim, 2004); any improvement in their understanding of human rights will allow policymakers and researchers to better promote the wellbeing of young people (Peterson-Badali & Ruck, 2008). Furthermore, if young people know their rights, they will be better equipped to speak up against violations (Howe & Covell, 2005; Peterson-Badali & Ruck, 2008); in this way, knowledge may enable assertion (Ruck et al., 1998).

Research that explores the perspectives of young people is also beneficial for the sake of learning. Children's views contribute important knowledge, and the inclusion of their perspectives respects their full human status as 'knowers' (Murris, 2013; Spyrou, 2011), values this knowledge and extends the boundaries of what is already known (Quennerstedt, 2016). But knowledge is not just for the sake of knowledge; if we, as professionals, better understand human rights in context, then our practices can be improved. We can design more ‘age-appropriate’ processes and training, and we can use our knowledge to help inform existing debates around autonomy versus protection (Hart & Pavolic, 1991; Ruck, 1994; Quennerstedt, 2016), with the hope of changing practice to allow for the least restriction whilst still maintaining the state’s duty of care. It is for all of the above reasons that this thesis puts the spotlight on *young people’s understanding* of human rights and human rights issues.

1.8.2. The Role of Models of Moral Development

Given that this study is an exploration of young people’s perspective on human rights, it is worth considering the role of child development. If one is of the belief that moral reasoning and ethical decision-making develop over time, then age and stage must be taken into consideration; one would question when children are able to understand rights in a meaningful way. Theories of moral development, such as the work of Piaget (1932, 1965) and Kohlberg (e.g. 1969, 1981) come to mind. These authors both proposed stage-like models, according to which moral development goes beyond the simple ‘passing on’ of morality from one generation to the next, to its active construction by the individual. These theories are not without criticism, for example due to the apparent inconsistency of moral development across different content (Carpendale, 2000). Nevertheless, general models of moral development have influenced theories of the development of rights reasoning (e.g. Melton, 1980, 1983).

Melton (1980, 1983) examined children’s understanding of self-determination rights across different age groups, and suggested a three-stage model of rights reasoning. According to this model, children progress from an egocentric orientation where rights are perceived as privileges that can be given or taken away by an authority figure, to rights as social rules based on the principle of fairness, to rights as abstract universal principles. This final stage, of rights as abstract universal principles, has been thought to only develop at the later stages of adolescence (e.g. Gallatin, 1985; Melton, 1980;

Melton & Limber, 1992; Peterson-Badali & Ruck, 2006). Whilst these stage-like models are worth holding in mind when developing a research paradigm that examines young people's understanding of human rights, they are again not without criticism; Helwig (1995), for example, found that younger adolescents can, in fact, display understanding of abstract concepts such as freedom of speech and religion. In addition to such findings that cannot be explained by global stage models, it is also worth acknowledging that these theories of moral development are based on methodological approaches in which the parameters of rights are defined by the researchers through pre-designed questionnaires and vignettes; these studies do not explore young people's construction of human rights as distinct from researcher-led frameworks. The focus of this study, on the other hand, is on the young people's constructions of their experience and understanding and, as such, their views are considered of interest and relevance regardless of age or stage. It would be of interest in the future to explore if or how their perspectives differ by age and development, but this small-scale study does not lend itself to this aim.

1.8.3. Literature Search Strategy

A literature search was conducted, searching the following databases: Child Development and Adolescent Studies, CINAHL Plus, PsycArticles, and PsycInfo. After attempting numerous search strings that yielded either far too many results to feasibly review, or seemingly irrelevant search results, a search string was used that combined synonyms for 'young people' with synonyms for 'understanding of human rights'. Notably, 'mental health' and related terms were not included in the search; this was a pragmatic decision after multiple failed attempts, yielding anywhere between 88 and 666,000 search results, with very little relevant material. The final search string was:

> *(child* OR young people OR adolescen*) AND ((understand OR explain) human rights OR (understand OR explain) rights)*

With no limit on the date or location of the research, the final search string revealed 168 results. From the title alone, 101 of these results were clearly irrelevant to this study; exclusion criteria at this stage included titles that mentioned ‘right handedness’ or ‘right hemisphere’, for example. The abstracts of the remaining 67 articles were then reviewed and, through this process, a further nineteen were considered irrelevant to our review. The inclusion criteria at this stage were two-fold: articles that spoke explicitly of young people’s *understanding* of human rights, regardless of context, and articles that did not mention understanding of human rights nor mental health, but spoke of a human right or rights principle that could feasibly hold relevance to a mental health context. As a result, articles were mostly discounted for reasons of specificity and irrelevance, for example in the case of an article about a child’s right to know their origin (Besson, 2007).

The remaining 48 articles were read in full, as were articles of relevance in their reference lists. At this stage, to be included, articles had to explore how human rights are constructed and understood by young people themselves. A key exclusion criteria was a focus on cognitive and developmental changes in reasoning, using a research paradigm where the parameters of the human rights domain were already set by the researcher. Whilst these studies are of interest and use, this thesis takes the position that the *young person’s perspective* of human rights and human rights issues is of crucial importance, rather than what they think of pre-specified rights. After these exclusions, the following is a review of the articles that remained.

1.8.4. The Importance of Age and Development

Of all the factors that might affect understanding, age has received notably more attention in the literature (Goodwin-De Faria & Marinos, 2012). When participants are asked to define a “right”, studies have often concluded some form of development, with age, from a more concrete understanding to a more nuanced conception of human rights (Grisso et al. 2003; Melton, 1980; Peterson-Badali & Abramovitch, 1992; Peterson-Badali & Ruck, 2006). Melton’s stage model attempts to provide an explanatory framework for why children may understand rights in different ways. This model proposes a progression from an understanding of rights as privileges that can be taken away by authority figures, to rights as rules and a means of maintaining social order, to rights as abstract universal principles (Melton, 1980). Note, though, that the role of age has not been consistent across studies (Crawford & Bull, 2006; Helwig, 1995; Peterson-Badali & Ruck, 2008), and factors other than understanding could account for age-related differences. Whist these stage models of human rights understanding may be limited, age and development are nevertheless key factors in the protection versus autonomy debate, and many participation rights are only bestowed once a child can demonstrate the required competencies (Peterson-Badali & Ruck, 2008).

1.8.5. The Importance of Context, Power and New Frameworks

When young people were asked for examples of rights, the majority of studies concluded that participants were able to generate a variety of responses, from protection from abuse, to psychological needs, education, access to basic needs, medical care, and the right to make decisions (Peterson-Badali & Ruck, 2006; Taylor, Smith & Nairn, 2001). However, this was not always the case, and some studies have claimed that participants' awareness is generally low (Akengin, 2008; Gwirayi & Shumba, 2011). There are key differences in country of study and other contextual variables. It is not possible to conclude the exact reasons for these differences, but it can be reasonably assumed that context plays a significant role in how young people come to understand their rights.

Very few studies have explored young people's understanding of human rights in a particular context, for example in school, criminal justice settings, or in mental health services. In the rare case of a mental health-focused study, the participants were students being asked about a hypothetical situation (Belter & Grisso, 1984; Molinari, 2001), rather than young people with lived experience of the services themselves. Studies of understanding in context are key; an approach that only asks general questions about children's perceptions of rights will not allow an examination of which rights are of paramount importance in that context, or why (Quennerstedt, 2016).

The literature search only revealed three studies that had considered young people's own perceptions of human rights in a particular context, of which they had relevant lived experience. Two were in an educational context, in Sweden (Quennerstedt, 2016) and Scotland (I'Anson and Allan, 2006), and the third in the context of the Canadian criminal justice system (Goodwin-De Faria & Marinos, 2012). Importantly, the fifty young recipients of non-custodial sentences in the Goodwin-De Faria & Marinos (2012) study spoke to the influence of power and their feelings of powerlessness. The authors suggested that it was this lack of power experienced by youth in the criminal justice system that had the greatest impact on their inability to exercise their rights. Comparably, I'Anson and Allan (2006) found, in a school context, that young children aged seven to eleven viewed their rights as limited by the school context, and viewed themselves as low in the hierarchy.

Power is a concept of great relevance to the experience of childhood and adolescence in general, with some claiming that young age can be considered an inequality in itself (Goodwin-De Faria & Marinos, 2012; Tyyskä, 2014), and others emphasizing the "dangerous and debilitating power [of adults], capable of stunting the personal development and potential of even the most resilient children" (Scraton, 1997, p. 186). Arguably, the role of power is additionally salient in an inpatient mental health context, given the freedoms that are limited from admission and beyond (Cady, 2010), and the powerful gatekeeping role of staff.

Finally, Quennerstedt (2016) found, in their interview study of eight- and twelve-year-old children's views on school-based rights, that most of the children's explorations of rights could fit into the established human rights framework of civil, political rights, and socioeconomic rights. However, and importantly, the author concluded that the children predominantly emphasized human feelings and the emotional aspects of rights issues in school. This emphasis fits less well into established frameworks and raises new ideas about the meaningful aspects of rights to young people in this setting.

1.9. Justification of Current Study

To summarise, human rights are of paramount importance to mental healthcare and human rights issues are an inseparable aspect of the current mental health system, including children's services. Whilst there has been research into adults' understandings and views of human rights in adult mental health settings (Patel, 2016) there is no existing study that explores young people's perspectives on human rights and human rights issues in the context of mental healthcare, and certainly none in the context of inpatient care. An understanding by clinicians of young people's views could inform practice and services and, it is hoped, help protect young people's rights within services.

1.10. Research Aims and Questions

The aim of the proposed research was to explore young people's understanding of human rights issues within the context of an inpatient psychiatric unit. The key research questions were:

- How do young service users understand human rights in the context of a young people's psychiatric inpatient unit?
- What do they experience as 'human rights issues'?

The research questions were framed in this way for two main reasons. Firstly, the separation of the two research questions is an attempt to explore both the young people's *definitions and understanding of the term* 'human rights' in this context, and also the *experiences* that they refer to when asked about human rights issues. Secondly, the term 'human rights issues' was used in preference to the term 'human rights violations'. The latter is a more concrete conclusion, as would be used in a court of law. This study cannot and does not attempt to determine whether laws have or have not been 'broken', but instead attempts to raise areas of potential interest or concern from the perspective of the young people. The term 'issue' is more reflective of this tentative approach.

2. METHODOLOGY

This chapter describes the ontological and epistemological positioning of the research, followed by details of the study design, recruitment, study procedure, and data analysis. The chosen approach and underlying theory are critiqued and justified throughout, with consideration given to the validity of the research methodology.

Before continuing, a brief note of clarification is needed. When this project was first proposed, the idea was floated of including the perspectives of parents and caregivers alongside those of the young people. Ethical approval was obtained for individual interviews or a focus group with parents, but with the understanding that this was a possible addition to the study, not its main purpose. In the event, parents and caregivers proved very difficult to recruit, with only one parent taking part. This interview followed the same procedure as with the young people, except that the location was on university grounds. For ethical and legal reasons, explained in the 'Further Discussion' chapter, this interview was not analysed. Since the method was broadly the same, and the data could not be included, no further mention is made in the text of this chapter, but the reader can refer to appendices C, G and J for the parent and caregiver recruitment poster, information sheet and consent form.

2.1. Epistemology, Methodology and Method

Epistemology, methodology, and method can be thought of as three fundamental facets of research, guiding its planning, implementation, and evaluation (Carter & Little, 2007). These three facets have been assigned various, often conflicting, definitions (Carter & Little, 2007). For the purposes of this study, epistemology can be defined as "the study of the nature of knowledge and justification" (Schwandt, 2001, p. 71). A methodology can be defined as "a theory and analysis of how research should proceed" (Harding, 1987, p.2), whilst the methods are the "procedures, tools and techniques" of research (Schwandt, 2001, p.158).

2.1.1. Critical Realism as an Epistemological Stance

In this study, my epistemological stance was that of critical realism. Critical realism as a philosophical movement is widely attributed to the British philosopher Roy Bhaskar, who combined ontological realism with epistemological relativism (Bhaskar, 1975). A critical realist position follows a realist's ambition to better understand a supposedly independent existing reality, whilst acknowledging that the data gathered may not provide direct access to this reality (Willig, 2013). There is the assumption that certain social and psychological processes or patterns shape the thinking of participants and that attempts can be made by the researcher to identify these. However, the data must be interpreted in order to access these underlying structures, and the extent to which these interpretations are thought to approach certainty can vary substantially between researchers (Willig, 2013).

In the case of this study, my position assumes that participants' responses, and my analysis, offer some reflection of 'real' underlying psychological and social processes, but they are also influenced, for example, by the beliefs, past experiences, cultural and societal factors, and so on, of both myself and the research participants. The research aim was to examine how young people understand human rights in practice and how they make sense of experiences that they consider to be human rights issues; from my epistemological stance, there is an implication that their descriptions of their experiences are underpinned by real processes.

2.2. Methodology

The research questions stress young people's *understanding* of human rights and human rights issues. This focus on the construction and negotiation of meaning has implications for the choice of study design, in striving to choose the right method for the right question (Oakley, 2000). Qualitative data collection techniques, or techniques in which the researcher relies on text rather than numerical data (Carter & Little, 2007), are participant-led and allow for meanings to be heard (Willig, 2013), as well as access to the views of those who are disadvantaged in terms of power (Oakley, 2000). They do not rely on predetermined hypotheses but are open-ended, exploratory in nature, and allow for consideration of phenomena in context (Carter & Little, 2007). As such, qualitative methods of enquiry are compatible with our research questions and epistemological position.

2.2.1. My Position on the Choice of Methodology

A qualitative design was also appealing to me personally. I arrived at this project believing that something about the current mental health inpatient system needed to change, but unsure of what or how. I also held, and continue to hold, a strong belief that most academia is derived from the powerful voices of a small number of highly-privileged individuals. As someone with a background in teaching, I have seen, first-hand, the incredible and insightful views of young people, whose voices, I believe, often go unheard. Qualitative research can allow for an exploration of lesser-heard views; as such, it was my clear preference.

In keeping with the markers of good quality qualitative research (Elliot et al., 1999), I believe that reflexivity is key. In line with this, I kept a reflective journal throughout the process. I also made use of supervision to consider the impact of the research on me personally, as well as on the perspective and personal context that I was bringing to the research.

2.3. Method

The method adopted in this study was informed by a previous study undertaken by my Director of Studies, with adults and staff in mental health services (Patel, 2016). A detailed research record was kept in line with research integrity frameworks (e.g. University UK, 2012).

2.3.1. Service User Consultation

I hold the view that service user-informed research is of paramount importance for policy and practice (Liabo, 2013). I also believe that it is our ethical duty to include people in the research that goes on to affect them. I presented the research to a service user research advisory group, consisting of ten service users and carers, who were paid for their time by the local NHS Trust. I chose to present prior to submission of the application for ethical approval, so as to alter the study in accordance with their recommendations.

Whilst many members of this research advisory group had past experience of CAMHS services, I must acknowledge that this decision to approach an adult-only research group was far from ideal. Though the group itself provided invaluable advice, I am regretful, on reflection, that I did not also seek the views of young people.

The members of this research group advised predominantly on research design and ethical implications. They gave feedback on the wording of the questions, and discussed how to make the study as meaningful as possible to those involved. Their suggestions informed the method.

2.3.2. Study Site

All participants were recruited from a single NHS CAMHS inpatient mental health site. This site consists of two psychiatric intensive care unit (PICU) wards, one with four beds and another with 12, in addition to a 12-bedded acute ward. The choice of study site was pragmatic, given the limited numbers of PICUs in London and the already-established links between this particular NHS Trust and the Director of Studies.

2.3.3. The Recruitment Process

The recruitment process was as follows. Posters, provided in Appendices B-C, were displayed around ward areas, with details of how to contact the researcher. More detailed information sheets, adjusted for different age groups, in line with the recommendations of the Research Ethics Committee, were also available in public areas of the ward as well as in the staff office. These information sheets are provided in Appendices D-G.

Participants were able to contact the researcher via the staff, but I also made sure that the young people knew I would be present on the ward at a regular time each week so that they could speak to me directly; in doing so, I attempted to remove additional staff-related barriers to participation.

I then met with the staff team to explain the study and their role in it. This ‘staff role’ was to guide service users towards information sheets should they indicate interest in participation and to support the young people to contact the researcher if they should so wish. Ward staff were explicitly requested to take on a supportive and information-providing role and were discouraged from actively convincing young people to participate, in an attempt to avoid coercion. Ward staff were also asked to support the researcher with ‘handover’ and informed consent, which are explained later in this chapter.

Over the course of around two months, I attended the ward on a weekly basis. I spent time in ward areas, speaking to young people, explaining the purpose of the study and, if a young person indicated interest, showing them the leaflets and information sheets.

Participants who had indicated their interest were booked in for a future interview time. For the young people under the age of 16, it was explained that we would need to gather parental/ caregiver consent and enough time was given in between ‘booking in’ and the interview date to do so. The parents/ caregivers were then contacted via telephone to explain the study and provided with information sheets and consent forms.

2.3.4. Inclusion and Exclusion Criteria

It was my aim, to the greatest extent possible, that all service users be given fair and equal access to study participation. In line with this, mental state was considered in the context of capacity, as discussed later in this chapter, but was not a strict exclusion criteria. It was my belief, from past professional experience, that actively unwell individuals may be at a higher risk of subjection to human rights issues (e.g. unnecessary restraint, seclusion) by virtue of their distress, and their involvement in the study was therefore of high importance.

The criteria for participation were as follows. Young people had to be an inpatient in the unit at the time of data collection, as interviews took place on the ward. Language was not an exclusion criteria, as there was the option to book an interpreter; in practice, this was not needed as all participants had English as their first or an additional language.

2.3.5. The Number of Participants and 'Data Saturation'

My recruitment estimate was eight to ten young people. The number of participants was, in part, a practical decision, given the time-limit of this doctoral thesis and the number of service users in the mental health unit to which we had access. However, some consideration was also given to data saturation.

Theoretical saturation is a concept closely related to grounded theory, but is also called upon in other qualitative analyses, including thematic analysis, as a justification for sample size (Ando, Cousins, & Young, 2014). Theoretical saturation was originally defined by Glaser & Strauss (1967) as the point at which no additional themes are identified in the analysis of further data. Some studies have concluded that 12 interviews are sufficient for theoretical saturation in cases of a relatively homogenous group (Ando, Cousins, & Young, 2014; Guest, Bunce, & Johnson, 2006). In the case of this study, one could argue that our sample size of eight should theoretically have allowed for a reasonable level of data saturation, but since the sample size was limited by the number opting to take part, it is not possible to tell whether additional participants would have significantly altered the findings.

2.3.6. Assessing Capacity

A person is said to lack capacity in relation to a matter "if at the material time he is unable to make a decision for himself in relation to the matter because of and impairment of, or a disturbance in the functioning of, the mind or brain" (Mental Capacity Act, 2005, Principle 2.1). In the case of this study, a young person would not lack capacity by virtue of their status as an inpatient on a mental health unit, but instead would have to be proven to be unable to make the decision to participate (MCA, 2005, Principle 1.2).

Young people who also hold the status of ‘mental health inpatient’ could be considered a doubly vulnerable group, by virtue of their youth and supposed psychological status. It is therefore imperative that any research in this context incorporates suitable safeguards, one of which would be the assessment of capacity. In this study, I received a ‘handover’ on the day of the young person’s interview, summarizing the young person’s current ‘mental health’ and including their views on whether the young person would currently meet the four criteria for establishing capacity: that they can understand the relevant information, retain it, weigh it up as part of the process of decision-making, and communicate their decision (MCA, 2005). However, this was not our sole source of information with regards to capacity, since it was my view that staff alone should not hold the power to prevent a young person from participation, especially given our focus on human rights issues in the context of their care. Instead, this information was taken as a contextual guide, and I also conducted a brief capacity assessment prior to commencing the interview, checking the four aforementioned areas.

2.3.7. Informed Consent

The construct of ‘informed consent’ is based on three aspects: participants gain knowledge through the provision of information that can be understood; consent is given voluntarily, and the participant has the capacity to give this consent (Beresford, 1997). Informed consent is a highly debated area of children’s research, with particular consideration given to the age at which a young person can consent and how researchers should approach the process of informed consent in order to find a balance between gatekeeping and coercion (Kirk, 2007).

All participants were provided with a detailed and clear information sheet and asked to sign either an assent form (for those under 16) or a consent form (for those aged 16 and over). Separate information sheets were available for those aged 12-13, 14-15 and 16-18; these varied only in the language used, not in the content, and were a request of the Research Ethics Committee in an attempt to meet the first criteria of informed consent: the provision of information that can be understood (Beresford, 1997). See Appendices D - F for the information sheets and Appendices H - J for the consent forms.

Parental consent was also acquired for those under the age of 16. Whilst parental consent for those under 16 is an attempt at protection, this gatekeeping role may nevertheless deny children the opportunity of participation or, conversely, result in coercion (Harden, Scott, Backett-Milburn, & Jackson, 2000). This denial of participation is a hard obstacle to overcome, particularly in the context of the ward, where many care decisions require parental permission, and is therefore a necessary critique of the current study. Coercion, though inherently present to some degree, was minimized by checking in with the young person about their reasons for participation and stressing that it was their choice.

For both young service users and parents/ caregivers it was not assumed that the information sheet had been read or understand in full. As an additional safeguard, I also went through the information sheets with the participants prior to obtaining their written consent and gave the opportunity to ask any questions.

2.3.8. Interview Procedure

The semi-structured interviews followed an interview schedule, provided in Appendix K. This interview schedule was based on the interview schedule used by my research supervisor in a similar, currently unpublished study on adult PICU wards (Patel, 2016). It was adapted slightly for use with young people, with more accessible language, and was also altered after feedback from a service user group. The interview schedule consisted of open-ended questions covering the young person's general impressions of being on the ward, what the young person understood by the term 'human rights', their experiences of human rights issues on the ward, and any suggested improvements for the hospital. Where necessary and appropriate, prompts were given from a range of options, also detailed in the interview schedule. For the most part, questions were asked in the order of the interview schedule but, in line with guidelines for semi-structured interview procedure (Gill et al., 2008), there was a level of flexibility in terms of the ordering of the questions and the direction of questioning.

Each interview lasted no longer than one hour and took place in a quiet room on the participant's ward. By virtue of the subject matter, it was expected that some participants might become distressed and it was emphasised, both in person and in the information sheets, that the participant could stop or pause the interview process at any time.

2.3.9. Data Collection Technique

This study used individual semi-structured interviews. Since the research question, choice of data collection technique, and method of data analysis, are all dependent on one another (Willig, 2013), it is worth noting that semi-structured interviews are compatible with thematic analysis (Braun & Clarke, 2006).

Interviews are the most commonly used method of data collection, in part because of their compatibility with multiple methods of data analysis, and in part because of their relative ease of organisation (Willig, 2013). In this study, it was also thought that individual interviews with young people would allow for the adaptation of pace to the young person, who vary in age and, likely, extent of interview-related anxiety. Interviews also have the potential to provide access to rich data. However, they are not without criticism. Potter and Hepburn (2005), for example, claim that researchers making use of interviews do not necessarily pay attention to the contextual features of the interview material, for example the stake that the interviewer and interviewee both have in the interview, the power relationship between interviewer and interviewee, and the meaning and experience of the interview for both participants. Acknowledging this critique, this study made use of interviews as a data collection method with the caveat that the words of the interviewee are not a simple reflection of their thoughts and feelings, but a product also of the interview context.

The level of ‘structure’ to an interview (structured, semi-structured, or unstructured) affects the speed of administration, the extent of guidance for the participant, the level of ‘depth’, and the extent to which the questions reflect preconceived theories or, conversely, allow for the discovery of information that was not previously thought pertinent by the researcher (Gill et al., 2008). In the case of this study, semi-structured interviews were a purposeful decision. They allow for some guidance for the participant, which may be particularly helpful for those who may never, or rarely, have discussed the topic of ‘human rights’ before. However, they also allow for participants to lead the discussion in a direction that may not have been expected by the researcher. This is particularly important given that our research aim was to explore the participants’ understanding of human rights, not the understanding of the researcher.

2.3.10. Method of Data Analysis

Data from the individual interviews were subject to thematic analysis, which can be defined as “a method for identifying, analysing, and interpreting patterned meanings or ‘themes’ in qualitative data” (Braun, Clarke, & Terry, 2015, p. 95). This form of qualitative analysis is hailed for its accessibility and flexibility (Braun & Clarke, 2006; Braun, Clarke, & Terry, 2015), the latter referring to its supposed compatibility with a range of epistemological positions and data collection methods, as well as its compatibility with both inductive and deductive data coding and analysis, and its suitability for the reporting of both semantic meanings and more latent ideas.

Whilst thematic analysis has the potential to suit a wide range of research questions and topics, this study included, its flexibility must be met with clear explanations of the choices made by the researcher (Braun & Clarke, 2006). In the case of this study, I took a dual deductive-inductive approach (Joffe, 2011). Themes can be deductive in the sense that they are drawn from a theoretical idea that the researcher brings to the research, or inductive if drawn from the data itself. In the current study, deductive themes can be derived from theories of human rights, or human rights principles, allowing for consideration of relevant legal frameworks. However, by combining these with inductive themes, one can also explore how people make sense of their experiences and allow space for ideas that do not match the existing framework, with the potential of producing new knowledge of the area.

With regards to semantic or latent themes, I also took a dual approach. In the initial stages of analysis, I relied predominantly on the young people's vocabulary and expressions: a semantic approach. In the later stages of analysis, I started to connect the themes with established human rights concepts: a more latent approach. With this dual approach, I attempted to remain as open as possible to alternative or new understandings of rights, whilst also connecting the findings to existing literature.

2.3.11. Transcription

The process of transcription can be thought of as an interpretative act (Braun & Clarke, 2006). A transcript is not simply 'talk written down' (Green, Franquiz, & Dixon, 1997), but a constructed representation of an event (Bird, 2005), with meanings created through the process of transcription (Lapadat & Lindsay, 1999).

In keeping with the flexible nature of thematic analysis, there is no one set of guidelines for transcription (Braun & Clarke, 2006). However, decisions must be made about the level of detail, punctuation, and the most suitable way to represent non-verbal utterances (Willig, 2013). In this study, all material was transcribed verbatim, with a few exceptions. Where information risked breaching confidentiality, it was removed or replaced with a descriptor. Non-verbal utterances were included and pauses were also denoted. A full key of symbols used in transcription and write-up is given in Appendix L.

2.3.12. Stages of Analysis (Braun & Clarke, 2006)

After transcription, a thematic analysis was conducted on the resultant data corpus, following the six phases of thematic analysis suggested by Braun and Clarke (2006).

In phase one, I familiarised myself with data through the process of transcription, note-taking, reading, and re-reading the transcripts. Following this, in phase two, initial codes were generated across the entire data set, where a code is considered to be the most basic meaningful element of the raw data (Boyatzis, 1998). An example excerpt of the coded transcript is provided in Appendix M. These codes differ from themes, which are developed in the third stage of analysis; themes are broader, and are where the interpretative analysis occurs.

In this third phase, codes were collated into potential themes; themes were searched for and constructed in an active process and did not simply ‘emerge’ from the data. With over one thousand original codes, the first step was to sort these into potential categories or themes, based on broad-level similarity in content. At the start of this process, there were thirteen categories, where the term ‘category’ simply means ‘initial theme’, but is used for clarity in this write-up. These categories had the general headings of: abuse, inhumane or degrading treatment; boredom, stimulation, interest; equality and discrimination; freedom, movement, leave; explanations of human rights; health, pain and medication; helpful aspects; independence, choice and involvement; need for flexibility; privacy and dignity; power; restrictions and restraint; relationships and connectedness; and identity. The codes for each of these categories were collated and reviewed for their internal consistency. Simultaneously, the lists of codes were constantly checked against the original data extracts to check that the codes were representative of the original data. An example of the codes listed under one of these categories, ‘relationships and connectedness’, is given in Appendix N, and an example of these codes being checked against their original data is given in Appendix O.

By drawing maps and tree diagrams of these categories, I was able to make better sense of the sub-categories within, as well as the overlap between different categories. Appendix P is an example of one of these initial category maps, again for the example category of ‘relationships and connectedness’. Appendix P also includes other examples of these candidate thematic maps.

Reviewing these potential themes, in this fourth stage of analysis, some themes were discarded or collapsed, whilst other categories were split between different themes. For example, after reviewing the data that fell under the category ‘health, pain and medication’, these extracts referred almost exclusively to the harm caused by treatment, and so were placed under the theme ‘harm and iatrogenic effects’. Reviewing the data for the category ‘restrictions and restraint’, on the other hand, it was felt that some of the data referred to the harm caused by restriction and restraint, and so was placed under the same theme as ‘health, pain and medication’, whilst other aspects of the data referred to the importance of finding a balance of safety and restriction, and so was placed under this theme. After a repeat process of collapsing, splitting, and checking, the original thirteen categories were whittled down to the final six themes. Appendix Q is an illustration of how these original thirteen categories relate to the final six themes. Again, there was constant checking against the original interview data to ensure meaning had not been changed or lost in this process.

In stage five of the analysis, the themes were named and defined and a final list of themes was constructed (in ‘Analysis’, Section 3.2). At this point, each of the six themes had a list of associated data extracts and codes and it was possible to finalise the number of sub-themes. Sub-themes were included only if there was enough data to justify this decision and if their inclusion added clarity. For example, there was an overwhelming amount of data under the theme ‘harm and iatrogenic effects’, and so this was split into the four sub-themes of: physical harm and violence; the spiral of response and escalation; not being believed; and iatrogenic effects of treatment. By contrast, there was less data under the theme ‘heard and involved’ and so it did not feel useful to split it down into further. As in the example of ‘relationships and connectedness’, this was split into the two sub-themes of ‘inside’ the ward and ‘outside’ the ward, as illustrated in Appendix O.

In the final stage, the thematic analysis was written-up in the analysis chapter of this thesis. In line with my epistemological position, this write-up is a ‘constructed’ argument, in the sense that it is one of many possible reflections of the underlying, ‘real’ experiences of the participants. At this final stage, some of the themes were re-named to include phrases from the participants themselves, where a particular comment appeared to sum-up the theme as a whole, as in the example of Theme 3: “I’m just told what to do” – Heard and Involved.

2.4. Ethical Considerations

An application for ethical approval was submitted to the NHS Health Research Authority (HRA) using the Integrated Research Application System (IRAS). As part of this application, I met with a local Research Ethics Committee (REC) who questioned me on the details of the study before offering their favourable opinion, see Appendix O, subject to a few minor methodological changes. The study then also received approval from the local research and development team, see Appendix P, via their research partnership with Noclor Research Support. The study was also in accordance with the Code of Human Research Ethics of the British Psychological Society (BPS, 2014).

2.4.1. Ethics and Research with Young People

Whilst there has long been interest in research around childhood, this research has, largely, avoided involving them directly and, instead, has made use of adult proxies attempting to speak on behalf of the young people (Hill, 1997). This approach was, in part, thought to be due to concerns of vulnerability to exploitation and the inherent power relations between adult and child (Beresford, 1997; Harden et al., 2000; Morrow & Richards, 1996; Punch, 2002).

In more recent years, there has been an increase in child-centred research (Kirk, 2007), on the basis that children can be competent and willing participants in the research process provided that there is adequate communication and facilitation from the researcher (Thomas & O’Kane, 1998). In an example of this facilitative approach, Kirk (2007) produced a list of strategies for managing the aforementioned inherent power differentials. Some of these suggestions were not possible in the current study; for example, conducting a group interview with the young people ran the risk of compromising confidentiality and silencing some voices. However, other strategies were incorporated in this study, including checking on the young person's willingness to participate throughout the interview, noting nonverbal cues and body language, practicing with the young person how to decline a question, and responding to the young person's agenda through the use of a more flexible interview schedule.

2.4.2. Confidentiality

The research adhered to the Caldicott Principles (The Caldicott Committee, 1997). As is considered 'good practice' (Alderson, 1995), the limits of confidentiality were clearly explained both in the information sheets and in person at the start of each interview and focus group. In particular, where a young person indicated that there may be a risk to their safety or the safety of others, the researcher had a duty to inform the relevant persons and services, in accordance with NHS Code of Confidentiality (Department of Health, 2003).

With these caveats, every effort was made to maintain confidentiality. The environment was quiet and private, recordings were immediately transferred to a password-protected computer, and all data was anonymised and stored in accordance with the regulations of the Data Protection Act (1998). Where a participant spoke of a situation that was highly specific to them, the researcher checked, post-interview, with both the participant and the research supervisor, as to whether to include the information in the study or remove that element of the data. Participant details were kept in a password-protected database, separate from the data to avoid cross-identification. The relevant healthcare professionals, including ward staff and general practitioners, were aware of who was taking part in the study but had no access to any of the research data. These arrangements were all made clear in the participant information sheets and were explained before the start of an interview.

2.4.3. Considering the Potential for Harm

2.4.3.1. *Participant distress:* It was expected that discussing human rights and human rights issues could cause distress to the individual. Wherever possible, I sought to reduce this distress; I checked in with the participant, allowed for silence where appropriate, and offered to stop, take a break, or postpone the study. The interviews were also followed by an informal debrief.

2.4.3.2. *Expectations of Advocacy:* I predicted that, should participants disclose negative care experiences, they may expect advocacy. It was stressed, in the information sheets and in person, that this was not possible within the remit of the study; in stressing this, I hoped to reduce this expectation and subsequent disappointment. However, whilst I could not advocate myself, I was able to guide participants towards complaints agencies and advocacy services that could support them.

2.4.3.3. *Reporting Incidents:* Though I was not able to advocate on behalf of the young person, I expected that I may be faced with difficult decisions around safeguarding when or if a young person reported a negative care experience. After discussions with my thesis supervisor and with the managers of each ward, we agreed that I would check with the young person if the staff were already aware of this event, and report any new safeguarding concerns to the relevant ward manager. We planned that I would let the young person know that I was raising a concern with staff. In the event, several young people reported incidents that raised concerns. In every case, the young person assured me that the staff were already aware of the incident. The majority of these young people opted to make a complaint and/ or contact an advocacy service. This was a difficult process as I was balancing the confidentiality of the young person with my concerns for their wellbeing, whilst attempting to not get ‘ejected’ from the system.

2.4.3.4. *Researcher Safety:* As per ward protocol, I had access to a personal alarm. I also notified staff on the unit before an interview took place and after it was finished. The clinical ward manager requested that I had ‘breakaway’ training, and I provided evidence that I had completed this as part of my doctorate induction.

3. ANALYSIS AND DISCUSSION

This chapter is a presentation of the research findings; it is, primarily, an arrangement of themes and the participants' words from which these themes have been derived. However, the reader will also notice the occasional connection to existing literature. This is the beginning of a shift from a simple presentation of surface-level findings to the construction of an argument. In the final 'Further Discussion' chapter, this argument is further developed, relevant literature is considered in more detail, and the implications to policy and practice are stressed.

3.1. Participants Recruited

To maintain the anonymity of the participants, only brief participant demographics are presented here. Interviews took place with eight young people, ranging in age from 15 to 17; there were two 15-year-olds, one 16-year-old, and five 17-year-olds. Three identified as male, four as female, and one as gender non-conforming. Four identified as 'White British', two as 'Black British', and two as 'other' minority ethnic background (not detailed to prevent identifiability). At the time of interviewing, four were staying in the acute ward and four were in one of the two psychiatric intensive care unit (PICU) wards, though several participants had past experience of both ward types. The length of time in the service ranged from one week to 14 months.

Most interviews lasted around thirty minutes, though one was significantly shorter. This young person, who has been diagnosed with a learning disability, chose to answer a few questions and then stop as soon as she felt she did not want to answer any more. As a result, there are fewer quotations from this participant, despite her voice being included in the analysis to the greatest extent possible.

3.2. Key Themes

Table 1. Summary of Themes and Sub-Themes.

Main Themes	**Sub-Themes**
"I Don't Know Anything About It" – Explicit and Implicit Understanding of Human Rights	*This is a briefer theme with no sub-themes.*
"Lost in the World" – Connections and Relationships in a Ward Context	Connections to the 'Outside World'
	Connections Inside the Ward
"I'm Just Told What to Do" – Heard and Involved	*This is a briefer theme with no sub-themes.*
Equality and Protection from Discrimination	Race, Nationality and Racism
	Gender and Gender Identity
	Socio-Economic Status
Harm and Iatrogenic Effects	Physical Harm and Violence
	Not Being Believed
	Iatrogenic Effects of 'Treatment'
	The Spiral of Response and Escalation
Balancing Safety and Restriction	*This is a briefer theme with no sub-themes.*

There were six main themes, some of which had a number of sub-themes. These themes are all inter-connected and, arguably, could be further collapsed. For example, experiences of discrimination and feeling disconnected, unheard, and uninvolved, could all constitute forms of harm by virtue of the distress that they cause. Whilst I acknowledge these connections, I have chosen not to collapse the themes further. I recognise that this has resulted in more themes that might usually be expected in a thematic analysis, and I am aware that this may be seen as a limitation of the study. However, when I attempted to integrate the themes further, I felt far too much of the nuance was lost, and I was concerned about stepping too far away from the voices of the young people.

A key for the presentation of extracts is provided in Appendix L.

3.3. Theme 1. “I Don’t Understand Anything About It”: Explicit and Implicit Understanding of Human Rights

When asked about their understanding of the term ‘human rights’, by far the most common answer was some variation of the phrase ‘I don’t know’:

> (Interviewer) Have you got any thoughts on how human rights relate to this?
>
> *I don’t even know much about human rights, I won’t lie. (P8).*

There are numerous reasons why a young person might state they “don’t know” about human rights, including confidence, not having the language to describe their understanding, and the interaction of hierarchy, experience and power. In suggesting reasons, we are going beyond the data. However, what was clear was that for every explicit statement of ‘not knowing’, there were numerous explanations of experiences felt, by that young person, to be “right” or “wrong”. This way of understanding human rights parallels the suggestion of human rights as basic moral norms (Nickel, 2019). Whilst most spoke of things that were “right” or “wrong”, one participant also explicitly connected these concepts with their definition of human rights:

> *What's right and what's wrong… and that's kind of the foundation of what human rights are. (P1)*

As well as labelling an experience or approach as "right" or "wrong", many participants also named 'established' human rights principles, in accordance with our current human rights framework. Named principles included privacy ("*I feel like, erm, privacy, is a good human right*" (P3)), safety ("*I have the right to… safety. From myself and others*" (P3)) and avoiding harm ("*Don't cause harm"* (P2)), as well as freedom of movement and activity ("*Freedom to go. Freedom to do stuff like* that" (P5)) and respect ("*Show people respect*." (P2)). This again implies understanding and knowledge of human rights, despite explicit statements of uncertainty and confusion.

Note, though, that not all participants expressed uncertainty, and some also stressed the importance of human rights to them:

> *Human rights mean technically everything to me cos… you're not human if you don't have your rights. You don't have liberty. You don't have freedom. You don't have… anything. (P1)*

It is perhaps of interest to consider the rights and principles that first come to mind for the young person, in this case of liberty and freedom. These rights are not dissimilar to the human rights issues that Cady (2010) explained come into play from the moment an adult is admitted to a psychiatric unit, and indicate potential similarity between the adult and the young person experience.

When asked about their understanding of human rights, some spoke to the idea of human rights as minimum conditions needed for survival:

> *Human rights are the rights that humans have to be able to survive and live on a daily basis. So… rights that mean that you don't get attacked randomly, you don't get sworn at, you don't get kicked, you don't get punched. These are what human rights are. (P4)*

For this participant, their understanding of rights appeared highly linked to their personal experiences on the ward; this participant went on to report that he had been punched and kicked by staff. Note that ‘harm’ is considered in more detail in a later theme.

Whilst, for the above participant, the minimum conditions for survival were centred on surviving physical violence, for others, ‘basic needs’ were food and some level of financial security:

> *So, human rights I’ve like heard of in school. So, like, the rights that a human deserves to like live. […] I think the human rights in this country would be to have a roof over your head, have food and to have drink, and to have, I want to say, a stable job […] But erm… yeah, just like the right to be able to live erm, live a decent life at least, where you’re not, where you’re not like having to scrape out one grain of rice for dinner, you know? Like actually being able to pay for food and stuff. (P3)*

This idea of human rights as basic needs holds somewhat of a parallel with the argument of human rights as minimums: the school of thought that suggests human rights should be centred around avoiding the worst, rather than striving for the best (Nickel, 2019). As such, the understanding of young people appears to fit into some form of existing human rights framework.

Consider another pre-conceived ‘key principle’ of human rights: universality. If the participants held this view, then their answers might reflect this notion of human rights applying to all humans, regardless of the person, and independently of whether these rights are found in practice. Whilst some participants nodded to this notion of universality, it was met with caveats:

> *Yeah, I’ve heard of the term… Yeah. We all have rights. It depends, it’s different for everyone to be honest. (P8)*

It is difficult to ascertain an understanding of the principle of universality from this response; the young person states that “We all have rights”, but then goes on to say that it is different for each person. This implication of differentiation between persons was also specified, by another participant, on the basis of country of living:

> *Erm… human rights… especially in this country, I don’t want to say for other countries because I’m not very erm educated on other countries. (P3)*

This potential confusion over the universality principle, as indicated in these responses, was similarly noted in a study on youth understanding of rights in a criminal justice system context (Goodwin-De Faria & Marinos, 2012), which implies that it may be a wider finding. Furthermore, if young people believe that their human rights are dependent on the person or country, or are privileges that can be taken away, then this may form a barrier to the assertion of their rights.

Since the implementation of rights can be subject to practice, some philosophers have proposed that human rights are rooted more deeply than in legal enactment alone. One argument is that human rights are in some way innate or inherently linked to the notion of humanity (Morsink, 2009). This innate rooting of human rights was suggested by one of the participants:

> (Interviewer) Where did you first hear about human rights?
>
> *It’s an actual term. I know it from birth. It’s in my genes, it’s in my blood. (P4)*

In a similar vein, others made a connection between human rights and the subjective experience of humanity:

> *Well I was always confused because there are very few things that, if you think about it completely logically, are human rights violations.*

> *But… it does feel like… your humanity. You stop feeling like a person and you become a patient for a while, and they're very different things. (P7)*

This statement makes reference to the link between human rights and humanity but also to the confusion over the concept of "human rights violations", as well as to the impact that human rights-related experiences can have on one's sense of self and how one is treated by others. This idea of 'patient versus person' was thread throughout the interviews, and is a key later theme.

Finally, several young people called for greater awareness and education of human rights and human rights issues:

> *If I'm honest I'm really not that well-rehearsed in my rights. I feel like… um… I should be because… in society that's kind of what's mandatory of people to know… um… we should uphold those values. (P1)*

This is not to imply that rights are never mentioned on the ward or explained by staff. Instead, one participant explained that the rights spoken of in a ward environment are not rights in their totality, and are not the only relevant rights in a ward context:

> *I've heard of human rights, like rights for children and stuff but honestly no one ever talked to me about the sort of rights that you'd need here? They always talked to me about the right to play, the right to see both parents and it just didn't really apply since I got here. Er… They read your rights. They do that every week, whether or not you're on section or you're informal, to make sure that you have the right to an advocate, you have the right to… all of this stuff, so there's… yeah. They do a lot of covering their butt, as well. (P7)*
>
> (Interviewer) And it sounds like they read you rights about the section or about being informal

> *Again, they miss the part that is your dignity and identity and stuff. (P7)*

It is these lesser-mentioned rights issues, of dignity and identity amongst others, that are explored further in this thesis.

3.4. Theme 2. “Lost in the World”: Connection and Relationships in a Ward Context

This theme centres around the young people’s need for connection with others, both inside and outside the ward, and the distress that can be caused by a perceived sense of disconnection from the people, places, and activities that are important to them. It connects to the understanding of human rights as unavoidably linked to humanity: to what it means to be a human. It is also heavily linked to the human rights principle of respect and the need to be valued as an individual, not a ‘number’ or ‘condition’, as illustrated by the following participant:

> *Obviously, people respond if there’s an incident or something, but people who actually take the time to recognise you as a person. People who would see you if you’re having a hard time and remember not just, you know, your care plan […] Erm… yeah, and people… people who, if you were in a one-to-one with them, would talk about something that’s relevant to them, something that doesn’t make you feel like you’re talking to an automaton. Something that makes you feel interesting, because you can tell them something weird [laughs] and they’ll actually have a conversation with you about it. You know, just human stuff, actual human stuff that people bring. (P7)*

3.4.1. Connections to the ‘Outside World’

Connections and relationships were discussed both in relation to the ‘outside world’, and within the ward context. This sub-theme explores the former. It holds relevance to the right to private and family life and correspondence, and it speaks to the need to be understood as, and allowed to be, a person with relationships, friendships, and networks, not a stand-alone ‘patient’.

> *[When I first arrived] I just felt really, like… I want to say lost in the world, at the risk of sounding dramatic. But it is like when you’ve lost a lot of things, like education, and friends, and family. Everything… your house, your area. Everything that you would assign to living, you don’t really feel like you’ve got anymore, and that’s like really weird [laughs], to go from good friends, and a good education, good grades, to like really really bad health and just coming here, and it was like a real shock… to me. (P3)*

Several young people spoke about the importance of telephones for their ability to allow connection with friends and family outside of the ward:

> *Um… I’d say not having a phone to contact friends is really hard… cos I used to be on another hospital with a different ward and they’d allow your phone and… I feel like it was such a privilege to be able to use my phone and be able to contact my friends. I wish that I could actually go back in time and… contact them more. (P1)*

Notably, telephone restrictions varied considerably between ward and individual, with the more restrictive rules in PICU, and those considered most at risk of, for example, self-harm via battery-ingestion, the most restricted of all. In these cases, the safety precautions taken by staff also had, perhaps unintended, consequences on the young person’s ability to hold a private conversation.

> (Interviewer) Okay, so is there anything that you would like me to know, that you haven’t had a chance to say so far?
>
> *Erm yeah, I’m not allowed to hold the phone for calls. I have to have it on loud speaker with somebody holding it, because I have a history of swallowing batteries. (P2)*

> (Interviewer) What does that mean in terms of speaking to people that you need to?
>
> *It's quite like… I only speak to my dad or my solicitor. I don't speak to anyone else. Yeah, because it would be too awkward otherwise. (P2)*

3.4.2. Connections Within the Ward

This sub-theme speaks to connections and relationships within the ward, both with other young people and with staff. Many spoke of the support provided by other young people on the ward, with one participant explaining that "*some of the people, young people, who stay on the ward um… give motivation to get up every single day and continue the process and treatment*" (P1). This mutual support was limited by some of the rules of the ward, as in the example of the 'no touching policy'.

> *But then I've also found amazing people who understand, who have again restored my faith that there's good people. And then, with relationships with them, there's stuff like a no touching policy, which sometimes is absolutely soulless because you just want a hug. Erm… and as long as you ask, "Is that okay? Are you someone who hates hugs?" Like… "Sure, do you want a hug too?". That's sort of a normal thing to do, and I think the staff that I like most are the people who are willing to bend rules like that, to let us. Instead of saying "Oh don't high five each other". Letting us be a little less fake. (P7)*

The above participant spoke of the need for flexibility of approach, a 'bending of the rules'. This of course links to the later-discussed theme of balancing restriction with safety but, in this case, has consequences predominantly for the young person's ability to form connections with others on the ward. For those staying for long periods on the ward or those with limited connection to others outside of the ward ("*my parents have only come twice since I've been here, because I live a million miles away*" (P3)), a hug from a fellow young person may be all the more important.

These in-ward connections are, of course, not limited to the young people, but extend to the staff as well. One young person spoke of the importance of "*the tiny things as well. Like, even if you've had a horrible day and people have had to even physically intervene, somebody just… spending time with you*" (P7). When asked what makes a good staff member, another young person spoke of "being there" for the young people and the importance of showing care.

> (Interviewer) What makes a good staff member?
>
> *Consistency. Empathy. Sympathy. Not brushing things off. Erm, what else. Being there most of the time. Having one-to-ones, if it's safe to be in a room, like me and you are here. Have that with that child. That child needs it. If the child says, "Please check under my bed, I'm scared of the monsters"… check under the fucking bed. (P5)*
>
> (Interviewer) Yeah help them out, be there for them.
>
> *Exactly. So if you're trying to train people, you need to cut out the jobsworth, and you need to… find the ones that care. (P5)*

This need for connection and care from staff was consistently discussed by the young people, with some also acknowledging the systemic barriers, including staff turnover.

> *Some days it's just random staff members on the ward from other wards and it's kind of hard to keep up when everyone is transitioning so much. If you want an actual relationship like with a staff member to try and bond with them, it can be a bit hard and… intimidating almost. (P1)*

In addition to the limits of time and system, a further hurdle to the forming of connections between staff and young person is that of consent and treatment.

Understandably, care from staff needs to be perceived as genuine. In the context of medication and treatment, at times against a young person's wishes, the connection between staff and young people can become strained, and caring responses can be interpreted as disingenuous by a young person if thought to only occur when persuasion is required.

> *I feel like the staff try to be like friends with you to be able to manipulate you. (P4)*
>
> (Interviewer) Tell me about that.
>
> *So, [NAME OF STAFF MEMBER 2], the man that just came in? He keeps doing [thumps fist on chest and makes 'peace sign' with fingers] "Bro bro bro" to me in the corridors. But the thing is, I feel like he's doing that not because he likes me as a person, but because he has to manipulate me as a patient. (P4)*
>
> (Interviewer) And what is he trying to manipulate you for?
>
> *Taking medication, doing my chores, things around the hospital. (P4)*

3.5. Theme 3. "I'm Just Told What to Do": Heard and Involved

This theme focusses on the young person's experience of feeling heard and involved in the discussions and decisions that affect them. Here, we explore the subjective experience of the young people on the ward, and consider occasions where they may have felt more or less listened to, and more or less included in the decisions that affect them.

> *They just… They don't really consider what you feel. Like… there's been one time where they've properly considered what I wanted and what I've been saying, but other times they just brush it off and do their own thing. (P2)*

For one participant, their experience of not feeling heard or listened to was explicitly linked to a feeling of powerlessness. They connected this powerlessness to stigmatized attitudes towards people with mental health difficulties:

> *I was in constant agony, like it was so bad […] But there's nothing I can do about it because I have no power here. I'm just sort of told what to do and… you do it. (P3)*
>
> (Interviewer) What do you make of that idea of power here?
>
> *Erm… I feel like they don't listen. Because they know that we, we are… on a mental health unit, and I think they assume that everybody is stupid, or crazy, or addicted to something, and it's not like that. (P3)*

This feeling of powerlessness was thread throughout responses, and particular mention was made of powerlessness in the context of involvement in decision-making processes, or lack thereof. These decision-making processes were predominantly around changes in medication, or the decision to allow leave from the hospital grounds. In these cases, power comes to the forefront in the form of hierarchy and professional expertise:

> *They just took me off my old [medication], which was working, and put me on this. (P5)*
>
> (Interviewer) Did they tell you why?
>
> *No. And they took me off my anti-depressant. So now I want to kill myself every morning. (P5)*
>
> (Interviewer) Why has there been no explanation, do you reckon?

> *Because they don’t have to give me an explanation. Yeah, there’s no rule that says they have to tell you why. They’re the consultant, they’re the doctor. There are different levels and they’re the highest. (P5)*

Intertwined with this idea of levels and hierarchy is the notion of ‘Us Vs Them’: a separation of patient and staff, with one holding power over the other. This difference is drawn upon by the young people to explain the disparity in involvement:

> *They’ve never explained why, I’ve just always seen it as… this is what makes us staff and this is what makes you patients. (P1)*

This difference between person and patient, along with the power disparity that goes hand-in-hand with age, profession, mental health status, and other visible and invisible difference, has consequences for the weighting of voices. Difficulties arise when a professional adult’s view of what is in the young person’s best interests conflicts with the views of the young person themselves. On these occasions, the views of the young person can take second place, and a display of giving choice to the young person can feel false:

> *I was under section for eight of my months here, which meant that I really didn’t have much choice and the choice that I did have was in a certain framework that was made by them and I was… a lot of the choices I was making, well, I was making the choice on paper but really it’s not how… it’s not a choice. […] “Do you want to do stuff other than what you actually want to do? I think that you do, I think that it would be a really good idea for you to do that”. I understand that people have my best interests at heart, but… it wasn’t my choice. That’s the, the choices that were given to me. When I was first here they just made them for me in the blink of an eye, because I didn’t want what they wanted. (P7)*

This notion of ‘false choice’ was discussed by multiple participants in the context of an informal admission to hospital, where ‘informal’ refers to the practice of voluntary admission without detention under the Mental Health Act (1983). Whilst, in principle, a young person informally admitted to hospital should have greater control over decisions, more freedom to leave the ward, and the ability to refuse treatment (Mind, 2018), several young people spoke of how this can play out in practice as false hope and a feeling of being misled:

> *About that ‘you can leave when you want to leave’ thing. They need to stop saying it like that, because people are thinking that if you want to leave you can just leave, but it’s more of, if you want to leave you can ask to leave, and they can say yes or no. So I don’t really think that rule of it should really be there, because it’s just annoying, I can’t lie. (P8)*

This young person went on to explain that the problem did not lie with the informal admission system, but with the explanation (*“I understand that they can’t always let you leave. I feel like that’s alright, but they should let people know their rules good and properly*” (P8)). Another participant explored the impact of ‘false hope’ further, in this case about a decision to disallow a move from one hospital to another, and described the resultant escalation of distress and anger:

> (Interviewer) What else would you like to tell me about when it comes to human rights or human rights issues?
>
> *[Long pause]. Being lied to. A lot. That happens a lot. […] I’m being lied to again by the ward manager. So that’s two ward managers which have lied to me. (P5)*
>
> (Interviewer) The old place and the new place.
>
> *Yep, this place right here. (P5)*

> (Interviewer) And… why do you think that's happened?
>
> *To keep you calm. To give me hope. But it's false harm, and it's false calmness. Now it's just anger. You're just delaying the inevitable. (P5)*

In the above cases, the young person's preference was not adhered to, and it could be argued that their view was outweighed by concerns around the safety of the young person and their best interests. However, when one also considers the impact of power and hierarchy, one might question this heavy weighting of professional's views over the young person's.

3.6. Theme 4. Equality and Protection from Discrimination

Several young people spoke of their experience of differential treatment on the basis of race, gender, gender identity, and financial means.

3.6.1. Race, Nationality and Racism

For one participant, perceived discrimination on the basis of race and nationality, had a significant impact on their level of distress:

> (Interviewer) What are the some of the feelings that you've had about this place?
>
> *Agitation. Knowing constantly knowing that there's a lot of people that hate you, it's a very bad thing. (P4)*
>
> (Interviewer) Why, why do people hate you?
>
> *Discrimination. Racial discrimination because I'm [National Identity]. So the fact that you know that constantly makes you feel agitated. You have to think about every move that you do, just in case someone sees it as wrong. (P4)*

In thinking about every move “just in case someone sees it as wrong”, this participant seems to be referring to a compensatory strategy (Miller & Myers, 1998; Shelton, Richeson & Salvatore, 2005): a strategy used to manage the effects of known conscious and unconscious racial stereotypes (Devine & Elliot, 1995; Graham & Lowery, 2004). It is also worth noting that the participant explicitly connected their racialized experiences as a non-British person of colour to their feelings of agitation. This lends itself to our growing formulation of increased distress as a result of experiences of difference in a ward environment.

3.6.2. Gender and Gender Identity

Gender was also discussed as a key predicting factor in how young people are treated on the ward. One participant spoke of the perceived staff preference for girls over boys:

> *I think there’s a gender issue as well. (P5)*
>
> (Interviewer) Yeah? Tell me about that.
>
> *There’s a girl here that assaulted a boy here and nothing happened. But I know that if I went and punched that girl. Oh fuck me, I’d get the worst. I’d get the book thrown at me for doing that. (P5)*
>
> (Interviewer) So it sounds like it might be a bit more lenient for girls here?
>
> *It’s more lenient in all mental health for girls. Everyone wants the girls to get better. Before the boys. I’m seeing it first-hand. (P5)*

Any relationship between gender and leniency is difficult to ascertain from this information alone, though related literature is considered in the next chapter. The key message here is that, for this young person, their experiences felt discriminatory on the basis of their gender, and this perceived gender-based discrimination may have amplified their negative views of the ward and staff ("*I'm stuck here in this shit hole. And I hate it*." (P5)).

Participants also spoke of the importance of considering gender identity, and of the perceived differential treatment of transgender and gender non-conforming individuals on the ward. One participant's experience on the ward as a gender non-conforming transgender individual, was negatively impacted by a perceived lack of awareness of the triggering effects of the gendered clothing provided in seclusion:

> *They have to take all of your stuff away. At one point I wasn't even allowed clothes. Not… clothes. I had to wear like anti-ligature stuff, that happened to be pink, which was like oh my god… And I wasn't allowed other clothing, so gender was… all over the place. (P7)*

For this participant, the experience of gendered clothing appeared to amplify a form of gender dysphoria, or the distress caused by a marked incongruence between the gender assigned at birth and one's gender identity (Alastanos & Mullen, 2017). One might wonder whether this increased distress only extended their time in seclusion, raising further issues of inequality and its impact on freedom.

The perceived lack of awareness of the needs of gender non-conforming or transgender individuals was further reported by another participant:

> *[Staff] kept calling him a she. And all the she pronouns. It was actually unacceptable. Like, you know LGBTQ, all that jazz. So they make out that they're really big on LGBT, which is cool. Well, […] I wouldn't have even known [that they were transgender] if all of them hadn't said 'she', and that's just, that's just made me furious. (P3)*

This participant is aware of the likely distress ("*he feels like shit*" (P3)) caused by 'misgendering' and 'outing', where misgendering is the misclassification of gender identity and 'outing' is the practice of revealing a person's gender or sexual identity. Whilst, in this case, the person reporting the experience was not the recipient of the remarks, it is not a stretch to imagine the impact that this experience may have had on the young person in question.

3.6.3. Money and Socio-Economic Status

Finally, on the theme of difference and inequality, some mention was made of the impact of various levels of financial freedom on the young people's experience on the ward. Several participants mentioned the phone restrictions on the ward, and some noted their appreciation for a more flexible approach:

> (Interviewer) Can you tell me a bit more about what they did that was more adaptable?
>
> *For example, you're not allowed your phone on the PICU, but they would let me lock my phone in the other room so that I could use my music through my Bluetooth headphones. (P7)*

However, this same flexible approach, by virtue of its reliance on an expensive piece of equipment, was not a possible avenue for others on the ward:

> *Like with me, to get to sleep, I need music kind of thing. I'm not going to just, like buy that Bluetooth thing or whatever, just 'cos I'm here and I need to listen to music to get to sleep. I don't, I don't need to use up money just to have what I need to go to sleep. (P8)*

This young person went on to explain the multiple avenues they had tried, including asking for the use of a cheap radio, which was denied. Thus, what for some people was perceived as a more flexible approach to rules and restrictions, for another young person was perhaps an experience of indirect discrimination on the basis of socio-economic status.

3.7. Theme 5. Harm and Iatrogenic Effects

This theme attempts to explore some of the experiences and understanding of participants on the topic of ‘harm’. The examples provided by the participants covered a range of different experiences, including distress from denial and dismissal, degrading treatment in seclusion, verbal mistreatment, sexual abuse and harassment, physical violence, food restriction, distressing repeated injections and restraints, and painful or debilitating medication side-effects. From a human rights perspective, these experiences link to Articles 3, 6 and 24 of the UNCRC, that of the right to life, the right to protection and care from services that conform to standards of safety and health, and the right to the highest attainable standard of health. There are also implications for the right to freedom from torture and cruel, inhuman or degrading treatment.

For clarity, this theme has been divided into four sub-themes: experiencing and observing physical harm and violence, not being believed, iatrogenic effects of ‘treatment’, and the spiral of harm and escalation. However, these sub-themes are very much interconnected. For example, one young person reported sexual assault, responded with violence, was then restrained and put in seclusion, further self-harmed as a result, and felt their disclosure was dismissed by staff; this narrative could fall under every single one of the aforementioned sub-themes.

3.7.1. Physical Harm and Violence

Several young people spoke of experiences of physical pain, either from experiences of restraint or from side-effects of medication. In these cases, the young people appeared to more explicitly label these experiences as harmful. It is possible that they are considered more extreme examples of harm, or perhaps they are more easily understood as harm, as opposed to, say, the distress caused by denial and dismissal of a problem. One participant disclosed that they had been “*mistreated by staff* (P4)”. Upon further exploration, the use of the term ‘mistreatment’ was a reference to physical violence from a staff member.

> (Interviewer) You said you can be mistreated. What do you mean by that?
>
> *Yeah. I've been punched by a member of staff. I've been kneed and kicked by a member of staff. (P4)*
>
> *(Interviewer) Are you okay to tell me a bit about it?*
>
> *Yes. His name is [STAFF MEMBER]. He actually worked in this department before. He kneed me in the stomach and he kicked me as well, just because I was misbehaving. And I made sure that… he didn't get sacked. He didn't get sacked. But he got moved to another department. (P4)*

In a later part of the same interview, the participant questioned why they were hurt in this way. He stressed that he had not posed a physical threat towards staff and thus questioned why physical force had been used on him. This implies an understanding of the balance of safety and restraint, but indicates that, from his perspective, a boundary had been crossed by staff.

> *Why did I get kicked? I was just talking back to them. I didn't make any physical contact, I didn't make any err foul language, I didn't make any… wrong moves. I was just talking back to them, and the fact that they decided to use violence when I was just trying to speak to them, means that they're not fit enough to work in this ward. This place needs to get shut down, I hate this ward to bits now. Now that I think about it, I hate it to bits. Even sleeping in this bed here, it feels uncomfortable because it feels like anyone can bust the door and hit me at any moment. (P4)*

For this young person, the reaction from staff was considered out of proportion to the risk ("*the violence in this ward… Wooo it's on another level"* (P4)). As well as considering the response extreme, he also related it to his understanding of human rights and of morality, or right and wrong:

> *They have the right to err… make physical contact with you. But I believe that that is one of the wrongest things that could ever be said. (P4)*

Here, the participant appears to hold the understanding that staff have a blanket right to make physical contact, which is not the case, and depends very much on the balance of safety. However, it is worth noting that, if a young person believes this right to be true, then this may have implications for their ability to question the actions of staff or make a complaint in the event of any wrongdoing.

For other participants, their understanding of harm was centred around their experiences of seeing others in distress, rather than their own personal experience. One participant, through his observations of the restraint of other people on the ward, connected the distressing impact of restraint to further time spent ‘stuck in the system’:

> (Interviewer) How did you feel about how it was handled when that happened?
>
> *(Participant) Um, I feel like I was restrained… with… no excessive force… (P1)*
>
> (Interviewer) So um, like, not too much force? Is that what you’re saying?
>
> *(Participant) … [Pause] [Nods]. I can’t say the same for other people… It does sound like sometimes there’s excessive force used on young people and… at times it can almost be… traumatic towards them and it sort of serves as a disservice to young people trying to pursue their treatment um… which means they end up having to spend more time in the system which is meant to be helping them getting better. (P1)*

This observing of others’ distress is a by-product of being in a group environment, and the unintended psychological consequences of seeing this distress could be likened to a form of harm in itself. In the following example, the young person spoke to the distress of observing the apparent mistreatment of another:

> *On the small PICU there was this nurse… and I don’t know like this girl, she kept getting kicked out of her room basically, and she kept on trying to sleep on the sofa. So, erm, what they did… they opened the garden door and like pinned her down just outside the door where it was really really cold, like the middle of winter, so she’d feel the cold and wake up… It was horrible. Yeah. (P2)*

The above description, along with several other here, are clear accounts of harm that, from these descriptions alone, cannot be understood as anything other than unacceptable; whilst we cannot make claims of human rights violations outside a court of law, we must be aware that harm and abuse does happen in ward settings (DoH, 2018). The participant giving this description clearly perceived the incident as both harmful to the young person in question, and distressing to those around them.

3.7.2. Not Being Believed

One young person spoke of the experience of disclosing an incident concerning a staff member, and the subsequent experience of being dismissed:

> *And she just, yeah [a staff member] started punishing me when I got upset by saying I can’t have lunch and stuff […] Yeah, I complained about her at the time, and everyone was like “Oh, you’re just, like, you’re just doing that for attention” (P2)*

This subjective experience of dismissal can have a significant impact on the distress of the young person (*“I was a mess […] I was really really depressed, I couldn’t get out of my bed and stuff”* (P2)). For others, the consequences of not being believed can extend to their freedom, as in the case of one young person, whose “assault” on staff led to a move from acute to intensive care, and later to a forensic unit:

> *I was sexually harassed. Indecently exposed. (P5)*
>
> (Interviewer) Here?
>
> *Not here, in my last place. A man spoke to me provocatively and derogatively. Then he exposed himself to me, and then he harassed me. (P5)*
>
> (Interviewer) I’m so sorry.
>
> *And then I assaulted him. And now I’m here. And now I can’t go back to a place that I loved. (P5)*
>
> (Interviewer) Was he a staff member?
>
> *Yeah, he was. (P5)*
>
> […]
>
> (Interviewer) And when you said you’d done something serious, is that what that was?
>
> *Yeah. ‘Cos of the assault, it was such a serious assault. (P5)*
>
> (Interviewer) It sounds like there was quite a big reason why you were distressed.
>
> *Yeah, but it’s hearsay. He said, she said. There was no proof of the sexual harassment, of the indecent exposure. But there was proof of a broken eye socket and fractured skull. So. (P5)*

This final word "So" seems to reflect the hopelessness felt by the young person. For this young person, the balance of consequences appeared to fall on them, and this experience of not being believed may well have furthered their anger at ward staff, only risking further escalation ("*I'd do anything to get out. I'd murder someone to get out*." (P5).

3.7.3. Iatrogenic Effects of 'Treatment'

This sub-theme speaks to the worsening effects of actions intended to help. Arguably, any number of actions could fall under this umbrella of iatrogenesis, but the focus here is on the distressing impact of seclusion and medication side-effects.

Seclusion was also spoken about as a harmful experience; in fact, every participant who spoke of experiencing seclusion, described it as distressing:

> *I feel like it's a problem because we're not animals. We're human beings. We shouldn't be thrown in a place to calm down. We should be talked at, not thrown in a place. How would you feel if you were thrown in there, Miss? You'd feel very annoyed. Like, you're here to help me but you're throwing me in a place. Like, what the heck? (P6)*

This young person appealed to my humanity to try to convey the distress caused by her experience of seclusion. She also made use of the comparison of animal and human, seemingly to explain seclusion's de-humanising effect. Her suggestion of an alternative, to be calmed down via verbal communication, was not the only call for an end to the practice of seclusion:

> (Interviewer) What was that experience like, being in seclusion?
>
> *I hated it. I cut… I cut myself while being in there. Everything. (P5)*
>
> (Interviewer) That sounds horrible.

> *Yeah it’s horrible. Really horrible. They shouldn’t have it. (P5)*
>
> (Interviewer) What, seclusion?
>
> *Yeah. They shouldn’t have it. (P5)*

For context, this young person explained that they had been in seclusion for five days. Their disclosure of self-harm appears to indicate that their levels of distress had increased in part as a result of seclusion. This iatrogenic, or worsening, effect of the very thing supposed to be of benefit to the person, was a consistent thread throughout many of the participants’ responses.

Medication was one of the examples of this iatrogenic effect, with many of the participants describing the intense pain and debilitating side-effects of treatment.

> (Interviewer) Can you tell me a bit about the health side of stuff?
>
> *Yes. Basically they’ve given me Acuphase. Acuphase is a drug that they give to psychotic people, and it stops me from speaking. (P4)*
>
> (Interviewer) Oh, okay.
>
> *I couldn’t speak until today because my muscles became tense. And because my muscles were tense, I couldn’t move my jaw, and it meant that I was basically disabled for a whole week until I recovered. (P4)*

For this participant, the painful side-effect of ‘Acuphase’ was apparent in the interview itself:

> (Interviewer) What’s… what’s happening? It seems like you might be in a bit of pain.

> *Yes, I'm in a lot of pain and they're not doing much about it. They've put a tube in there to be able to give me food. (P4)*

Physical pain and restricted speech and food intake were only some of the named side-effects of medication. One participant commented on the sheer number of side-effects of a particular medication, haloperidol, and stressed the seemingly dated approach to treatment:

> *They changed my medication and put me on haloperidol. I shouldn't be on haloperidol. Do you know how nasty haloperidol is? It's the worst one out of all of them. Gives you a shuffle, that's why I'm constantly jivvering. I'm drooling, that's why I can't pronounce my words properly. I'm tired 24/7. I'm not on it today, I refused it today, and look at me. I'm bubbly, I'm fine. Increased saliva, blurred vision, headaches, aches, pains, sores… it's the first ever drug to counteract schizophrenia. It's that old. It's 1800s. (P5)*

This young person's account again implies that the medication, at least in some ways, worsens the condition of the young person. For other participants, the side-effects of medication were apparent in the interview in the form of slowed speech and difficulty concentrating.

3.7.4. The Spiral of Response and Escalation

This sub-theme explores the cycle of response between staff and young people, in which the young person's distress, anger or injustice is triggered by a restrictive or harmful event, such as a restraint, leading to further escalation of distress and, ultimately, further restriction or harm.

> *I mean, so you start getting upset, and those interventions have to be taken, and then you get more upset, and then more interventions have to be taken, and then before you know it, you're in the depths of PICU for a second time, which was me, and… you have no idea how the hell you're going to get out, because your way of managing everything*

> *that's going wrong is making everything go wrong, and it gets into a cycle. (P7)*

This sense of hopelessness and inevitability appeared prevalent throughout the interview ("*this place is like quick sand. It is very easy to sink*" (P7)). In some cases, the cycle of response and escalation can lead to a labelling of the young person as a 'trouble-maker', only further increasing the likelihood of a response-escalation spiral:

> *Here I'm treated like a criminal. Yeah, I'm treated like a violent offender. (P5)*
>
> (Interviewer) In what way do they make you feel like that?
>
> *If I raise my voice, some people can just press the alarm for no reason. Just me raising my voice. Or… stuff like that. (P5)*
>
> (Interviewer) So if you express frustration, it's reacted to quite strongly?
>
> *Yeah. Like someone will pull the alarm on me, probably just because I raise my voice. (P5)*
>
> (Interviewer) And what happens when they pull the alarm?
>
> *I don't like it. People come running, yeah. And then that sets me off even more. (P5)*
>
> (Interviewer) And when that happens, how does it make you feel?
>
> *It makes me even more angry. Like I have to do something. Like I have to hurt someone. (P5)*

This spiral of response and escalation cannot be separated from issues of difference and inequality. The above-mentioned participant is the same that had mentioned the perceived leniency for girls on the ward ("*It's more lenient in all mental health for girls*" (P5)). Another participant directly related their experiences on the ward to their ethnicity, and explained how this causes an escalation in their behaviour:

> *I feel like people are ganging up on me because I'm [Nationality]. (P4)*
>
> (Interviewer) How have you been coping with it all?
>
> *Lash back. (P4)*
>
> (Interviewer) Lash back? What does that mean?
>
> *Violence. Kicking them. Punching them. Hitting them back so they can learn their lesson. You don't touch someone unless you have a really good reason to do so. If you touch someone, then you need to have a good reason to back it up. If you touch someone and you don't have a good reason, then that person has the right to turn back and lash back at you. That's what I've been doing. Lashing back at staff, and lashing back at the other patients here. Because you know what? I'm the only [Nationality] boy in this place, but I don't give a shit about this hospital so, if I need to, I will get it shut down. (P4)*

It is worth noting that several young people not only described their experiences and understanding of harm, including the cycle of response and escalation, but also suggested alternatives for practice. For some, it was to talk to the young person, as noted in an earlier example from Participant 6, and for others, it was to suggest set rules that should be followed:

> *They need to pass a new law saying that patients must not be hit no matter what they say. Mental health patients are the most important patients. You do not hit a mental health patient. It's that simple. (P4)*

As the interviewer, it was unsettling to hear that ‘no hitting’ was a rule that a young person felt they had to specify; from their perspective, it was not already assumed.

In addition to blanket rules of no violence, some young people suggested a review of the procedures in place for their potential to cause distress:

> *I think one thing they could do at least is… think about every procedure they have in place […] But think about like oh, who could that affect if it was to affect anyone? Because you might find that oh it could affect people with panic attacks, and it could affect people with depression, and it could affect people with PTSD, and like… and then you think oh shit we’ve been doing all this stuff, and then the people who are struggling with this stuff are going to struggle more coming to a mental health unit. They’re going to come out worse, do you know what I mean? (P3)*

This young person not only commented on the potential iatrogenic effect of procedures on the ward, but also suggested an alternative, or balanced approach. As suggested by this participant, reviewing procedures for their potential to cause harm may be one possible avenue to prevent the spiral of restriction and escalation.

3.8. Theme 6. Balancing Safety and Restriction

This is a broad theme that explores the relationship between safety and restriction, a concept similar to the tension of ‘autonomy vs protection’ described in the Mental Health Act Review (DoH, 2018). Restriction, in this case, is used as an umbrella term for any action or procedure taken by staff, most likely in the interests of the young person’s safety, that in some way compromises the young person’s preferred state of being. There are human rights implications to these practices and, here, the young people spoke predominantly of the impact on privacy, dignity, and freedom.

Several young people explicitly acknowledged the link between the staff's actions and concerns for their wellbeing or safety:

> *There's so many rules, you have to like, you can't leave the premises, you have to always be like supervised every 15 minutes. Like, it's stress. And I think that if you're in a place where you have to be in a mental health unit, stress isn't what you're looking for. Erm… but I guess it's just to keep everyone safe, but like, yeah, it's just daunting. (P3)*

In the above example, the participant acknowledged the tension between annoyance and safety. This was a common understanding amongst participants, with some also referencing the potential for significant harm if the safety procedures were not in place:

> [Staff member looks in room through the window].
>
> (Interviewer) What's that like, when they look in?
>
> *It's annoying. Its 24/7. Every fifteen minutes. (P5)*
>
> (Interviewer) Do you think that's related to rights?
>
> *It's needed. I can moan all I want, but someone might be trying to kill themselves, and if that person don't look in for fifteen minutes, well that's an extra fifteen minutes. Say it was half an hour. That person's dead. That person ain't waking up if they've tied a noose around their neck. (P5)*

For another participant, their experience of restrictive practice, in this case observation, was seen as both a help and a hindrance, and in some ways necessary:

> *My first impression of it was that it was super restrictive, I wasn't allowed anything. Erm… I was under constant observation, it just wasn't… It wasn't nice… but… it passed and like… I guess that my feeling about this place goes up and down depending on how I feel, what's going on. There's been times when I have really thanked this place because it's shifted something that I don't think I would have been able to shift on my own, but [laughs] overall… I wouldn't say that it's a very positive experience in my life. (P7)*

This shift from negative to somewhat positive appraisal appeared to happen over time. It is worth noting that the above-quoted participant had been in the unit for a longer period of time than most other participants.

Participants' acknowledgement of the need for certain restrictions was not limited to the practice of observation, but, for some, extended to the practices of physical and chemical restraint:

> *It was like, I just came here. They injected me because I'd been fighting them. And then, they injected me, they restrained me, put me on the floor. Restrained and injected me again. Put me in seclusion. Injected me again and again and again. Restrained me again and again and again. I was in there for days. (P6)*
>
> (Interviewer) That sounds really tough.
>
> *Yeah. I've got over it now. Because I know that it was good for my health. (P6)*

Note, though, that this young person ended the interview shortly after this explanation, and it felt, in the room, as though there was a question around whether the participant truly was "over" their experience of repeated physical restraint and injection. It is possible that framing their experience as 'good for [their] health' was one means of acknowledging and accepting what had happened to them. As part of my responsibility to not cause further distress or harm, I felt it important not to question this protective framing to any great extent. I also worried, however, that should the person later understand their experience as traumatic, my silence would have played a part in not naming it as such, and caused further distress through the denial and dismissal of trauma. I felt this balancing act between validating versus amplifying distress throughout the interview process, only complicated by the limits of my role as a researcher as compared to a therapist, and yet further muddied by my wish to not be ejected by the staff and system.

Whilst some acknowledged the need for restrictive practices, others appeared to understand the restrictions as necessary in principle, but too extensive in practice.

> *I feel like everyone is different to be honest and you can never really tell what someone's going to think or do, kind of thing. So I understand that, but then if you can't really help us with… to be fair, everyone is different, so I understand that. But then there's certain things… they're stretching. There's certain things you can leave. Like… having staff in a room, I don't feel like that's necessary at all points. (P8)*

As with this young person, the tension between safety and restriction was, for many, centred around the practice of observation and the impact on privacy and dignity.

> *I feel like, erm, privacy, is a good human right. I know that this is a mental health unit, but I can shower on my own, you know? […] I mean, a nurse has come into the bedroom when I've been in the shower, and when I've been in the toilet, somebody has come right in to the bathroom. Which is real embarrassing, and really awkward, and it's just like fuck man, piss off, you know? (P3)*

For this person, and likely others, the safety procedures, and their impact on privacy, were experienced as an irritation; this is similar to the aforementioned spiral of restriction and escalation, but perhaps to a lesser degree: annoyance as compared to anger. Furthermore, this relationship between privacy and showering, toileting, and changing clothes, was commonly discussed by participants, and accidental invasions of privacy were mentioned by more than one participant ("*one time I was changing and someone forgot to knock and legit opened the thing*" (P8)). On these occasions, there seemed to be an overlap between the principles of privacy and dignity. For those who had experienced seclusion, and thus constant observation, dignity was named as a particular issue:

> *No, there's no dignity. They watch you have a shower. They watch you have a shit. You have to ask for toilet paper. You have to ask for your toilet to be flushed. You have to be asked for your water to be turned on so you can wash your hands. (P5)*

Privacy issues were discussed in a number of contexts, of which the practice of observation was only one. Several participants mentioned privacy in relation to communicating with friends and family, which has implications for the right to 'respect for one's private and family life', in accordance with Article 8 of the European Convention on Human Rights and Article 16 of the UNCRC. One young person described the disconcerting experience of being unsure whether conversations could be overhead by staff:

> *I don't know what it's called, some family room or something, but it's got a camera in it and a microphone hanging from the ceiling. Now, I'm not entirely sure whether it's on, I'm not sure whether it's even wired up. It could be on, I don't know, but either way it's just a bit, like when you want to talk about stuff and you're just a bit like mmm what if the camera's listening, what if there's people watching us. (P3)*

Regardless of whether the camera and microphone were working, the impact is similar; the participant felt unable to speak to family members in privacy. For this person, the effect was a sense of unease; for others, the effect was of disgust or anger:

> *Yes, they grab [your mobile phone] off you no matter what. So they come in the room, you're writing a message, they grab the phone off you, close the app and take it from you. It's disgusting. That's your privacy. It's disgusting. (P4)*

The disgust expressed by this young person is another example of agitation or distress as a result of staff's attempt to adhere to protocol. It is also an example of safety restrictions that are deemed unnecessary and overly-extensive, with subsequent impact on the right to privacy and to private family life.

In response to their concerns about the extent of restriction, several participants went on to suggest alternatives to practice. These alternatives centred around the notion of flexibility and adaptability to the individual. For some, this involved an acknowledgement that their experiences of restriction were not a result of their own actions, but a result of blanket restrictions put in place to protect the safety of others on the ward:

> *So I just feel like… just, just certain things they need to calm down with, like cool, I understand, like I understand me personally I haven't really been riskful or whatever […] I feel like, they should understand as well that… certain things just doesn't work for everyone, kind of thing. (P8)*

This recognition that certain things don't "work for everyone" could be interpreted as a call for a more individualised, or person-centred, approach. There are undercurrents of the need to consider the individual and what works for them in the following extract. This young person spoke of the appreciation they had for staff members who showed them "trust" and took positive risks:

> *I know that they had a logical reason for everything, I mean, I think at some points… at some points, when they were deciding to let me off these observations, when they were deciding to let me have a bit more of my own space, it took some staff members who were willing to trust*

> *me, who were willing to… really engage, and not just be scared of me […] It took some people who were willing to, you know, go out on a limb. So, I think that, if you're a staff member starting here, maybe try and see every single person as someone who is capable of change and improvement, even if you're scared of what they're going to do. (P7)*

In some ways, this positive risk-taking from staff seems somewhat of an antidote to the cycle of increased restriction and escalation. Rather than spiraling down to more and more restrictive practices, positive risk-taking has the potential to lead to an upward spiral of freedom, independence, and positive appraisal for the young person. The same interviewee described the impact of having a staff member show encouragement and belief in their ability to stay safe and take responsibility:

> *You need people who are going to tell you, "Look. You know you're going to manage this. You are going to manage this. I trust you to manage this". And let you try, at least. So that you can, I don't know, surprise yourself. Because, when you're in the mind set of being a patient, someone that everyone is sort of being watched all the time, it's good for them to let you… breathe a bit. (P7)*

4. FURTHER DISCUSSION

In this section, the analyses are further discussed, with specific reference to the study's main research questions. The limitations of the research are considered and implications for future research, practice and services are identified.

4.1. Young People's Understanding of Human Rights in Mental Health Services

Research question 1: How do young people understand human rights in the context of a young people's psychiatric inpatient unit?

One of the most overt features of participants' responses was of their perceived uncertainty around what human rights really mean for them. This is not necessarily an indication of lack of knowledge but may be, in part, a reflection of experience and power and, in part, a reflection of a common understanding of the complex, legal nature of human rights language. One might wonder, though, about whether knowing the language of human rights in itself holds power (Ng & Deng, 2011) and therefore the impact that this uncertainty has on the ability of young people to notice when their rights are being compromised and take action.

Despite the explicit statements of 'not knowing' what human rights entail, every participant was able to speak to some form of experience which they saw as a human rights issue. Many also spoke of human rights principles, for example respect, that these experiences invoked. A variety of human rights were named explicitly by participants, including the right to privacy, the right to safety and freedom from harm and the right to liberty. As well as naming specific rights, some spoke of human rights as basic needs or minimum requirements (Nickel, 2019), and others nodded to the intrinsic link to what it means to be human (Morsink, 2009). In this way, the participants' understandings of human rights appeared, in some ways, to fit with existing theories and frameworks of human rights.

Furthermore, some participants stressed the importance of understanding human rights and expressed their wish to learn more. Of note was the distinction made between the rights that *are* discussed on the ward, such as the right to an advocate, and the human rights principles that are not discussed but are perceived as important, such as being treated with respect and protecting the dignity of the young person. This highlights the question of what exactly would constitute a human rights-based approach – and can the mere reading aloud a young person's right to an advocate, for example, equate to a human rights-based approach to healthcare, particularly when various human rights principles may be breached in the healthcare they receive. The arbitrariness of what are rights, and when are rights respected, may add to a young person's sense of powerlessness within services, and not knowing what can be challenged or not.

4.2. Young People's Views of 'Human Rights Issues'

Research question 2: What do young people experience as 'human rights issues' within mental health services?

There are a number of striking themes in relation to what young people viewed as human rights issues in their experiences within services, which emerged in the analyses, and although they are inter-connected, they are discussed separately here for clarity.

4.2.1. "Lost in the World": Disconnection and Relationships in a Ward Context

This theme centred around the need for connection with others, both inside and outside of the ward. The participants spoke in particular about the impact of telephone restrictions on their ability to contact family and friends. This desire for connection over the phone appears amplified in an inpatient context, given the restricted freedom of movement and the potential distance of the ward from home (HCHC, 2015).

Mobile telephones are, of course, multi-purposed, and allow for the contacting of others but also the ability to take photos and record video. As such, there is a need to balance the right to privacy and dignity of others with the right to private life and to establish and develop relationships. This need to balance is recognised in relevant policy (DoH, 2009), but the reported experiences of young people in this study question whether the balance is too heavily in favour of restriction, and whether alternative approaches should be considered within services, for example, electronically blocking the use of camera and video on a device: an approach some wards are known to take.

Within the ward, there was an emphasis on the importance of connection with other young people, and the importance of a supportive relationship with staff. This connection between young people on the ward was understood to be hindered by the ‘no touching policy’. This policy, whilst understood to be for their protection and to ensure safe boundaries, was also perceived to be too restrictive, with negative consequences for the young person’s wellbeing. One participant suggested that hugging should be allowed if consent is established first; this approach, arguably, would allow for mutual respect and support, and could help young people learn about respect, consent and boundaries, whilst providing the human connection we all need.

With regards to staff and service user interaction, many young people spoke of the importance of empathy and consistency. This arguably holds relevance to the human rights principle of respect and its focus on allowing a person to feel valued as an individual (Curtice & Exworthy, 2010). However, participants also acknowledged the systemic barriers to this goal and, in particular, the high turnover of staff. A dissection of systemic barriers to the successful implementation of human rights based approaches is crucial if we are to avoid falling into a blame-centric narrative (Robertson & Collinson, 2011).

4.2.2. “I’m Just Told What to Do” – Heard and Involved

The need to be heard and involved speaks directly to the human rights principle and right of a person to involvement in decision-making processes that affect them. Article 12 (para. 1) of the UNCRC, states that:

> “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”

It is this caveat, of capability to form his or her own views, that brings to mind issues of capacity and development. At times, there may be concerns about a young person's capacity to make a decision (MHA, 2005); and concerns about risks to a person's safety; and in parallel, a view held by staff that they are acting in a young person's 'best interests' (see Article 3.1 of the UNCRC), even if they are not in accordance with the young person's wishes. These issues create complex dilemmas in clinical practice and risk the young person not feeling heard or involved to the greatest extent possible.

Capacity and cognitive development, however, are not the only barriers to involvement. Feeling heard and involved seemed to be understood by the young people as intrinsically linked to the concept of power, or the ability of a group or individual to influence others in line with their interests (Smail, 2005). However, the participants also went further; they noted the connections between power, hierarchy, 'othering', and perceived stigmatised assumptions of them as "stupid, or crazy, or addicted" (P3). Indeed, there is an increasing collection of literature on the topic of mental health-related stigma and its perpetuation by mental health services (Carlisle, Mason, Watkins & Whitehead, 2005; Rao, Mahadevappa, Pillay, Sessay, Abraham & Luty, 2009). Specifically, in the context of this study, it seems important to question whether, by claiming that a decision is made on the basis of only a young person's 'best interests' and making no reference to the role of power, there is the risk of perpetuating significant existing inequalities through acts of denial and dismissal.

Furthermore, any attempt to hear and include a young person's wishes must not be performative. Here, participants spoke to the confusing and frustrating experience of being given 'false choice'. Informal admission procedures were of particular relevance here; many participants explained that they had felt misled by the seemingly false promise of greater freedom to make choices if admitted informally than if admitted under section. In some cases, this experience of feeling misled led to an escalation of frustration and anger. This finding highlights the need to review how we explain the process of informal admission and, more generally, the need for greater transparency around decision-making.

4.2.3. Equality and Protection from Discrimination

Human rights documents repeatedly stress their application to *all*, and emphasize that human rights should be enjoyed without discrimination (e.g. United Nations, 1948). Yet, a key sub-theme was that of young people's experiences of what they viewed as differential treatment on the basis of race, gender, gender identity, and financial means.

4.2.3.1. *Race and racism:* for one participant, perceived discrimination on the basis of race and nationality, had a significant impact on their level of distress. The longstanding need to improve access to treatment, experiences of care, and outcomes for people from black and ethnic minority communities has been well documented (e.g. Davies et al., 1996; DoH, 2018; Keating, Robertson & Kotecha, 2003; Keating, Robertson, McCulloch & Francis, 2002; Parkman et al., 1997). For the young person in this study, this experience led to feelings of anger and agitation. In a negative spiral similar to the 'circles of fear' (Keating, Robertson, McCulloch & Francis, 2002), this young person's resultant distress, along with staff's perhaps conscious or unconscious prejudice and fear of violence, may lead to an escalation in terms of treatment (e.g. high doses of medication, restraint), something the same young person later alludes to when speaking of physical harm from staff and extreme medication side-effects.

The racialized experiences of young people, particularly within mental health services, and institutional racism within mental health services (Fernando et al., 1998; Fernando, 2017) cannot be dismissed. An inquiry into the death of David Bennett, headed by Sir John Blofeld, stressed the institutional racism and discrimination within the NHS as a major contributing factor (Blofeld, Sallah, Sashidharan, Stone & Struthers, 2003), with institutional racism defined as the "collective failure of an organisation to provide the appropriate and professional service to people because of their colour, culture, or ethnic origin" (Macpherson, 1999, Point 6.34). This prevalence of institutional racism in NHS mental healthcare services explicitly contradicts the human rights principles of equality and non-discrimination and, in some cases, may also involve breaches of the right to freedom from torture, cruel, or inhuman treatment, and even the right to life.

4.2.3.2. *Gender:* one young person spoke to the perceived staff preference and leniency for girls over boys. It is difficult to ascertain the relationship between gender and ‘leniency’ in CAMHS inpatient units, but proxies of leniency, such as the use of restraint or service user satisfaction, may shed some light. Whilst there is more frequent use of restraint for men in adult psychiatric units (Stewart, Bowers, Simpson, Ryan & Tziggili, 2009), there is little in the literature on potential gender-related differences in the use of restraint in CAMHS settings, and inconsistency or no apparent effect of gender on adolescent satisfaction with mental health services (Turchik, Karpenko, Ogles, Demireva & Probst, 2010). Regardless, the finding that young people may *perceive* such gender-based discrimination warrants attention in services, particularly as this perception may impact on young people’s distress and care.

4.2.3.3. *Gender identity:* two participants spoke of the importance of considering gender identity and the experiences of transgender and/or gender non-conforming young people on the ward. This took different forms: one participant spoke of staff ‘outing’ and ‘misgendering’ another young person, whilst a young gender non-conforming participant spoke of the distressing experience of seemingly gendered clothing in seclusion. ‘Misgendering’ is known to be distressing, particularly when occurring repeatedly (McLemore, 2018) and, interestingly, some suggest that mental health professionals may invalidate or pathologise self-designated genders to a greater extent, at least in writing, than authors from other professions (Ansara & Hegarty, 2012). Furthermore, in the case of the gendered clothing, it is quite possible that this experience of distress only increased their time in seclusion, which raises further human rights issues around inequality and the restrictions to the right to liberty young people experience within mental health services.

Though there is a lack of literature on the experiences of transgender and gender non-conforming young people in inpatient mental health units, concerns have been raised about the needs and welfare of LGBT+ people more generally in mental health services, and about the impact of known or suspected hostility from professionals and wider society (Lucksted, 2004). Furthermore, transgender service users, when compared to their non-transgender counterparts, are thought to have disparately negative mental health outcomes (Reisner et al., 2015). Clearly, there is a substantial need for improved practice in this area.

4.2.3.4. *Socio-economic status:* brief mention was made of ward procedures that differentially impact on young people with less financial means. Specifically, young people referred to the practice of allowing young people to only listen to music through the use of 'Bluetooth' headphones, which are, of course, an additional cost. On the one hand, this practice was an attempt by staff to keep to the rules on phone use whilst still allowing an element of flexibility. On the other hand, these experiences call attention to the need for consideration of difference and accessibility when designing and implementing practices on the ward, in order to ensure that no young person is further restricted or distressed simply on the basis of finance or, indeed, any other protected characteristic.

4.2.3.5. *Intersectionality:* though the participants spoke of separate aspects of difference and perceived inequality or discrimination, it is important to consider the intersectionality within their experiences. 'Intersectionality' is a term coined by black feminist Kimberlé Williams Crenshaw to explore how aspects of discrimination and oppression overlap with gender (Crenshaw, 1989). Though Crenshaw originally focussed on the overlap between race and gender, intersectionality has expanded to encompass other aspects of social identity, including disability, sexuality, and class (e.g. Erevelles & Minear, 2010; Lorde, 1984; Taylor & Casey, 2010; Williams, 1987). In this context, it is quite possible that gender stereotypes and the aforementioned 'gender preference', for example, interact with conscious and unconscious racism, thus substantially increasing the likelihood of restrictive practices for certain intersections, in this case black men or men of another ethnic minority background. Indeed, there is extensive evidence that young black men are heavily over-represented in the most restrictive of mental health services (e.g. Keating, Robertson, McCulloch, & Francis, 2002; Fernando, 2017). Little research has been done in CAMHS settings, but there is indication of a similar pattern of over-representation of young people from ethnic minorities in higher security settings (Chowdhury et al., 2005). Similarly, there may be many other types of discrimination within mental health services for young people, further highlighting the importance of intersectionality.

4.2.4. Harm and Iatrogenic Effects of Treatment

Harm or abuse to patients in healthcare settings is an under-studied area, fraught with difficulties: lack of access, denial of abuse from staff, and fears around disclosure from service users, to name just a few potential barriers. Rather than being researcher-led, our sources of information tend to derive from media-led freedom of information requests (e.g. “Abuse of mentally ill patients”, 2017), or government-requested independent reviews, such as the recent ‘Independent Review of the Mental Health Act 1983’ (DoH, 2018). These independent reviews are relatively rare, and freedom of information requests can only rely on what is reported. Thus, it is difficult to ascertain the prevalence or nature of harm and abuse in mental health settings, although it is widely acknowledged that abuse and avoidable deaths do happen in mental health inpatient settings (DoH, 2018).

Whilst staff have a duty to do no harm, to pin blame solely on the ‘shop level’ is a disservice to the vast majority of staff who strive, every day, to care for and create a supportive environment for young people in distress. It is also simply a false assumption that blame lies solely here; it is well known that systemic factors are key to understanding abusive practice. Even amongst well-intentioned and caring staff, abusive practices can develop and go unchecked in organisations (Curtice & Exworthy, 2010). Examples of these organisational, or systemic, factors, include quantitative staffing difficulties, a lack of training and supervision, geographical isolation, an introspective culture, and weak organisational leadership (Commission for Health Improvement, 2003).

4.2.4.1. *Experiencing and observing physical harm and violence:* several participants reported physical harm from physical violence, restraint, or the side-effects of medication. Some participants also reported observing harm to others on the ward; this observing of trauma can itself be traumatizing and, if a young person then goes on to support a fellow service user, it could also meet the criteria for vicarious trauma (Jenkins & Baird, 2002). The participants appeared to quite clearly understand these occurrences as wrong, with one participant, for example, calling for a ban of all physical contact from staff.

According to the MHA Code of Practice (2015), restrictive interventions knowingly impact a service user's movement, liberty, and/ or freedom of action and as such, should be proportionate to the risk of harm, be used for no longer than necessary to prevent harm, and take the form of the least restrictive option – all in accordance with human rights principles. Yet, hearing young people's descriptions of their experiences was deeply concerning - disclosures of being pinned down on cold ground, allegations of sexual assault, and physical violence, amongst others. In accordance with the ethics procedures, approved by the relevant NHS Trust, all participants were made aware of the Trust's complaints procedure and risk and safeguarding issues were discussed with my thesis supervisor. Since there were no disclosures by participants that staff were not already aware of, no further action was taken. However, as the researcher, it was difficult to hear these stories and feel relatively powerless to probe, within the context of the research, or to make any changes.

4.2.4.2. *Not being believed*: a separate but related aspect of this theme was the experience of not being believed; in a sense, this sub-theme is an overlap between the sub-themes of 'harm' and 'not being heard', highlighting their interwoven nature. Here, participants spoke to the very distressing experience of not only experiencing harm or abuse, but, additionally, being labelled as attention-seeking or to blame. As professionals bound by a duty of care, we should, of course, be seeking to reduce distress, not increase it; invalidating a disclosure is at best not helpful and at worst significantly and additionally distressing (Greenberg & Lepore, 2004). From a human rights perspective, dismissal and denial of harm cuts across numerous human rights principles, from fairness, to respect, to dignity and, if considered an act of discrimination on the basis of age or mental health, then it is also an issue of equality. Further, if a young person, as a result, is then discouraged from reporting abuse, either directly or through an indirect effect on their confidence, then an experience of denial or dismissal cuts across the principle of autonomy. Fundamentally, any disclosure of abuse or harm must be investigated and the young person in question must be kept informed and involved, regardless of whether staff personally deem the disclosure likely or unlikely. In addition to the ethical argument for investigation, dismissal is also short-sighted from a pragmatic perspective; as participants explained, this experience of not being believed led to an escalation in their distress and, as a result, likely increased the risk of a serious incident.

4.2.4.3. *Iatrogenic effects of 'treatment':* participants spoke of two main areas of iatrogenesis: restrictive attempts to 'calm' an incident, such as restraint or seclusion, and medication side-effects. For those who had experienced seclusion, the experience was highly distressing across the board. It is acknowledged within guidelines that seclusion can be harmful, and even more so for young people; seclusion can have "particularly adverse implications for the emotional development of a child or young person" (MHA Code of Practice, 2015, p. 293). Seclusion and restraint are known to adversely impact physical health, in the form of bruises, broken bones, muscle atrophy, choking, circulatory problems, dehydration, incontinence, self-harm and even death (WHO, 2017). These practices are also known to be counter-therapeutic (WHO, 2017) and to have a powerful effect on psychological and emotional wellbeing through the subjugation of oneself to a person in power, loss of control and dignity, re-traumatisation, and degradation, demoralisation, humiliation, helplessness, disempowerment and dismissal (Borckardt et al., 2011). As a result, there have been calls to end the use of seclusion, restraint, and other such coercive practices (WHO, 2017; UN; 2017a; UN, 2017b), or, at the very least, greatly reduce its frequency (e.g. Duxbury, 2015). The findings of this study add to a growing list of calls to review this practice, as well as for clearer mechanisms of accountability and real change to be seen in practice.

Medication side-effects were also reported to have significant or extreme effects on physical and mental wellbeing. Participants reported extra-pyramidal side-effects, pain, fatigue, and blurred vision, amongst others. It is known that governments sometimes endorse the use of cheaper treatments despite their profoundly disturbing and painful effects (Sartorius, 2002). These accounts and observations have implications for the right to health and, relatedly, the right to be free from non-consensual medical treatment (OHCHR, undated). Restraint, seclusion, and extreme medication side-effects, such as those described here, also have implications for the right to be free from cruel, inhuman, or degrading treatment (e.g. UN, 1984).

Participants called for change, with one suggesting that participants should not be hit, another asking to be spoken to in times of distress, and yet another requesting that procedures be reviewed for their potential to cause distress. These are hardly paradigm-shifting requests, and it was saddening to hear young people ask for what are, essentially, basic needs.

4.2.4.4. *The spiral of restriction or harm and escalation:* this sub-theme explored the cycle of response between service user and staff, whereby a young person is distressed or poses some form of risk, is met with a restrictive or harmful response from staff, feels additional distress and anger as a result of this intervention and, subsequently, poses further risk and is subject to further restriction from staff. As well as describing this cycle, participants also explored factors that might make this cycle more likely to occur, such as when a young person is, or believes they are, labelled as difficult or dangerous. Relatedly, participants spoke of the interaction with discrimination on the basis of gender or race; if a staff member holds implicit or explicit racial or gender bias, it may make it more likely that they respond in a restrictive manner. This finding is similar to that of the aforementioned ‘circles of fear’ described in adult settings (Keating, Robertson, McCulloch &

Francis, 2002) and holds similar implications: the need for open discussion of these issues, as well as the need for advocacy, training, representation in the workforce, and community linking.

4.2.5. Balancing Safety (Protection) and Restriction (Autonomy)

The debate on autonomy versus protection (e.g. DoH, 2018) was also evident in young people's views of their experiences. Of note was the explicit recognition by several young people of the need for restriction where there was a safety concern. This relationship between safety and restriction was noted as an integral part of the practice of 'observation': watching and noting a young person's behaviour at regular time-intervals in an attempt to monitor safety. Participants understood this to be important to protect against self-harm or suicide, and appeared to view this right to life as of paramount importance, whilst still acknowledging the impact on privacy and their dignity.

Though participants appeared to consider the high importance of protection, there was also the understanding that these restrictions, in some cases, were excessive: observations were too intrusive and frequent, and rules around phone usage were deemed overly and unnecessarily limiting. One participant reported being in seclusion for five days, raising the possibility of a breach of the guidance of 'no longer than necessary', established within the Mental Health Act (MHA) Code of Practice (2015).

In the case of observation and, for some, seclusion, there was also overlap between the principles of respect (including for one's privacy) and dignity. Dignity in care is defined as any setting which promotes, and does not undermine, a person's self-respect (Curtice & Exworthy, 2010). Some participant accounts raised significant issues around dignity, such as in one participant's experience of being watched using the toilet whilst in seclusion. Though there is no universally accepted definition, case law of the European Court of Human Rights appears to suggest 'degrading treatment' to be that which humiliates or debases a person, indicating a lack of respect or diminishing their human dignity (European Migration Network, 2019). The above-mentioned experience might well constitute degrading treatment, although this would be a matter for a court of law.

As well as understanding some procedures as overly restrictive, participants also went on to suggest improvements to practice. These were interrelated, but could roughly be thought of as working with the individual, rather than with blanket rules, and taking positive risks. According to the MHA Code of Practice (2015), ‘blanket restrictions’ are “rules or policies that restrict a patient’s liberty and other rights, which are routinely applied to all patients, or to classes of patients, or within a service, without individual risk assessments to justify their application” (p. 64). Participants did not state specific examples of these blanket rules, but spoke more generally; this was a missed opportunity for further questioning, and further research in this area would be of use.

Participants spoke more in depth with regards to the second suggestion. Whilst summarised as ‘positive risk taking’ here, as this is a term used in services and in literature, staff risk-taking was framed, by participants, as an act of trust and belief in the young person’s potential for change and improvement. This experience of holding belief in, and for, the young person, even when they may not have the capacity to do so for themselves, seems an antidote to the experiences of dismissal of harm, as well as a potential means of breaking the cycle of restriction and escalation. Whilst researchers have described positive risk-taking as a necessary aspect of mental health care and key to improving service user quality of life (e.g. Ramon, 2004), the powerful relational effects of belief and trust are somehow lost in the literature. This is not to say that it is easy; these services exist in a blame-centric culture (Robertson & Collinson, 2011), and a staff member taking a positive risk may well be risking their own job security. These systemic pressures must be addressed for any substantial change to occur.

4.3. Limitations of the Research

As with all studies, there are methodological limitations of this study and related ethical considerations. Methodological and ethical concerns at the time of data gathering have already been discussed (Methodology, Section 2). Since the completion of this study, I have reflected on a number of additional methodological limitations and ethical concerns, detailed below.

4.3.1. Sample/ Participant Limitations

The sample was small and self-selected; the study only involved young people who were present on the ward during the course of the research and who chose to take part. The age range was limited to between 15 and 17, not through a purposeful act, but as a likely by-product of the very small number of younger service users staying on the ward at the time of recruitment. Since age and development are key factors in the ‘autonomy versus protection’ debate, the restricted age range and older sample is a limitation of the current study; the sample does not allow for exploration of age or development. These limitations are acknowledged but, given the complexities and difficulties in gaining access to this population within statutory mental health services (which can also be wary of what service users may say), the study is seen as a step towards better understanding of young people’s experiences and views.

4.3.2. The ‘Accuracy’ of Accounts

A critical realist position does not suppose one true version of reality that can be separated from how that reality is understood or how its story is told. Nevertheless, several professionals in the service asked how I would go about assuring that participants’ descriptions of their encounters with the system are indicative of reality. Putting to the side the potential defenses underlying this question, the ‘truth’ is that we cannot make claims of accuracy. This thesis takes the perspective that the findings are not about *what* happened, but about what young people *understand* to have happened. Decisions around whether human rights have been breached are left to a court of law.

4.3.3. Thematic Analysis as a Method

Additionally, in thematic analysis, themes are constructed not ‘revealed’

(Braun & Clarke, 2006), and are a reflection of what the researcher considers significant, not necessarily the interviewee (Glucksman, 1994). This leads to an uncomfortable question mark over who this research is really for. Participatory Action Research (PAR) is an alternative approach that would have allowed for greater co-construction of the questions and methods, consistent with the notion of respect for young people as citizens and with the right to participation. However, within the constraints of a doctorate thesis, of which I must be the sole author, full participation in all aspects of the thesis would not have been possible. At the very least, I will seek to ensure that this research is disseminated so that it may be of benefit to those who took part.

4.3.4. Recruitment

Given the inherent power imbalance between myself as a researcher and the young persons in mental health services, I had concerns about the pressure put on a young person to take part. I stressed, both in person and in the information sheets, that participation was completely voluntary. Indeed, several service users opted not to take part in the study, at various points from initial advertisement to obtaining written consent. I was hopeful that this was an indication of their perceived freedom to say “no”, but I am also aware that a level of coercion is always present in any research setting, and perhaps particularly so in an inpatient mental health context, where power and hierarchy are exceptionally salient, and where some young people are under a section of the Mental Health Act.

4.3.5. Distress of the Interview Process Itself

It was expected that discussing human rights and human rights issues may cause distress to the individual. I attempted to safeguard against this, warning the young people in advance of the interview that the topic could be distressing, showing them the questions before they chose whether or not to take part, pausing interviews, encouraging breaks, and so on. However, there is an argument to be made that, despite advanced warning, a participant can never know how they will feel until they feel it, and it is unlikely that any one of these participants had experienced this type of questioning before. In the event, a few participants became tearful during the interview process but chose to carry on, a few participants appeared hopeful about actions they could take to protect their rights as a result, and several participants expressed their gratitude at the opportunity to take part: itself an uncomfortable power dynamic. With qualitative research such as this, there will always be a fundamental tension between distress and empowerment, and it is my hope that this research fell on the side of the latter.

4.3.6. Decision to Not Include the Parent Interview

Parent and carer interviews were part of the intended methodology. However, in practice, it proved very difficult to recruit these individuals. The intended avenue of recruitment was not successful; posters and leaflets did not yield interest. Further, parents and carers were rarely present on the ward and, when they were, they understandably had other priorities. One parent asked to take part in the interview and one option was to analyse this interview as a single case study. However, after discussion with my supervisor, it was clear that the interview risked breaching the confidentiality and identity of the parent, and individual staff in the service and Trust. There was also an additional concern - since there was indication that the issues raised were part of a formal complaints process, the accessibility of this thesis in the public domain was thought to risk negative consequences for the parent. I have therefore erred on the side of caution and chosen not to include the parent interview in the analysis or discussion. This was an extremely difficult decision, since I did not wish to diminish the time and effort the parent had given to participate in the interview. In an effort at a compromise, I shall send the parent a copy of the transcript, along with an explanation of our reasons for not including it in the study, and the freedom to use the transcript for whatever purpose the parent deems necessary.

4.4. Quality of the Research

For quantitative research, there is a set of relatively well-established and acknowledged conventions for evaluating the quality of research (Yardley, 2000). For the most part, the standards for quantitative research are not relevant to qualitative approaches (Elliot et al., 1999; Yardley, 2000). There have been attempts to devise quality criteria for qualitative research (e.g. Elliot et al., 1999; Yardley, 2000), but these are in their relative infancy.

Elliot and colleagues (1999) suggest examining the quality of the research by the following criteria: owning one's perspective, situating the sample, grounding in examples, providing credibility checks, coherence, accomplishing either a general or a specific research task in line with the research aims, and resonating with the reader. Whilst I acknowledge the research's imperfections and limitations, I have attempted to be transparent in the research process and in research supervision about my own background and assumptions and to situate the research in context to the greatest extent possible whilst maintaining a suitable level of confidentiality. Furthermore, I have attempted to ground the findings in examples of both the interview data and the analytic process, and to aid its coherence through the use of diagrams. However, I am aware that I have not made use of credibility checks, as this was felt to be both difficult in practice and too much to ask of the participants, and I recognise that this is a potential limitation of the study.

4.5. Implications of the Study

The implications of this study are numerous and diverse, and have been threaded throughout this Further Discussion chapter. The key implications are summarised below, specifically for future research and services.

4.5.1. Implications for Future Research

This study has taken the broad focus of human rights, and is the first such study specifically with young people. However, the downside to a broad perspective is a lack of nuance. Though it is an artificial separation, further research is needed into each of the issues raised in the study, for example, focusing on human rights issues faced by gender non-conforming and transgender individuals, or to human rights issues raised by the intersection of inequality and experiences in mental health services.

In addition to further research into each of the human rights issues raised here, further attention could also be paid to how young people define human rights and the implications that these definitions have on their actions. The findings from this study indicate a difference between explicit statements of ‘not knowing’ and implied knowledge. However, it is a logical leap to assume that this uncertainty has implications for a young person’s ability to assert their case in the face of wrongdoing; the sense of wrongdoing may be enough. Researchers have claimed that understanding is needed for assertion (Peterson-Badali & Ruck, 2008), but this thesis argues that further investigation is needed into the relationship between understanding and assertion.

Though the stance of this study was broad in terms of its focus on human rights issues as a whole, it was also narrow in its examination of the perspective of young people on the ward, and theirs alone. This was a purposeful act and a decision made on the basis of power and voices unheard, as well as for reasons of academic interest and time constraints. However, in deciding to take this focus, what is missing is the perspective of staff. We need the ‘other side’ of the cycle of restriction and escalation: staff’s actions and beliefs (see study by Patel, 2016). We also need an understanding of how, why, and on what occasions staff are more likely to take positive risks.

Relatedly, a systemic perspective is needed. We know that systemic issues allow abusive practices to develop and go unchecked (Commission for Health Improvement, 2003). In order to avoid adding further staff blame in an already blame-centric system (Robertson & Collinson, 2011), research is needed on these broader structures that enable or inhibit human rights-based practice.

4.5.2. Implications for Services and Organisations

Participants called for further education on the topic of human rights. Indeed, this is a responsibility under Article 42 of the CRC, which outlines the need for States to make the provisions and principles of the Convention known to both adults and children. Advocating patient rights is also a key role of the nursing profession (Cady, 2011). Thus, it is problematic that explanations of rights appear limited to the rights stated in the Mental Health Act (1983), with far less, if any, focus on broader human rights principles such as respect, dignity, or equality.

To add an additional level of complexity, teaching young people about human rights is, in itself, not sufficient. Without an acknowledgment of the role of power and hierarchy, significant barriers to the assertion of human rights will remain, including coercion (Peterson-Badali & Ruck, 2008). Issues of power need to be brought to the forefront of practice, which can only happen in the event of systemic change: staff teaching, support, and space for reflection.

Systemic change is also needed for empathic connection between staff and service users. Relationships need time and space to build, and the constant staff pressures and staff turnover are significant barriers to this goal. A recent report from the Care Quality Commission (Britain & Care Quality Commission, 2018) detailed the findings of a qualitative thematic analysis of ten fieldwork visits to different parts of England. The report explains that staff shortages have a significant impact on the relationship between young people and support staff; these shortages result in reduced time spent with young people, a restricted range of activities on offer, compromised consistency of care, reliance on short-term agency staff and thus higher staff turnover, ‘burnout’ for existing staff members, and less training and supervision with a resultant impact on staff confidence and morale (Britain & Care Quality Commission, 2018; Street, 2004). All of these factors lower the likelihood of good, sustained therapeutic relationships with young people and their families. In practice, what this implies is that one cannot expect staff to build more empathic connections with service users solely by drawing attention to the young people’s experiences of services. One must also build an environment that emphasizes staff wellbeing and development. Yet, importantly, this cannot happen via a short-sighted, austerity-like model.

Thus, human rights training and guidance is necessary but not sufficient.

To further elaborate on this point, consider the example of involvement (Theme 3). The results of this study indicate a need for greater transparency with, and involvement of, young people with regards to the decisions that affect them. This is the case across the board, but was particularly apparent in cases of medication change. Human rights training and guidance for staff may help to stress the importance of transparency and involvement. However, transparency is not enough and neither, clearly, are the existing complaints procedures. This study is a reminder that young people can experience significant harm in the very services that are designed to protect them. Without rigid structures of investigation and accountability, we cannot expect meaningful change. This accountability must hold at all levels of staffing, and undue and unfair blame should not fall solely on the nurses and support staff, who exist in a hierarchy of procedure and pressure.

Finally, there is no easy solution to the fundamental tension of autonomy versus protection, or restriction versus safety, but safety cannot be used as a blanket excuse for practices that are unnecessarily restrictive. Questions must always be raised about the necessity of a restrictive intervention. We need to work towards a culture of hope and belief in the young person. But to do so, we must again acknowledge the systemic pressures faced by staff; staff need to be encouraged by their superiors to take positive risks, and they must feel a level of safety in their position.

4.5.3. Implications for Dissemination

In addition to being written up for publication in academic journals, the study will also be shared with services, professionals and interested bodies, in a format that is accessible to young people. In keeping with the theme of involvement, it is important that the service users and parents/ caregivers are kept up-to-date with the outcomes of the study. I will attempt, wherever possible, to make use of service user consultation in the process of dissemination.

When disseminating this research, consideration must be given to how the research is used and the impact it may have. It is not enough to critique the current system without offering suggestions of an alternative. Moreover, we must be cautious of overly staff-blaming narratives; the roles and responsibilities of wider social and political structures must also be considered.

4.6. Reflexivity

I knew, when I set out to conduct this research, that it was likely to have a powerful impact on me. I expected human rights issues, by their very nature, to pull on some of the deepest parts of myself: what it feels like to be treated, or not, as a human ‘should be’. I also knew that I had guilt from my own role in past events that I had felt were ‘wrong’; in particular, my involvement in the practice of restraint and seclusion as a support worker, and the things I had seen and heard that I had not done anything to change.

Furthermore, I was aware that violence, from adult to child, is something that I can find particularly difficult to process. I know my own history has a significant role to play in how I think and feel when faced with stories of harm from a powerful adult authority to a young person in their care. It can sometimes take effort for me to step back from the idea of a ‘perpetrator’ and reflect on how the adult has come to act in this way.

Thus, I knew, entering this research, that I wanted to see a change in the system, and that I had a strong and emotive position against, what I perceive to be, the unjust treatment of young people. I did not expect, however, the extent to which this position would amplify my feelings of helplessness and guilt.

Hearing the stories of the participants, I wished I could ‘make it better’ for them, but felt powerless to do so. In my position as a researcher, I felt a pressure to do ‘proper’ research and this, I was under the impression, was meant to be from a neutral perspective. I was also aware that the service had allowed this study to go ahead despite its potentially controversial nature, and I was nervous to step outside this neutral stance for fear of being ejected from the system. I would oscillate between various states of guilt; I would worry about only offering a complaints or advocacy number to a young person who had just described incredibly distressing experiences, and then I would step inside the staff office and see staff members appearing to try their best in a very difficult system, and feel further guilt at how I had positioned them.

As a white woman associated with an academic institution, conducting research in a service with, arguably, multiply disadvantaged young people, including many young people from BME backgrounds, I wondered how my visible privilege affected who opted to take part, and what they felt comfortable sharing with me.

Stand-alone, the interview transcripts, from my perspective, are incredibly powerful and emotive. When writing up this study, I knew that I had to put these quotes into a framework that is understandable and adds something, either in clarity or understanding, to the data. However, I worried that my analysis was stepping away from the voice of the young person and taking some of the power out of their message. I now believe that, should I undertake future research, I will involve the participants in the research and analysis to a far greater extent than I have done here.

4.7. Concluding Remarks

The impetus for this research came from the need to understand how services can better respond to young people's experiences of mental health services as places where 'care' may raise human rights issues. Seeking to understand young people's views on human rights has exposed the breadth of care practices that could be experienced as harmful, disrespectful, discriminatory and diminishing of young people's dignity and opportunity to exercise autonomy. Whilst taking the perspectives of young people alone, without detailed consideration of staff views and statutory duties, may give a partial picture, this study has highlighted the enormous complexity, and urgency, of developing mental health services which enable young people's views and wishes to be respected – as human beings with human rights and needs for respect, dignity, autonomy, and equality.

Changes to services require more than good intention. In order for change to occur, we need to tackle: organisational policies and practices; staff awareness and understanding of human rights and how they apply to their work with young people (and the dynamics of power which prevent young people from voicing their fears and views); and education for young people to be better informed of their rights. To this end, it is hoped that this study may contribute to improved understanding of what human rights mean for young people, within a mental health service context; and improved services as a result.

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6. APPENDICES

6.1. APPENDIX A – Definitions of the ‘FREDA’ Principles

The following definitions are provided for pragmatic purposes, to allow a clarity when reading the rest of this thesis and, unless otherwise stated, are based on the definitions provided by Curtice and Exworthy (2010).

Fairness:

The principle of ‘fairness’ requires that a person is afforded due consideration of their opinion, and the opportunity to have that view heard and weighed alongside other relevant factors in any decision-making. There is a direct link between fairness and the ‘right to a fair trial’.

Respect:

Respect is the unbiased and objective consideration of the values, rights, beliefs, property of others. It is seen in the actions of one person to another, and in communication that allows the receiver to feel valued as an individual and not a ‘number’ or ‘condition’. Significant obstacles to respect can be a result of organisational and administrative bureaucracy. This principle links to the right to respect for private and family life and correspondence, and the right to respect for a person’s physical integrity.

Equality:

The principle of equality is multi-faceted, with non-discrimination as a key component. It is a significant principle in that it formed the founding principle of the NHS, that of equity of access and treatment, and it is now one of the seven guiding principles of the NHS (NHS Constitution reference). Freedom from discrimination is a key tenet of the Universal Declaration of Human Rights (United Nations, 1948), and is, of course, central to the Equality Act (2010). In the UNCRC, Article 2 (para. 1) states:

> States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Equality can also have implications for the ‘right to health’, as in the case of the Disability Rights Commission’s report into the inequalities in healthcare for those with a diagnosis of a mental health problem or intellectual disability when compared with the general population (Disability Rights Commission, 2007).

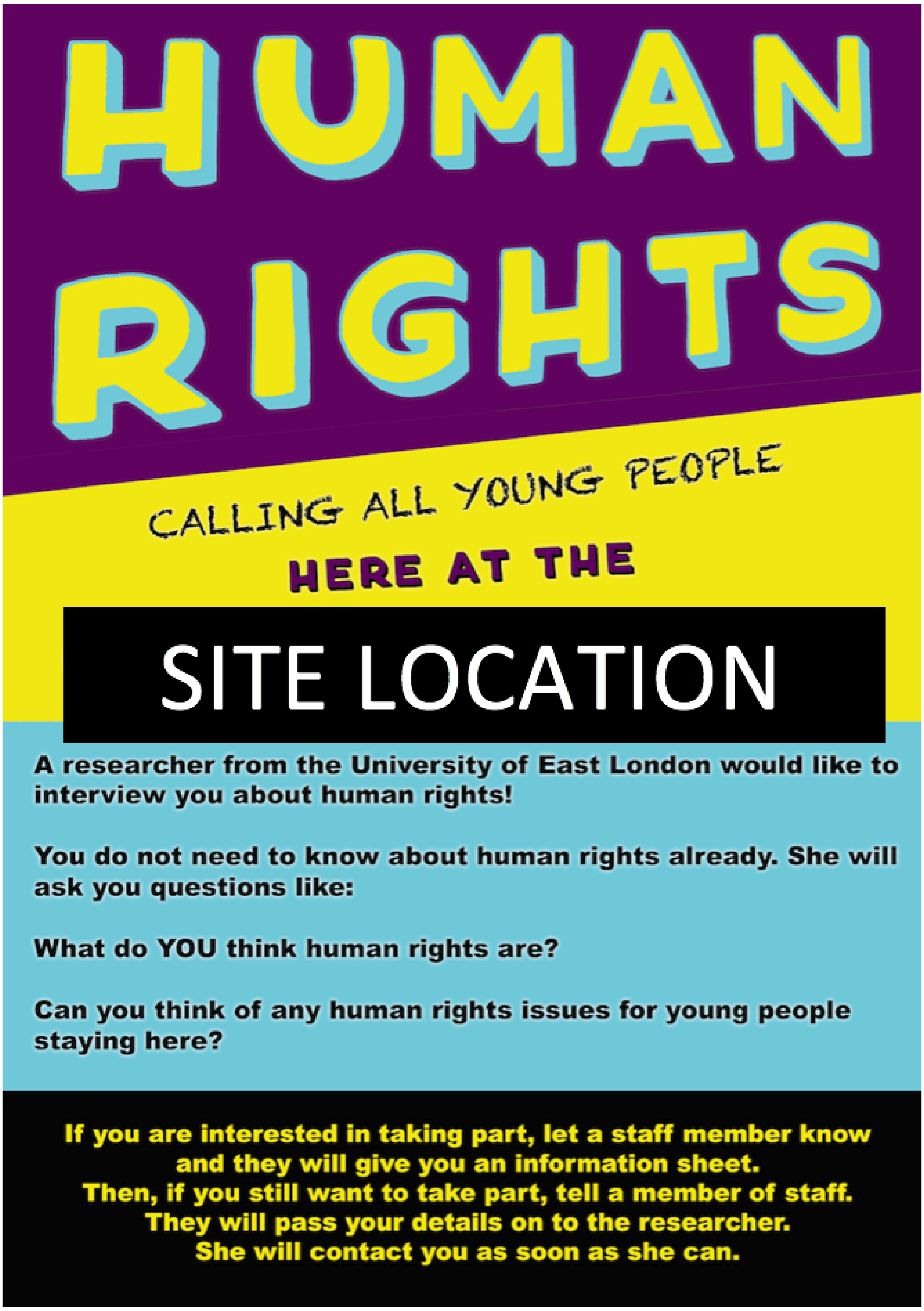
Dignity:

Dignity can be considered a state or manner worthy of respect and, by extension, self-respect. This state of dignity can arise from the dynamic between one’s self-worth and the manner in which they are treated (Haddock, 1996). The principle of dignity relates to many rights, including the right to be free from torture, or inhuman or degrading treatment or punishment. In a clinical setting, a rights issue could be engaged in a range of cases, including physical abuse, excessive restraint and neglect. However, an approach that avoids breaching this right does not equate to a good level of care, and a human rights-based approach would aim to treat everyone with dignity, not avoid the worst care that the law will tolerate.

Autonomy:

Autonomy is the principle of self-determination. It speaks to the freedom of a person to choose what happens to them and, relatedly, the freedom to act, the freedom to decide, and the freedom to participate in the decision-making. In learning disability settings, an individual’s ability to exercise choice is impacted by an overly paternalistic style of care (Commission for Healthcare Audit and Inspection, 2006), and one might wonder if a similar case could be made in children’s mental health settings.

6.2. APPENDIX B – Recruitment Poster for Young People



HUMAN RIGHTS

CALLING ALL YOUNG PEOPLE

HERE AT THE

SITE LOCATION

A researcher from the University of East London would like to interview you about human rights!

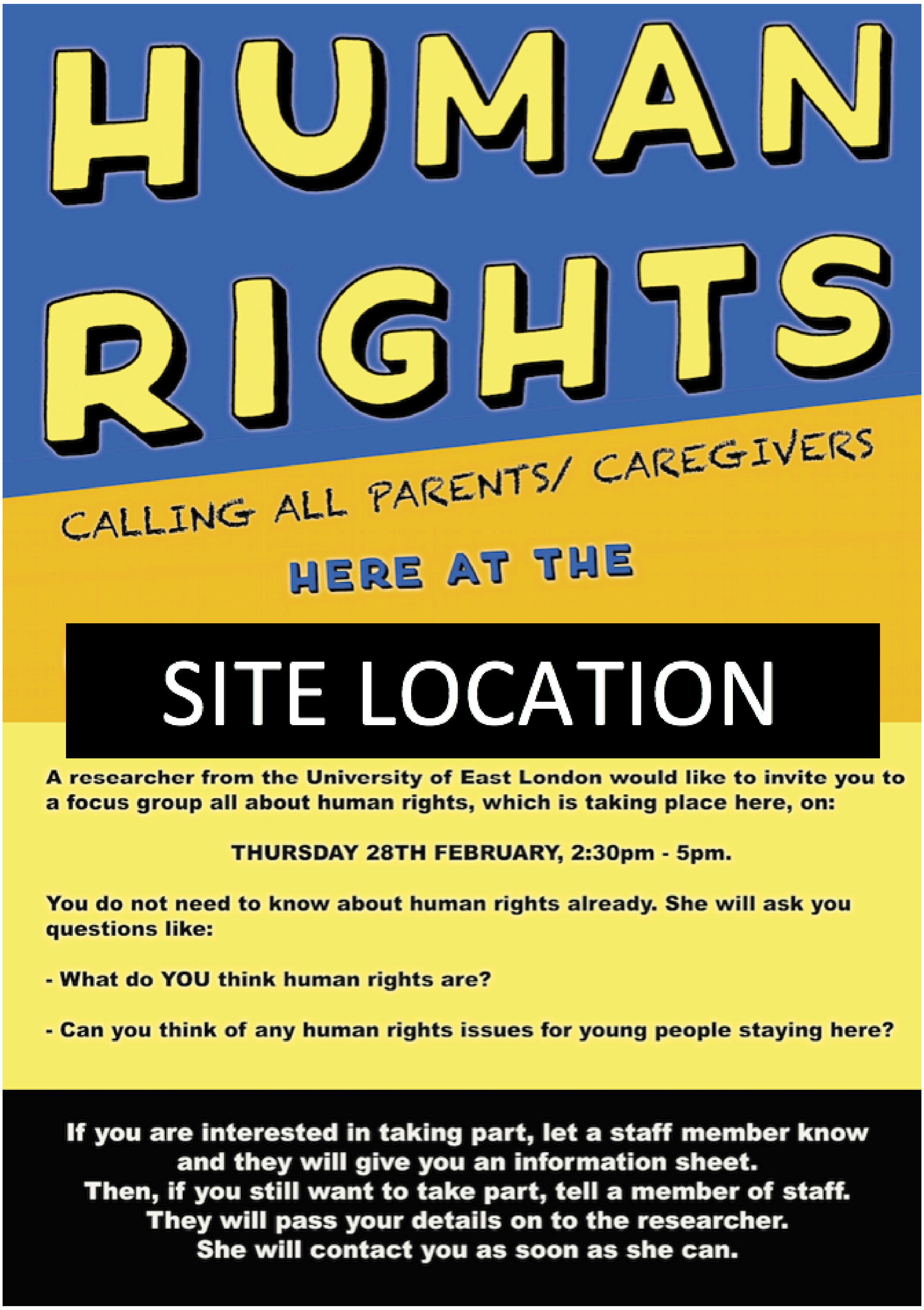
You do not need to know about human rights already. She will ask you questions like:

What do YOU think human rights are?

Can you think of any human rights issues for young people staying here?

If you are interested in taking part, let a staff member know
and they will give you an information sheet.
Then, if you still want to take part, tell a member of staff.
They will pass your details on to the researcher.
She will contact you as soon as she can.

6.3. APPENDIX C – Recruitment Poster for Parents/ Caregivers



HUMAN RIGHTS

CALLING ALL PARENTS/ CAREGIVERS

HERE AT THE

SITE LOCATION

A researcher from the University of East London would like to invite you to a focus group all about human rights, which is taking place here, on:

THURSDAY 28TH FEBRUARY, 2:30pm - 5pm.

You do not need to know about human rights already. She will ask you questions like:

- **What do YOU think human rights are?**
- **Can you think of any human rights issues for young people staying here?**

If you are interested in taking part, let a staff member know and they will give you an information sheet.
Then, if you still want to take part, tell a member of staff.
They will pass your details on to the researcher.
She will contact you as soon as she can.

6.4. APPENDIX D – Information Sheet for Young People Aged 12-13

HUMAN RIGHTS AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES:

INFORMATION SHEET FOR YOUNG PEOPLE (AGED 12-13)

Thank you for being interested in this project! This information sheet is here to tell you more about the research. Hopefully, it can help you decide if you want to take part.

Who is doing the research?

The research is being done mainly by one woman, called Rosie. She is a student at a university called the University of East London. Her job title is "Trainee Clinical Psychologist".

Why are we doing this research?

Have you ever heard the words "human rights"? Maybe you've heard people use those words, or maybe you haven't, or maybe you know quite a bit about them?

Sometimes people have difficult experiences whilst they are staying in a mental health hospital. For example, maybe they are not treated with respect or fairness. Some people might call these experiences 'human rights issues'.

The researcher wants to learn more about human rights. Especially, she wants to know what *you* think about them! She would like to know if you have any thoughts about them, or even if you have never heard of them before. That is still helpful to know. She would also like to know if you have had any difficult experiences here that you think might be human rights issues.

What will happen if you take part?

If you want to take part, this is what it looks like:

- You will meet with the researcher for about an hour.
- If you want to break it up into two shorter interviewers, that’s okay too.
- The researcher will talk to you about the research and check you still want to be involved.
- She will ask you to sign a form to say that you are happy to take part. This is called a consent form.
- She will then ask you some questions. For example, she will ask you “Can you tell me a little bit about being here? What has been helpful? What has been unhelpful?”
- You don’t need to know much about human rights. If you don’t know what they are, that’s okay! It will still be useful to talk to you, if you want to.
- You don’t have to speak about anything you don’t want to talk about.
- You can also stop the interview at any time. You don’t even have to explain.

Who will we tell things to?

This research will be *confidential.* This means that the researcher will keep what you have said private in most cases. Let me tell you a bit more about that…

- The researcher will record what you have said on an audio-recorder.
- She will then write it up in a paper.
- Importantly, she will *take your name off everything that is written.*
- She will use a number instead of your name.
- She will not tell hospital staff or your parent(s) or guardian(s) what you have said.
- This means nobody else will know who said what.

However, there are a few things that the researcher will have to tell people…

- She will not tell them what you have said in the interviews.

- The only times when she will have to say something is if she is worried about your safety or worried about other people around you, like if you told her that you were going to hurt yourself.
- If that happens, she will have to tell hospital staff what you said.

How else will the researcher keep everything private?

- She will have to keep a list of names of everyone that is being interviewed. This is so she can contact them if she needs to.
- However, this will be kept locked away in a cabinet so nobody else can read it.
- She will destroy this list and the recordings of your interview as soon as the research is finished.
- When she writes up the interviews, for example in a research paper, she will take out your name and nobody should be able to tell who was being interviewed.
- There are new guidelines that mean we have to tell you extra information about how your data is used. “Data” in this case just means your name, contact details, and your interview transcript. We have added a blue box at the end of this information sheet with these extra details.

Could this study cause me problems?

Nothing you say in the interview will change the care that you get in the hospital.

If you become upset when you are talking in the interview, the interviewer will check if you are okay and will ask if you want to stop. You can stop at any time.

Am I old enough to take part?

Anybody staying in the hospital is allowed to take part. However, if you are aged 15 or under, we will need to check with one of your parents or guardians that they are okay with you taking part. They will need to sign a form.

Where will the meetings take place?

If you want to take part, we will work out a good time for the interview.

Together, we can decide where you would feel most safe and comfortable to meet. It should be somewhere quiet and private so you can talk openly.

What if I want to make a complaint about the staff or hospital?

The researcher wants to hear about your thoughts and experiences. However, she will not be able to change anything about your current situation right now.

If you are concerned about the care in this hospital, you or your parent/ guardian can contact the *Patient Advice and Liaison Service (PALS).* They will support you if you have any worries about your care.

Their details are:

[DETAILS]

Will you be talking to my parent(s) or guardian(s)?

The researcher is also hoping to ask parents or guardians what they think about human rights, and what they think are some of the relevant human rights issues. If they want to, they can take part in an interview with the researcher.

Your interview is separate, and nothing you say will be told to your parents. If they don't want to be interviewed, that's okay. You can still be interviewed, as long as you get their permission.

Okay, what next?

- You do not have to take part in this study – it is completely your choice.
- However, if you want to, then tell a member of staff and they will help book your interview.
- If you don't want to go through staff, don't worry. I will be here every [DAY OF THE WEEK] and you can speak to me directly.
- If, after the interview, you change your mind about taking part, tell a member of staff. If you would like, the researcher can delete your interview information, as long as the report has not been published yet.
- After everything is finished, this research will be written up into a report and academic paper(s), and it might be presented at a conference.
- Again, everything you say will be kept private – she will not mention any names.

Any other questions?

Thank you for getting through to the end of this long information sheet! If you still have any questions, let a member of staff know or contact the researcher.

There will also be time to ask the researcher any questions you have before you start the interview. This information sheet is yours to keep!

Thank you!

Rosie Sharville

Trainee Clinical Psychologist

Supervised by: Professor Nimisha Patel

HOW WILL MY DATA BE USED AND PROCESSED?

New guidelines (The General Data Protection Regulation, 2018) recommend that we provide clear and transparent information about how your data is processed. The University of East London (UEL) is the sponsor for this study based in the United Kingdom. The researcher at UEL will be using information from you in order to undertake this study and will act as the data controller for this study. This means that UEL are responsible for looking after your information and using it properly. UEL will keep identifiable information about you in the form of a list of names of participants. This is needed so that we can contact you whilst the study is ongoing or let you know the findings of the study after it is over. This list of names will be kept separately from the anonymised interview transcript and will be kept in a locked cabinet until the study is completed and the findings have been shared with you. The anonymised transcript will be kept for 10 years after study completion.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained (i.e. the anonymised interview transcript). To safeguard your rights, we will use the minimum personally-identifiable information possible. Your name will never be present in the findings or write-up and all quotes will be anonymised.

If you say that you are interested in taking part, the [MHU] will pass on your name, NHS number, and contact details to the researcher at UEL. UEL will use these details to contact you about the research study and to oversee the quality of the study. Individuals from UEL and regulatory organisations will not look at your medical and research records.

The only people in UEL who will have access to information that identifies you will be the researcher and her supervisor, who may need to contact you to arrange an interview time or audit the data collection process. No other people from UEL will be able to identify you and will not be able to find out your name, NHS number or contact details. Your individual interview data will not be kept by the [MHU], who will only have access to an anonymised summary and any anonymised published materials that result from the study.

6.5. APPENDIX E – Information Sheet for Young People Aged 14-15

HUMAN RIGHTS AND YOUNG PEOPLE’S MENTAL HEALTH SERVICES:

INFORMATION SHEET FOR YOUNG PEOPLE (AGED 14-15)

Thank you for being interested in this project! This information sheet is here to tell you more about the research. Hopefully, it can help you decide if you want to take part.

Who is doing the research?

The research is being done mainly by one woman, called Rosie. She is a student at a university called the University of East London. Her job title is “Trainee Clinical Psychologist”. The organisation that runs this hospital is called the [TRUST], and they have agreed that this research can go ahead.

Why are we doing this research?

Have you ever heard the words “human rights”? Maybe you’ve heard people use those words, or maybe you haven’t, or maybe you know quite a bit about them?

The researcher wants to learn more about human rights. Especially, she wants to know what *you* think about them! She would like to know if you have any thoughts about them, or even if you have never heard of them before. That is still helpful to know.

Some people have difficult experiences whilst they are staying in a mental health hospital. Maybe they were not treated with respect or fairness, for example. For some, they might call these difficult experiences ‘human rights issues’. The researcher would also like to know your thoughts on this. Have you had any experiences that might be ‘human rights issues?’

What will you need to do?

If you want to take part, the researcher would like to speak to you. This would be an interview, and it would probably last about an hour. If you want a break, or to split it into two shorter interviews, that is okay too.

In the interview, the researcher will ask you what you think about human rights. She will also ask if you have had any experiences that seem like human rights issues. Remember, you don't need to have lots of knowledge about human rights – the researcher is interested in any of your thoughts about them.

You don't have to speak about anything you don't want to talk about. You can also stop the interview at any time. You don't even have to explain why.

Who will we tell things to?

The researcher will record what you have said on an audio-recorder. She will then write it up in a paper. Importantly, she will take your name off everything that is written. She will use a number instead of your name. This means nobody else will know who said what.

The researcher will not tell hospital staff or your parent(s) or guardian(s) what you have said. She will only say that you have agreed to be involved in the study and she will check with them that it is okay for you to take part.

There are a few times when the researcher might have to break this rule of privacy. This is only if you say something that makes the researcher worried about your safety, or the safety of other people, like if you said you were going to hurt yourself. If this happens, the researcher will have to tell hospital staff what you have said.

The researcher has to have a list of the names of everyone being interviewed, so that she can contact them if she needs to. She will keep this locked away and nobody else can read that list of names. She will destroy this list and the recordings of your interview, as soon as the research is finished.

There are new guidelines that mean we have to tell you extra information about how your data is used. “Data” in this case just means your name, contact details, and your interview transcript. We have added a blue box at the end of this information sheet with these extra details.

Could this study affect me?

Nothing you say in the interview will affect the care that you get in the hospital.

If you become upset when you are talking in the interview, the interviewer will check if you are okay and will ask if you want to stop. You can stop at any time.

Am I old enough to take part?

Anybody staying in the hospital is allowed to take part. However, if you are aged 15 or under, we will need to check with one of your parents or guardians that they are okay with you taking part.

Where will the meetings take place?

If you want to take part, we will work out what the best time for an interview would be. Together, we can decide where you would feel most safe and comfortable to meet. It should be somewhere quiet and private so you can talk openly.

What if I want to make a complaint about the staff or hospital?

We want to hear your general thoughts about human rights and human rights issues. In the long term, we hope that this will make experiences better for people staying in hospital. Unfortunately, the researcher will not be able to

change anything about your particular situation, or about the hospital, right now. However, you can complain about your care or a member of staff to the *Patient Advice and Liaison Service (PALS).* They will support you if you have any concerns about your care.
Their details are:

[DETAILS]

Will you be talking to my parent(s) or guardian(s)?

The researcher is also hoping to ask parents or guardians what they think about human rights, and what they think are some of the relevant human rights issues. If they want to, they can take part in an interview with the researcher.

Your interview is separate, and nothing you say will be told to your parents. If they don't want to be interviewed, that's okay. You can still be interviewed, as long as you get their permission.

Okay, what next?

You do not have to take part in this study – it is completely your choice.

However, if you want to, then tell a member of staff and they will help book your interview.

If you don't want to go through staff, don't worry. I will be here every [DAY OF THE WEEK] and you can speak to me directly.

Before the interview, you will need to sign a form saying you are happy to take part. Your parent or guardian will also need to sign one when they come in for their next visit. You must get your parents' permission *before* your interview.

If, after the interview, you change your mind about taking part, tell a member of staff. If you would like, the researcher can delete your interview information, as long as the report has not been published yet.

After everything is finished, this research will be written up into a report and academic paper(s). Again, everything you say will be kept private – there will be no names. The research may also be presented in a conference and the same rules apply about privacy.

Any other questions?

Thank you for getting through to the end of this long information sheet! If you still have any questions, let a member of staff know and they will ask the researcher to contact you. There will also be time to go through this information with the researcher before you take part. This information sheet is yours to keep!

Thank you!

Rosie Sharville

Trainee Clinical Psychologist

Supervised by: Professor Nimisha Patel

HOW WILL MY DATA BE USED AND PROCESSED?

New guidelines (The General Data Protection Regulation, 2018) recommend that we provide clear and transparent information about how your data is processed. The University of East London (UEL) is the sponsor for this study based in the United Kingdom. The researcher at UEL will be using information from you in order to undertake this study and will act as the data controller for this study. This means that UEL are responsible for looking after your information and using it properly. UEL will keep identifiable information about you in the form of a list of names of participants. This is needed so that we can contact you whilst the study is ongoing or let you know the findings of the study after it is over. This list of names will be kept separately from the anonymised interview transcript and will be kept in a locked cabinet until the study is completed and the findings have been shared with you. The anonymised transcript will be kept for 10 years after study completion.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained (i.e. the anonymised interview transcript). To safeguard your rights, we will use the minimum personally-identifiable information possible. Your name will never be present in the findings or write-up and all quotes will be anonymised.

If you say that you are interested in taking part, the [MHU] will pass on your name, NHS number, and contact details to the researcher at UEL. UEL will use these details to contact you about the research study and to oversee the quality of the study. Individuals from UEL and regulatory organisations will not look at your medical and research records.

The only people in UEL who will have access to information that identifies you will be the researcher and her supervisor, who may need to contact you to arrange an interview time or audit the data collection process. No other people from UEL will be able to identify you and will not be able to find out your name, NHS number or contact details. Your individual interview data will not be kept by the [MHU], who will only have access to an anonymised summary and any anonymised published materials that result from the study.

6.6. APPENDIX F – Information Sheet for Young People Aged 16+

HUMAN RIGHTS AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES:

INFORMATION SHEET FOR YOUNG PEOPLE (AGED 16-18)

Thank you for asking about the project! This information sheet is here to tell you more about the research. Then, you can decide whether you still want to take part.

Who is doing the research?

This research is being done by the University of East London. [THE TRUST] who run this hospital, are also involved. The main researcher is a Trainee Psychologist, who has experience doing research and interviews.

Why are we doing this research?

Young people sometimes have to stay in mental health hospitals. For some, this raises problems that could be thought of as "human rights issues". We want to know what you think about human rights. What do you think they are? What do you think they mean? Have you had any experiences that you think are "human rights issues"?

We hope that speaking to you will help us understand human rights more. We also hope that, after this, we will be able to recommend ways of helping make hospitals better for young people.

What will you need to do?

If you decide you want to take part, a researcher (a woman) will meet with you for an individual interview. This should last around one hour, but if you need breaks or want to split it into two shorter interviews, that is okay too.

During the interview, the researcher will ask you some questions about human rights and human rights issues in the hospital. But don't worry, you don’t need to know all about human rights! We are just interested in what they mean to *you.*

You don’t have to speak about anything you don’t want to talk about, and you can stop the interview at any time. You don’t even have to explain why.

Who will we tell things to?

What you say to the interviewer will be kept confidential or private. What this means is that your name won’t be on any of the research when it is finished. Nothing else will be written that could give away who you are, like the date that you were born or what you look like. The researcher also won’t talk to people about what you told her, unless she is worried about your safety or the safety of other people. If she talks to research staff at the University of East London about the research, she will not say your name. However, she will tell hospital staff that you have agreed to take part.

Your interview will be recorded with an audio-recorder. This is so the researcher can type up what was said (without your name, of course). Instead of your name, the researcher will use a number. The typed document will then be kept in a locked cabinet or password-protected computer for 10 years, when it will be destroyed.

The only thing that will have your name on it will be a list of people taking part. This is so we can contact you. This list will be kept separate, locked in a filing cabinet, and destroyed as soon as the study is complete. All of these things are done to make sure that what you say is confidential.

There are new guidelines that mean we have to tell you extra information about how your data is used. “Data” in this case just means your name, contact details, and your interview transcript. We have added a blue box at the end of this information sheet with these extra details.

Could this study affect me?

Nothing you say in the interview will affect the care that you get in the hospital.

If you become upset when you are talking in the interview, the interviewer will check if you are okay and will ask if you want to stop. You can stop at any time.

If you tell us that you are going to hurt yourself or other people, we will have to tell a member of staff on the ward. This is because your safety and the safety of other people are really important.

Am I old enough to take part?

Anybody staying in the hospital is allowed to take part. However, those aged 15 or under will also need the written permission from a parent or guardian.

Where will the meetings take place?

We will arrange with you and the staff the best time for an interview for you. Together, we can decide where you would feel most safe and comfortable to meet. It should be somewhere quiet and private so you can talk openly.

What if I want to make a complaint about the staff or hospital?

We want to hear your general thoughts about human rights and human rights issues. In the long term, we hope that this will make experiences better for people staying in hospital. Unfortunately, the researcher will not be able to change anything about your particular situation, or about the hospital, right now. However, you can complain about your care or a member of staff to a complaints agency.

The *Patient Advice and Liaison Service (PALS)* is a confidential service that supports service users and relatives/ carers when they have concerns about their care or when they need some advice. They can help you if you need to make a complaint or are worried about your care. Their details are:

[DETAILS]

Will you be talking to my parent(s) or guardian(s)?

The researcher is also hoping to ask parents or guardians what they think about human rights, and what they think are some of the relevant human rights issues. They will be invited to participate in their own interview, separate from yours. Nothing you say in your interview will be shared with your parent(s) or guardian(s).

We will let your parents know that you are taking part in the study but we will not tell them what you tell us in the interview (except if we are worried about safety). If you are 16 or over, we do not need their permission for you to take part, but we still like to keep them in the loop. If you are under 16, we will need your parent's / caregiver's permission for you to be interviewed.

Okay, what next?

You do not have to take part. This study is completely voluntary. However, if you want to, then tell a member of staff and they will start the process of booking in your interview with the researcher. If you don't want to go through staff, don't worry. I will be here every [DAY OF THE WEEK] and you can speak to me directly.

Before the interview, we will need you to sign a consent form saying you are happy to take part. I will give this to you at the start of the interview.

If, after the interview, you change your mind about taking part, tell a member of staff and they will contact the researcher to let them know. If you would like, the researcher can delete your interview information, as long as the report has not been published yet.

After everything is finished, this research will be written up into a report and academic paper(s). Again, everything you say will be kept private – there will be no names. The research may also be presented in a conference and the same rules apply about privacy and confidentiality.

Any other questions?

Thank you for getting through to the end of this long information sheet! If you still have any questions, let a member of staff know and they will ask the researcher to contact you. There will also be time to go through this information with the researcher before you take part. This information sheet is yours to keep!

Thank you!

Rosie Sharville

Trainee Clinical Psychologist

Supervised by: Professor Nimisha Patel

HOW WILL MY DATA BE USED AND PROCESSED?

New guidelines (The General Data Protection Regulation, 2018) recommend that we provide clear and transparent information about how your data is processed. The University of East London (UEL) is the sponsor for this study based in the United Kingdom. The researcher at UEL will be using information from you in order to undertake this study and will act as the data controller for this study. This means that UEL are responsible for looking after your information and using it properly. UEL will keep identifiable information about you in the form of a list of names of participants. This is needed so that we can contact you whilst the study is ongoing or let you know the findings of the study after it is over. This list of names will be kept separately from the anonymised interview transcript and will be kept in a locked cabinet until the study is completed and the findings have been shared with you. The anonymised transcript will be kept for 10 years after study completion.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained (i.e. the anonymised interview transcript). To safeguard your rights, we will use the minimum personally-identifiable information possible. Your name will never be present in the findings or write-up and all quotes will be anonymised.

If you say that you are interested in taking part, the [MHU] will pass on your name, NHS number, and contact details to the researcher at UEL. UEL will use these details to contact you about the research study and to oversee the quality of the study. Individuals from UEL and regulatory organisations will not look at your medical and research records.

The only people in UEL who will have access to information that identifies you will be the researcher and her supervisor, who may need to contact you to arrange an interview time or audit the data collection process. No other people from UEL will be able to identify you and will not be able to find out your name, NHS number or contact details. Your individual interview data will not be kept by the [MHU], who will only have access to an anonymised summary and any anonymised published materials that result from the study.

6.7. APPENDIX G – Information Sheet for Parent Interview

HUMAN RIGHTS AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES:

PARENT/ CAREGIVER INFORMATION SHEET

Thank you for your interest. The purpose of this letter is to provide you with the information that you need to decide whether or not to participate in the research. If you have any questions, there are contact details at the end of this info sheet.

This study is being conducted by the University of East London in collaboration with the [TRUST]. The researchers are experienced health professionals. Please note that taking part in this research will in no way impact on the care provided to the young person you support at the [SERVICE NAME]

Why are we doing this research?

Young people, children and adolescents, sometimes stay in mental health hospitals as part of their treatment and care. For some, the experiences of healthcare practices may raise human rights issues.

We are interested in understanding how you understand 'human rights'. We would also like to understand how you think and feel about any experiences you or your child have had within the CAMHS unit which you consider to be 'human rights issues'.

We hope that, through speaking with and listening to you, we will gain a better understanding of these issues. We hope to provide recommendations and guidance to health professionals and service managers, based on our findings from the research, to help improve services for young people with mental health difficulties and their families.

What will you be required to do?

The researcher (a woman) is conducting interviews with parents and caregivers of the young people at the [SERVICE NAME]. This interviews will last up to one hour. During the interview, I will ask the group some general questions about your understanding of ‘human rights’ and about your experience as a parent/ guardian of someone cared for in a CAMHS inpatient unit- experiences which you may consider human rights issues.

I will NOT ask you about the mental health or personal history of the person you are a parent/ guardian of, or of your own. You will not be required to talk about anything you do not wish to speak about. You can say as much or as little as you feel comfortable.

How might this study impact on you?

If at any time you become distressed during the group, we can pause the discussion and you can choose whether and when you want to continue with it. You are more than welcome to leave at any point and you are also welcome to come back in again. If you would like, I can discuss with you how and where appropriate support can be found.

Will what I say be confidential?

In order to properly consider what you say, we will need to record the interview using an audio-recorder. However, if you choose to participate in this study, we will make sure that anything you tell us is kept strictly confidential, unless information is disclosed regarding the risk of harm to yourself or others. We will transfer all recordings onto a secure computer, which only the researcher will have access to and which will be password-protected.

We will then type out a transcription of the recording personally, and make immediately anonymous any information which may reveal your identity. We will refer to anything you may say using a reference number rather than your name and nothing that reveals who you are will be included in any documents that other people may read. We will keep a list of participants’ names to be able to contact you, in a locked filing cabinet at the University of East London, only until the interview is completed. After the interview has been recorded and the data transcribed, the names and any personally identifiable information will be deleted.

The anonymized transcript of what you say will be kept securely for a period of ten years after the study is complete. After this date, all data and the consent forms will be destroyed, in accordance with the Data Protection Act (1998). All information provided by participants will be kept confidential unless a participant discloses information regarding risk to themselves or others. In such an event, the participant will be informed of the action that would be necessary in order to ensure the safety of that participant and others.

The researcher requests that participants do not share information outside of the group conversation, in order to protect the privacy of the members of the group. However, please note that, despite this request, the researcher cannot guarantee complete confidentiality in a group setting.

For more detail about how we will use your data, please see the box at the end of this information sheet.

Making a complaint

We want to hear your general thoughts about human rights and human rights issues. In the long term, we hope that this will make experiences better for people staying in hospital. Unfortunately, the researcher will not be able to change anything about your particular situation, or about the hospital, right now. However, you can complain about the care or a member of staff to a complaints agency.

The *Patient Advice and Liaison Service (PALS)* is a confidential service that supports service users and relatives/ carers when they have concerns about their care or when they need some advice. They can help you if you need to make a complaint or are worried about the care being received. Their details are: [DETAILS]

Will there be any payment?

We will not be offering payment for interview participation. We will reimburse you for any travel expense (return fare) to attend our meeting if you are travelling for the purpose of this interview.

Can I say no?

Participation in this study is entirely voluntary. You are not obliged to take part in this research and you should not feel in any way forced to do so. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. If you withdraw from the study this will not affect any services you or your child are receiving or any legal proceedings you may already be involved in or initiating. If you choose to participate, or not, in the research, either way, this will not affect any services you or the person you support/family member are receiving. Should you withdraw, and analysis of the research has already commenced, the researchers will ask permission to use the anonymised data in the write-up of the study and in any further analysis that may be conducted by the researcher, but if you request us to remove all your quotations used in the analysis this wish will be honoured, as long as we are informed before the data has been published.

Will this research be published?

This research will be written up into a report and for an academic journal article. As above, anything you say as part of this research will remain confidential, and no identifying personal details will be included within any publication. This research may also be presented at a conference where the same confidentiality will apply.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Camberwell St. Giles Research Ethics Committee.

Any other questions?

If you have any other questions, I am happy to answer them over the phone or in person. I will be around the [SERVICE NAME] every Thursday afternoon from 2pm onwards for the next few months. If you would like to speak over the phone, just tell staff that you would like to be contacted and they will pass the message on to the researcher, who will give you a call as soon as possible.

If you are happy to continue you will be asked to sign a consent form prior to your participation. You will be given this at the start of the interview.

This information sheet is yours to keep.

Thank you!

Rosie Sharville

Trainee Clinical Psychologist

Supervised by: Professor Nimisha Patel

HOW WILL MY DATA BE USED AND PROCESSED?

New guidelines (The General Data Protection Regulation, 2018) recommend that we provide clear and transparent information about how your data is processed. The University of East London (UEL) is the sponsor for this study based in the United Kingdom. The researcher at UEL will be using information from you in order to undertake this study and will act as the data controller for this study. This means that UEL are responsible for looking after your information and using it properly. UEL will keep identifiable information about you in the form of a list of names of participants. This is needed so that we can contact you whilst the study is ongoing or let you know the findings of the study after it is over. This list of names will be kept separately from the anonymised interview transcript and will be kept in a locked cabinet until the study is completed and the findings have been shared with you. The anonymised transcript will be kept for 10 years after study completion.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained (i.e. the anonymised interview transcript). To safeguard your rights, we will use the minimum personally-identifiable information possible. Your name will never be present in the findings or write-up and all quotes will be anonymised.

If you say that you are interested in taking part, the [MHU] will pass on your name, NHS number, and contact details to the researcher at UEL. UEL will use these details to contact you about the research study and to oversee the quality of the study. Individuals from UEL and regulatory organisations will not look at your medical and research records.

The only people in UEL who will have access to information that identifies you will be the researcher and her supervisor, who may need to contact you to arrange an interview time or audit the data collection process. No other people from UEL will be able to identify you and will not be able to find out your name, NHS number or contact details. Your individual interview data will not be kept by the [MHU], who will only have access to an anonymised summary and any anonymised published materials that result from the study.

6.8. APPENDIX H – Assent/ Consent Form for Young People

HUMAN RIGHTS AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES:

ASSENT/ CONSENT FORM FOR YOUNG PEOPLE

[FOR RESEARCHER USE]: Participant Identification number for this study:

Name of Researcher: Roseanna (Rosie) Sharville, Trainee Clinical Psychologist

Please tick all boxes if you are happy to take part:

1. I have read and understand the information sheet for this study. I have been able to think through the information, ask questions and have had these questions answered. ☐

2. I understand that it is my choice to take part and I am free to stop at any time without giving any reason, without it affecting my care at the hospital. ☐

3. Though my name will be kept private, I understand that people may read some of the quotes from me, either in the researcher's thesis write-up or in a published paper. I give permission for them to read these quotes. ☐

4. I understand that if I tell the researcher something that makes them concerned about my safety or the safety of other people, they will have to tell certain staff at the hospital. ☐

5. I agree to take part in the above study. ☐

6. I agree for this interview to be audio-recorded. ☐

7. I understand that, if I am under 16 years old, a parent or caregiver will also have to give permission for me to take part in the study. ☐

Name of Participant	Date	Signature
…………………………………..	………………..	…………….
Name of person taking consent	Date	Signature
…………………………………..	………………..	…………………
Name of interpreter if present	Date	Signature
…………………………………..	………………..	…………………

6.9. APPENDIX I – Parental Consent Form for Young Person Participation

HUMAN RIGHTS AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES:

PARENT/ CAREGIVER CONSENT FORM FOR CHILD PARTICIPATION

[RESEARCHER USE] Participant Identification number for this study: ……………..

Name of Researcher: Roseanna (Rosie) Sharville, Trainee Clinical Psychologist

You have been asked to sign this consent form because your child is under the age of 16 and has indicated that they want to take part in the study.

Please initial all boxes:

1. I confirm that I have read and understand the information sheet for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my child has indicated that they would like to take part, but that their participation is voluntary and that I am free to withdraw my consent at any time without giving any reason, without my child's medical care or legal rights being affected. ☐

3. I understand that anonymous quotes from my child (with their name and identify features removed), will be included in the researcher's doctoral thesis and in any published academic papers or conferences. I give permission for them to use my child's quotes for these purposes. ☐

4. I understand that, if my child discloses something that references risk of harm to themselves or others, the researcher has a professional duty of care to inform the relevant staff or authorities. ☐

5. I agree that my child can take part in the above study. ☐

6. I agree for the interview to be audio-recorded. ☐

Names of Participant + Parent	Date	Signature
………………………………………..	………………..	…………………
Name of person taking consent	Date	Signature
………………………………………..	………………..	…………………
Name of interpreter if present	Date	Signature
………………………………………..	………………..	…………………

6.10. APPENDIX J – Parental Consent Form for Parent Participation

HUMAN RIGHTS AND YOUNG PEOPLE'S MENTAL HEALTH SERVICES:

PARENT/ CAREGIVER CONSENT FORM FOR THE FOCUS GROUP

[RESEARCHER USE] Participant Identification number for this study: ……………..

Name of Researcher: Roseanna (Rosie) Sharville, Trainee Clinical Psychologist

Please initial all boxes:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without the medical care or my legal rights being affected. ☐

3. Though my name will be kept private, I understand that people may read some of the quotes from me, either in the researcher's thesis write-up or in a published paper. I give permission for my quotes to be included. ☐

4. Though the researcher asks that nobody share the conversations of the group outside of the group, I understand that complete confidentiality can never be guaranteed in a group setting. ☐

5. I agree that I will only be referred to other clinicians or a GP with my consent, except in the case of disclosure of the risk of harm to ☐

myself or to someone else where I understand that the researcher has a professional duty of care that outweighs my wishes.

6. I agree to take part in the above study. ☐

7. I agree for this interview to be audio-recorded. ☐

Names of Parent/ Caregiver + Child	Date	Signature
…………………………………..	………………..	…………………
Name of person taking consent	Date	Signature
…………………………………..	………………..	…………………
Name of interpreter if present	Date	Signature
…………………………………..	………………..	…………………

6.11. APPENDIX K – Interview Schedule

Individual interviews were semi-structured, using open-ended questions. Where necessary and appropriate, prompts were given. Prompts are noted as bullet points below. Questions were not necessarily in the given order, but were dependent on the participant's previous answers.

1. *Can you tell me a little bit about what it is like being in here?*

- *What were your first impressions?*
- *What has been helpful?*
- *What has been unhelpful?*
- *Feelings, thoughts, hopes, expectations, fears?*

2. *Some people think human rights are really important for young people, like you, staying in mental health hospitals. What do human rights mean to you?*

- *Have you heard of the term 'human rights' before? Where?*
- *What do you think it means?*
- *What do you think of as 'human rights'? Can you give any examples?*

3. *What do you think of as a human rights issue here?*

- *What kind of experiences come to mind when you think of 'human rights issues'? Why?*
- *What are your fears/ concerns/ hopes/ expectations when you think about those experiences?*
- *Do you feel you have been treated with respect/ dignity/ fairness?*

4. *How do you think services could improve things for people staying here? How could services help with any human rights issues?*

    - *What could people do differently?*
    - *How might you design a service that treats people with respect/ dignity/ fairness?*

6.12. APPENDIX L – Key of Symbols used in Transcription and Write-Up

Symbol	**Meaning**
...	The participant paused
[ ]	Non-verbal activity, e.g. laughing, gesture or disruption OR word removed for confidentiality purposes, e.g. staff member’s name OR word replaced for clearer understanding out of context, e.g. “it” replaced with [mobile phone]
[…]	Words have been omitted to shorten quotes
(P1), (P2) etc.	Participant identification number
(Interviewer)	Interviewer’s words. For further clarity, participant words are italicized; the interviewer’s words are not italicized.
“”	The participant is referring to the speech of another person
.,	Punctuation used to aid reading OR very short pauses in participant’s speech

6.13. APPENDIX M – Example Excerpt of Coded Transcript

Line No.	**Transcript 7** **Participant:** [DEMOGRAPHICS REMOVED AS TOO IDENTIFIABLE] **Setting: Acute side-room**	**Initial code**	**Reflections/ notes**
	So could you tell me a little bit about what it's like being here?		
	Being here… well I'd say to most people it's really weird, to me it's not weird anymore because I've been here for… ages. I've been here since last January. It's a very, very controlled environment and feels fake most of the time. Erm… the dynamics are always changing because the people here are always changing, and sometimes it's really confusing. Sometimes… sometimes it feels helpful and sometimes you just really want to be anywhere else in the world, and you wonder why stuff is happening to you to keep you here… stuff like that.	Unusual experience/ not 'the norm' Becoming normal to self with time Fake environment Controlled environment Multiple new people/ ever changing Confusing place Mixture of helpful and unhelpful/ worst place to be Stuck here	
	There's a lot in that. Can I ask you a bit about each of those parts? So you said that, you know, you've been in here for a long time. Can you tell me a bit about your first impressions, when you first came here?		
	It wasn't my first time on a unit, er, I'd been transferred from another unit, and I wasn't here I was in [NAME OF WARD], which is a PICU. I really really didn't want to be there. I understood that it was helpful but I wasn't in a place to accept that at all erm… My first impression of it was that it was super restrictive, I wasn't allowed anything. Erm… I was under constant observation, it just wasn't… It wasn't nice. I was really wrapped up in my own head though, so that time was difficult but… it passed and like… I guess that my feeling about this place goes up and down depending on how I feel, what's going on. There's been times when I have really thanked this place because it's shifted something that I don't think I would have been able to shift on my own, but [laughs] overall… I wouldn't say that it's a very positive experience in my life.	Different experiences in different wards/ levels of ward Don't want to be here/ there Acceptance is different from understanding reasons Very restrictive environment Observation as restriction Observation as unpleasant Difficulties passing with time The experience is dependent on how YP feeling and context Thankful for experience Seen a change in self Couldn't do this alone Overall not a positive experience	Can understand helpful whilst also not wanting to be there. Human rights as related to restrictions? Many of these themes relate more to experience than human rights. On the surface, this seems because it is the question that I asked, but it may also be that it is easier to speak of your experiences and harder to link to human rights, which isn't a language that we use as much in life. It could also be that human rights are understand *as experiences*, as good or bad experiences, so a good experience is seen as okay in terms of human rights, and a bad experience is seen as not okay.
	And you touched on things being… some things being helpful and some things being unhelpful, and the changes that have been positive, but it's also been quite a difficult experience		
	Yeah		
	Can you tell me, I'll ask you about both sides, but first off can you tell me a bit about what has allowed it to be helpful, or what has been a positive experience here?		
	Well, places like this attract a lot of really cool people, really different people. The pool of staff is amazingly diverse and they're great people. So, I've met lots of people that I would never have met otherwise and, at times, it's really restored my faith that good people exist because there are enough good people here and I've been able to find people that I've really got on with. So… that's good. Erm, the therapy's good I mean, the head honchos … they seem to know what they're doing. I say	YP and staff as cool, different, diverse, helpful Staff as ethical people/ good people New experiences, met new people Shown that good people exist Get on with people/ made connections Good therapy	

[CONTINUED ON NEXT PAGE]

that now but it really wasn't always my opinion of the people here, so that's the positive part. That's honestly emerged over the last couple of months.	Agreement with senior staff decisions Improved opinion of staff and YP decisions with time Context and time-dependent opinions of staff and care	
So there's quite a long period of time when you didn't feel like that?		Relating to the right to involvement?
Yeah, before that it was quite up and down but there was times when I was really in conflict with people here because what they wanted wasn't what I wanted and er I was under section for eight of my months here, which meant that I really didn't have much choice and the choice that I did have was in a certain framework that was made by them and I was… a lot of the choices I was making, well, I was making the choice on paper but really it's not how… it's not a choice. And even when you're not on section there's some things that they ask you to do that, it's a choice but… you're able to leave because you're informal but if you try to leave we'll section you again, which is a grey area that I really haven't liked.	Up and down experience Conflicting goals between self and staff Section as restricting choice The system's framework conflicts with personal wants/ choice False choices/ not a real choice Falsely informal/ false freedom Desire for clarity about right to leave/ falsely informal	More choice given as they stayed longer, or less resistance over time?
That makes a lot of sense. Can you… it sounds like you've got quite a lot of examples in mind of these choices that felt like they weren't really free choices. Could you tell me a bit more about that?		
I mean, anything from the small things like… do you want to go to groups, do you want to take part in these activities, to stuff like… do you want to follow your meal plan? Do you want to… do all of these things? Do you want to do stuff other than what you actually want to do? I think that you do, I think that it would be a really good idea for you to do that. I understand that people have my best interests at heart, but… it wasn't my choice. That's the, the choices that were given to me. When I was first here they just made them for me in the blink of an eye, because I didn't want what they wanted. I didn't want to be here and they wanted me to be here. Yeah. And when safety and stuff is… in… question. If they think that you're going to jeopardise that they can do a lot of things that you wouldn't want them doing.	False choices can be small or large False choice of taking part in an activity False choice of food Choice Vs 'good for you' Best interests vs choice/ free will Decisions made for you if in disagreement Quick decisions Safety as a justification for less choice/ freedom	
And some people might, you know, think about those things in terms of human rights?		
Yeah		
What do you make of the link between what you've just spoken about and the idea of human rights? What connections can you see there?		Are these rights less concrete? More intangible than, say, the right to an advocate? You can easily tell if someone has an advocate, you cannot easily tell if someone has been treated with dignity, or their identity has been respected.
Well I was always confused because there are very few things that, if you think about it completely logically, are human rights violations. But… it does feel like… your humanity. You stop feeling like a person and you become a patient for a while, and they're very different things. I've heard of human rights, like rights for children and stuff but honestly no one ever talked to me about the sort of rights that you'd	Human rights as related to logic Human rights violations are rare Difference between technical human rights and humanity Patient is not a person/ treated differently	

[END OF EXCERPT]

6.14. APPENDIX N – Example of Codes Listed under the Category/ Initial Theme of ‘Relationships and Connectedness’

Staff as not caring/ here for the money.
MH as particularly likely to have uncaring staff?
Majority of staff as uncaring
Staff as not caring
Not deserving to work there
Staff as not responsible
Anger/ frustration at ward/ staff
Staff as idiots.
Staff as stupid
Concern seen as pretense
Distance of staff/ less involvement
Anger at staff/ system
Long time to fix a problem
Busy staff
Wanting support
Feeling unable to express need for support
Feeling let down by staff
Frustration at staff
Staff like child
Lack of communication
Feeling not cared about
Impact of not feeling cared for on own care for self
Feeling unable to ask for help/ unsure how
Unsure/ can’t remember staff roles
Some contact with MH support but not seen as enough
Expectation of staying long and thus no need to rush with MH support
Importance of contact with professionals
Time with professionals as indicative of care
Not seeing consultant enough
Doctors as not caring
Staff are inspirational
YP and staff as cool, different, diverse, helpful
Staff as ethical people/ good people
New experiences, met new people
Shown that good people exist
Get on with people/ made connections
Good therapy
Agreement with senior staff decisions
Improved opinion of staff and YP decisions with time
Use of phones as important/ calming
Limited phone use
Feeling lost
Feeling empty
Taken out of school
Isolation from friends
Lonely/ isolation
Phone restrictions
Isolation
Distance from loved ones/ family
Unfamiliar place

Unfamiliar people
Lost
Phone use restriction
Over-heard by staff
Risk reduction as rights restriction
Loss
Loss of education and people
Far from home
Feels alone/ unsure if alone in stress
Taking away what you're close to
Parental involvement
Staff closer to parents than young person
Parents more involved in care than YP
Issues with communication between staff, YP, and parents
Phones as a human rights issue
Phones as a means of connection
Phone contact as a privilege/ highly valued
Needing more connection with others
Importance of connection and friendship
Good communication with family
Family as the only source of support
Lack of contact leading to institutionalization
Forget the outside world/ institutionalization
Fear of institutionalization/ not being able to re-adapt to outside world
Carousel of treatment/ institutionalization
Must have phone in private side-room
Phone restrictions
Challenging relationship with other YP
Threats of violence from other YP as human rights issue
Other YP invading your space/ breaking your boundaries
Difficult experiences of being with other YP
Human rights issue as no choice in who you spend time around
Putting up with unpleasant experiences
Experience has built compassion and tolerance
The idea of 'good people'
Helpful experiences with other YP
No touching policy is soulless/ inhumane/ human rights issue/ contact with consent and connection as a human right/ normal
Need- consent for contact
Human rights as allowing normal interactions/ normality/ freedoms
Need- flexible approach/ less strict rules
Need- connection with others
Daunting experience
Unfamiliar people
Isolation on the ward
Not wanting to be alone
Distance of staff/ less involvement
Desire for consistency
Desire for support
Importance of regular contact with professionals
Respect as being listened to/ views heard
Respect as care
Hearing others' stories
Seeing others' experiences
Other young people as supportive/ motivational

Other young people as mutually supportive
Mixed respect and disrespect
Feeling disliked by others and impact
Other YP as difficult to be around
Disrespect from staff and other young people
Negative impact of staff changeovers
Negative impact of YP turnover/ changes
Multiple new people/ ever changing
Need – time with staff/ interaction/ care
Changing/ new staff as intimidating/ difficult to bond
Effects of staff changeover
Staff do not care
Staff as not interested in patient distress
YP and staff as cool, different, diverse, helpful
Staff as ethical people/ good people
New experiences, met new people
Shown that good people exist
Get on with people/ made connections
Good therapy
Agreement with senior staff decisions
Improved opinion of staff and YP decisions with time
Context and time-dependent opinions of staff and care
Group effects – transferred/ linked/ group distress
Idea of ‘good staff’/ good people
Need- connection with staff/ two-way conversation/ interesting discussion/ not us vs them
Connecting as humans
Person Vs Patient
Importance of working with families and systems
Working with families/ systems has positive impact on YP
‘Problem’ cannot be ‘fixed’ only in the context of the ward
Focus on entirety of person and system
Need- understand our distress/ the challenges YP are facing
Group effects – shared space
Can talk to some staff
Some staff care/ exceptions
Need consistency from staff
Need empathy
Need staff to not minimize distress
Need time with staff
Need requests to be met
Staff that care as most important
Staff as manipulating
False friendliness from staff
Staff manipulate YP to take medication/ do tasks

6.15. APPENDIX O – An Example of Code Checking against the Original Data Extracts, with Included Suggested Sub-Themes

Interview Excerpt	Initial Codes	Sub-Theme
Obviously, people respond if there's an incident or something, but people who actually take the time to recognise you as a person. People who would see you if you're having a hard time and remember not just, you know, your care plan […] Erm… yeah, and people… people who, if you were in a one-to-one with them, would talk about something that's relevant to them, something that doesn't make you feel like you're talking to an automaton. Something that makes you feel interesting, because you can tell them something weird [laughs] and they'll actually have a conversation with you about it. You know, just human stuff, actual human stuff that people bring. (P7)	Dignity through connection with others Dignity through allowances and flexibility Need both the risk response and the person-centred approaches Need- remember the person behind the care plan/ not only protocol-focused, but person-focused Team care plan is needed but not sufficient Follow the person not only the paperwork Need- connection with staff/ two-way conversation/ interesting discussion/ not us vs them	INSIDE CONNECTION/ GENERAL
[When I first arrived] I just felt really, like… I want to say lost in the world, at the risk of sounding dramatic. But it is like when you've lost a lot of things, like education, and friends, and family. Everything… your house, your area. Everything that you would assign to living, you don't really feel like you've got anymore, and that's like really weird [laughs], to go from	Lost Loss Loss of education and people Effect of loss on MH Support actually makes you worse/ iatrogenic Shock	OUTSIDE CONNECTION

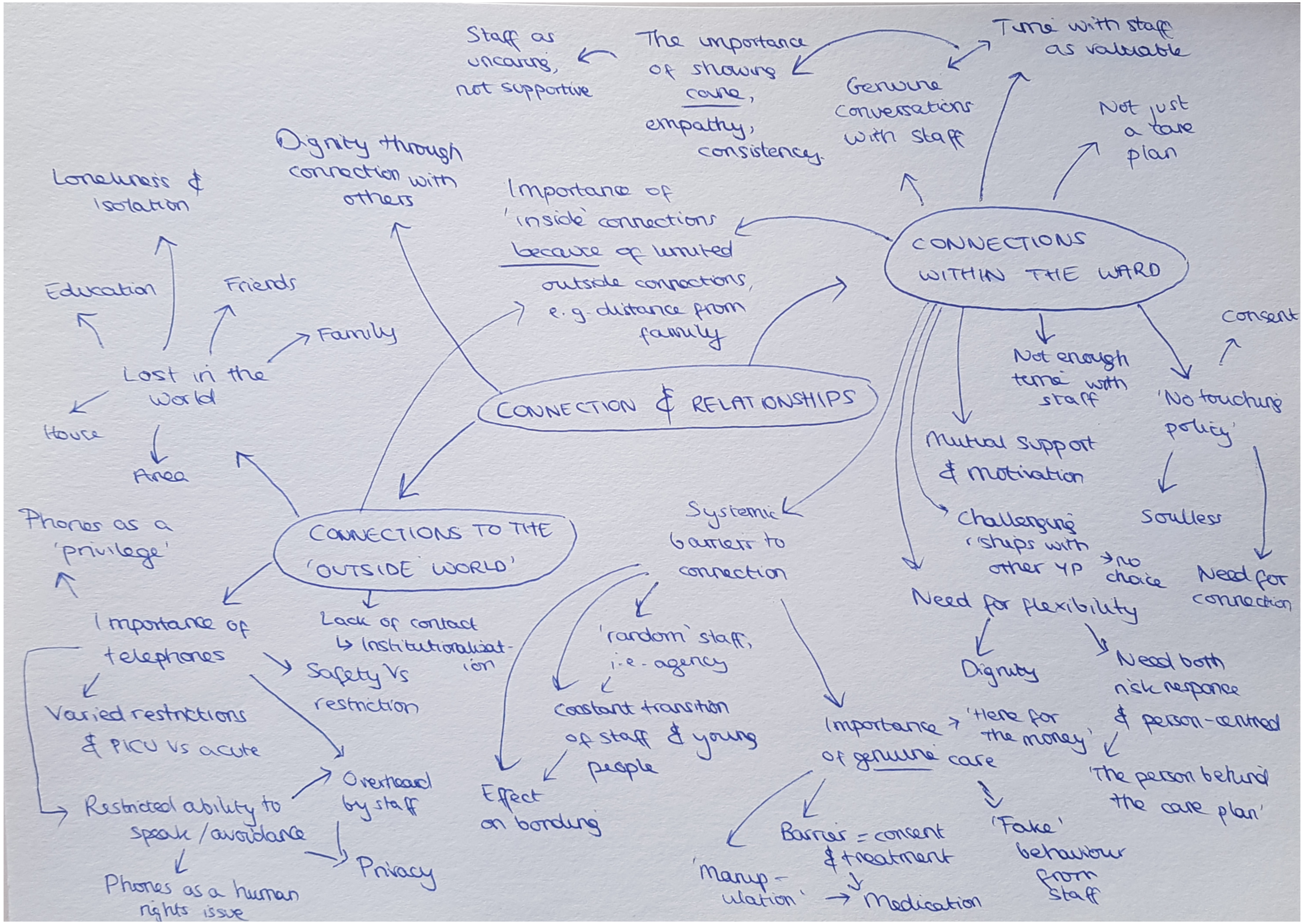
good friends, and a good education, good grades, to like really really bad health and just coming here, and it was like a real shock… to me. (P3)		
Um… I'd say not having a phone to contact friends is really hard… cos I used to be on another hospital with a different ward and they'd allow your phone and… I feel like it was such a privilege to be able to use my phone and be able to contact my friends. I wish that I could actually go back in time and… contact them more. (P1)	Phones as a human rights issue Phones as a means of connection Phone contact as a privilege/ highly valued Needing more connection with others Importance of connection and friendship	OUTSIDE CONNECTION
(Interviewer) Okay, so is there anything that you would like me to know, that you haven't had a chance to say so far? *Erm yeah, I'm not allowed to hold the phone for calls. I have to have it on loud speaker with somebody holding it, because I have a history of swallowing batteries. (P2)* (Interviewer) What does that mean in terms of speaking to people that you need to? *It's quite like… I only speak to my dad or my solicitor. I don't speak to anyone else. Yeah, because it would be too awkward otherwise. (P2)*	Phone use restriction Over-heard by staff Risk reduction as rights restriction Effect of phone restriction on who is spoken to Subjective experience of being observed Awkward to be observed Uncomfortable to be observed	OUTSIDE CONNECTION
People's characteristics. I'd say um… strong characteristics of some of the people, young people, who	Other young people as supportive/ motivational	INSIDE CONNECTION

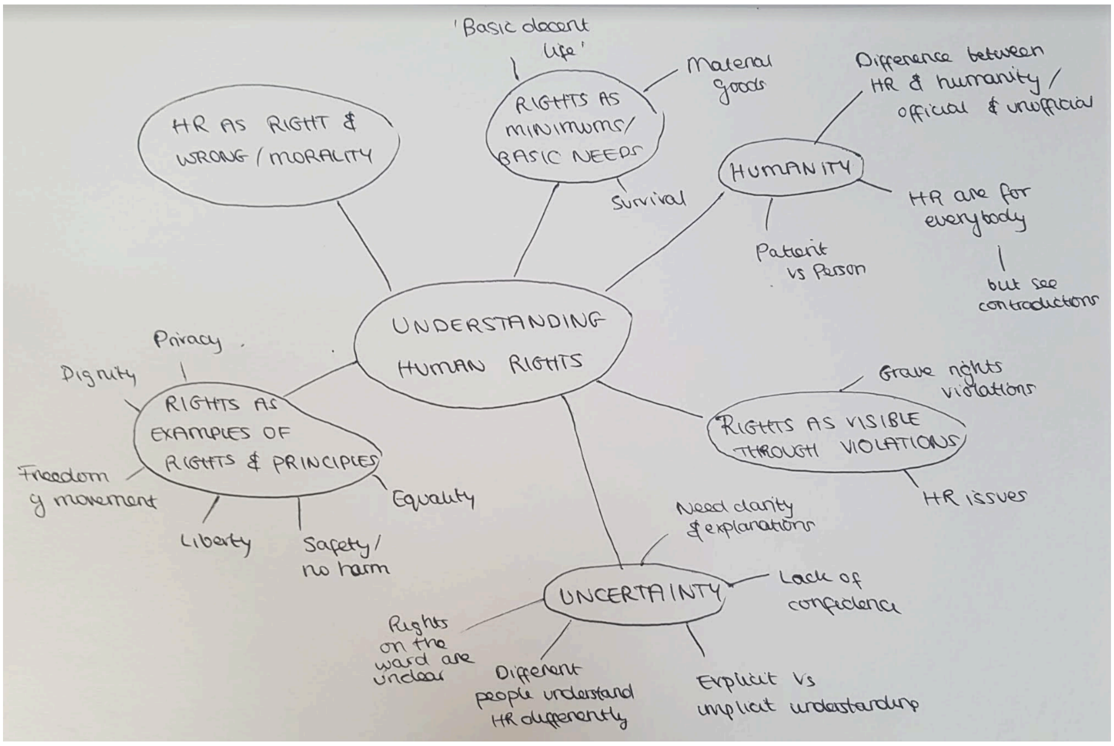
stay on the ward um… give motivation to get up every single day and continue the process and treatment *(P1)*	Treatment as something that needs to be 'got through'/ effortful/ difficult	
But then I've also found amazing people who understand, who have again restored my faith that there's good people. And then, with relationships with them, there's stuff like a no touching policy, which sometimes is absolutely soulless because you just want a hug. Erm… and as long as you ask, "Is that okay? Are you someone who hates hugs?" Like… "Sure, do you want a hug too?". That's sort of a normal thing to do, and I think the staff that I like most are the people who are willing to bend rules like that, to let us. Instead of saying "Oh don't high five each other". Letting us be a little less fake. (P7)	The idea of 'good people' Helpful experiences with other YP No touching policy is soulless/ inhumane/ human rights issue/ contact with consent and connection as a human right/ normal Need- consent for contact Human rights as allowing normal interactions/ normality/ freedoms	INSIDE CONNECTION
Yeah, the tiny things as well. Like, even if you've had a horrible day and people have had to even physically intervene, somebody just… spending time with you. (P7)	Need – time with staff/ interaction/ care Need- a flexible approach Need- space and time after distress	INSIDE CONNECTION
(Interviewer) What makes a good staff member? *Consistency. Empathy. Sympathy. Not brushing things off. Erm, what else. Being there most of the time. Having one-to-ones, if it's safe to be in a room, like me and you are here. Have that with that child. That child*	Need consistency from staff Need empathy Need staff to not minimize distress Need time with staff Need requests to be met	INSIDE CONNECTION

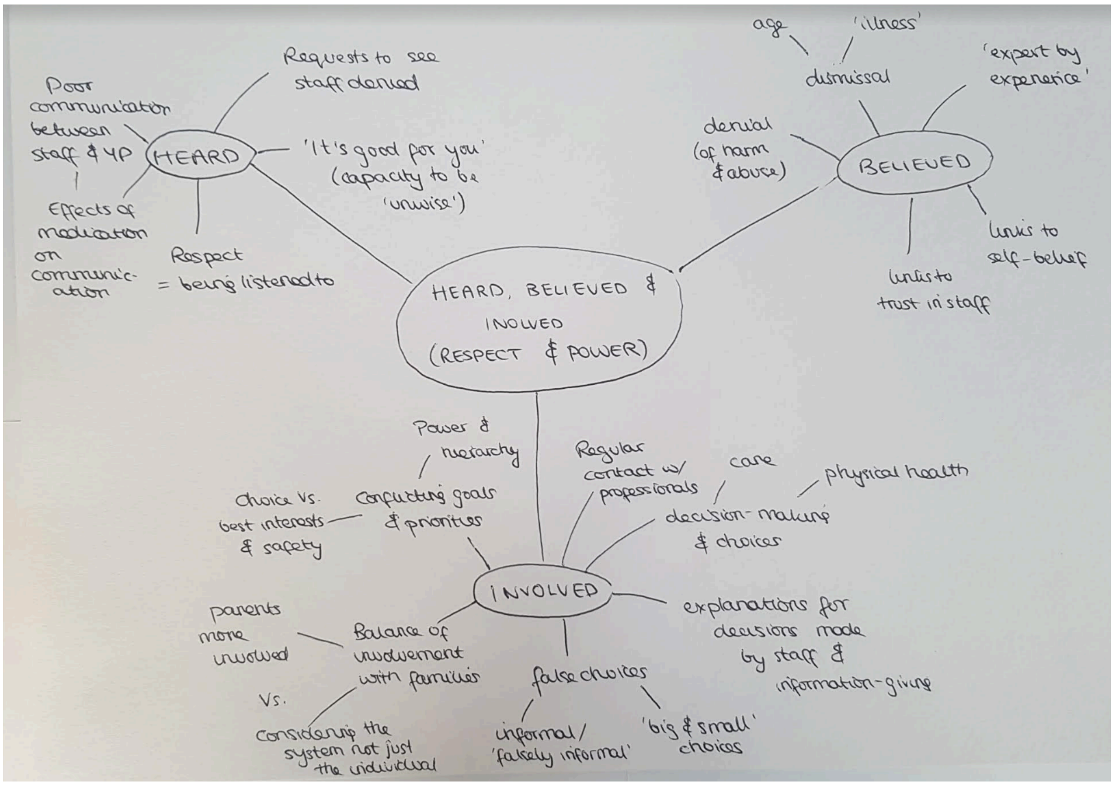
needs it. If the child says, "Please check under my bed, I'm scared of the monsters"… check under the fucking bed. (P5) (Interviewer) Yeah help them out, be there for them. *Exactly. So if you're trying to train people, you need to cut out the jobsworth, and you need to… find the ones that care. (P5)*	Staff that care as most important	
Some days it's just random staff members on the ward from other wards and it's kind of hard to keep up when everyone is transitioning so much. If you want an actual relationship like with a staff member to try and bond with them, it can be a bit hard and… intimidating almost. (P1)	Need for more regular meetings with staff Negative impact of staff changeovers Negative impact of YP turnover/ changes	INSIDE CONNECTION
I feel like the staff try to be like friends with you to be able to manipulate you. (P4) (Interviewer) Tell me about that. *So, [NAME OF STAFF MEMBER 2], the man that just came in? He keeps doing [thumps fist on chest and makes 'peace sign' with fingers] "Bro bro bro" to me in the corridors. But the thing is, I feel like he's doing that not because he likes me as a*	Staff as manipulating False friendliness from staff Staff as manipulating Difference between patient and person/ us vs them	INSIDE CONNECTION

person, but because he has to manipulate me as a patient. (P4) (Interviewer) And what is he trying to manipulate you for? *Taking medication, doing my chores, things around the hospital. (P4)*	Staff manipulate YP to take medication/ do tasks False friendliness	
Not allowed, not allowed my phone. Only allowed fifteen minutes per phone call. Erm. Only allowed one phone call per shift. Three in total. And I don't like that. I think that's wrong. (P5)	Restricted phone use. Right vs wrong. Rights issues as things that are wrong Phone restrictions as wrong.	OUTSIDE CONNECTION
Erm, I feel like, when you're feeling shitty, and you're feeling really low, erm and suicidal or whatever, and you want to talk to somebody, but you don't want to go out of your way to find them, you just want to wait for them to get there and then you'll talk to them then, but I feel like whenever you need that they never turn up. (P3)	Wanting support Feeling unable to express need for support Feeling let down by staff Desire for consistency Desire for support	INSIDE CONNECTION

6.16. APPENDIX P – Candidate Thematic Maps

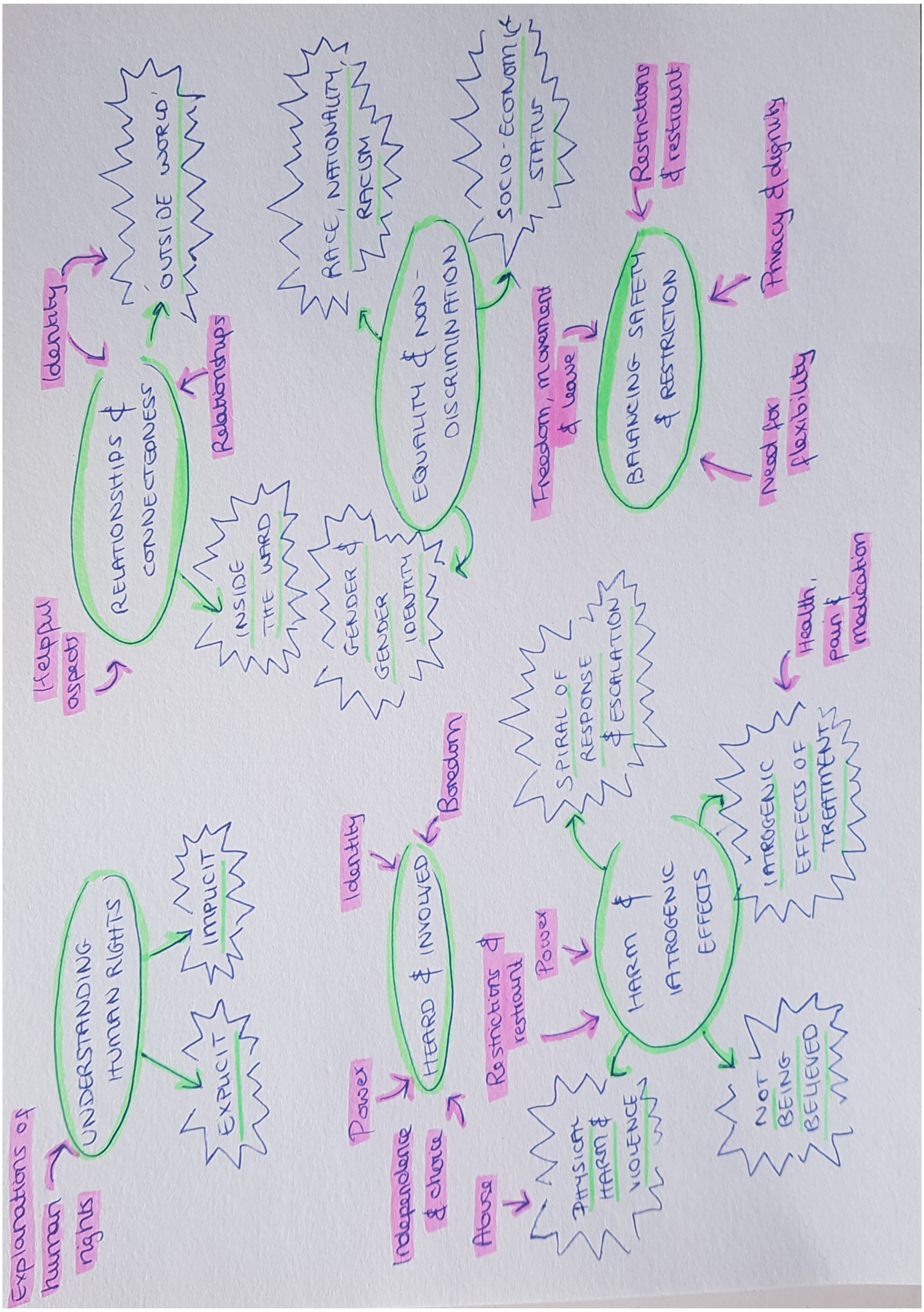



'Basic decent life'
Material goods
RIGHTS AS MINIMUMS/ BASIC NEEDS
Survival
HR AS RIGHT & WRONG / MORALITY
Difference between HR & humanity / official & unofficial
HUMANITY
HR are for everybody
but see contradictions
Patient vs Person
UNDERSTANDING HUMAN RIGHTS
Privacy
Dignity
RIGHTS AS EXAMPLES OF RIGHTS & PRINCIPLES
Freedom of movement
Liberty
Safety / no harm
Equality
Grave rights violations
RIGHTS AS VISIBLE THROUGH VIOLATIONS
HR issues
Need clarity & explanations
UNCERTAINTY
Lack of confidence
Rights on the ward are unclear
Different people understand HR differently
Explicit vs implicit understanding


Requests to see staff denied
Poor communication between staff & YP
HEARD
'It's good for you' (capacity to be 'unwise')
Effects of medication on communic-ation
Respect = being listened to
age
'illness'
dismissal
'expert by experience'
denial (of harm & abuse)
BELIEVED
links to self-belief
links to trust in staff
HEARD, BELIEVED & INVOLVED (RESPECT & POWER)
Power & hierarchy
Conflicting goals & priorities
Choice vs. best interests & safety
Regular contact w/ professionals
care
physical health
decision-making & choices
INVOLVED
explanations for decisions made by staff & information-giving
parents more involved
Balance of involvement with families
vs.
considering the system not just the individual
false choices
informal / 'falsely informal'
'big & small' choices

6.17. APPENDIX Q – Collapsing and Splitting Themes – How the Final Six Themes Relate to the Original Thirteen Categories

[PINK = INITIAL THEMES/ CATEGORIES; GREEN = FINAL SIX THEMES]



6.18. APPENDIX R – Research Ethics Committee Approval Letter

NHS
Health Research
Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 020 7104 8044

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

07 December 2018

Miss Roseanna Sharville
Trainee Clinical Psychologist
Camden and Islington NHS Trust
University of East London
Water Lane
London
E15 4LZ

Dear Miss Sharville

Study title:	**Exploring Human Rights in the Context of Young People's Mental Health Services**
REC reference:	**18/LO/1735**
Protocol number:	**N/A**
IRAS project ID:	**244164**

Thank you for your letter of 27 November 2018 , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

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

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster for Young People. IRAS 244164]	Final Version 1	12 August 2018
Copies of advertisement materials for research participants [Poster for Parent/ Caregiver Focus Group. IRAS 244164]	Final Version 1	12 August 2018
Covering letter on headed paper [Covering Letter in Response to the Provisional Opinion of the REC Committee. 27/11/2018. IRAS 244164.]	Version 1	27 November 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Certificate of Employer Liability/ Insurance for UEL. IRAS 244164]	Version 1	01 August 2018
Interview schedules or topic guides for participants [Interview Schedule for Young People. IRAS 244164]	Final Version 1	12 August 2018
Interview schedules or topic guides for participants [Focus Group Schedule for Parents/ Caregivers. IRAS 244164]	Final Version 1	12 August 2018
IRAS Application Form [IRAS_Form_13092018]		13 September 2018
Participant consent form [Consent/ Assent Form for Young People. IRAS 244164]	Final Version 1	12 August 2018
Participant consent form [Parent/ Caregiver Consent Form for Young Person's Participation (if under 16). IRAS 244164]	Final Version 1	12 August 2018
Participant consent form [Parent/ Caregiver Consent Form for Focus Group. IRAS 244164.]	Version 2	27 November 2018
Participant information sheet (PIS) [Info Sheet for Interviews with Young People aged 12-13. 27/11/2018. IRAS 244164.]	Version 2	27 November 2018
Participant information sheet (PIS) [Info Sheet for Interviews with Young People aged 14-15. 27/11/2018. IRAS 244164.]	Version 2	27 November 2018
Participant information sheet (PIS) [Info Sheet for Interviews with Young People aged 16-18. 27/11/2018. IRAS 244164.]	Version 2	27 November 2018
Participant information sheet (PIS) [Info Sheet for Parent/ Caregiver Focus Group. IRAS 244164]	Version 2	27 November 2018
Referee's report or other scientific critique report [Letter from Independent Review (Scientific Critique). IRAS 244164]	Version 1 (Only Version)	12 December 2017
Referee's report or other scientific critique report [Report from Independent Review (Scientific Critique). IRAS 244164]	Version 1 (Only Version)	12 December 2017
Research protocol or project proposal [Protocol for IRAS 244164]	Final Version 1	12 August 2018
Summary CV for Chief Investigator (CI) [CV - Chief Investigator - IRAS 244164]	Final Version 1	12 August 2018

Summary CV for student [CV of Student (also Chief Investigator). IRAS 244164]	Final Version 1	12 August 2018
Summary CV for supervisor (student research) [CV for Academic Supervisor. IRAS 244164]	Final Version 1	12 August 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of Protocol. IRAS 244164]	Final Version 1	12 August 2018

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

HRA Training

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

18/LO/1735	**Please quote this number on all correspondence**

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

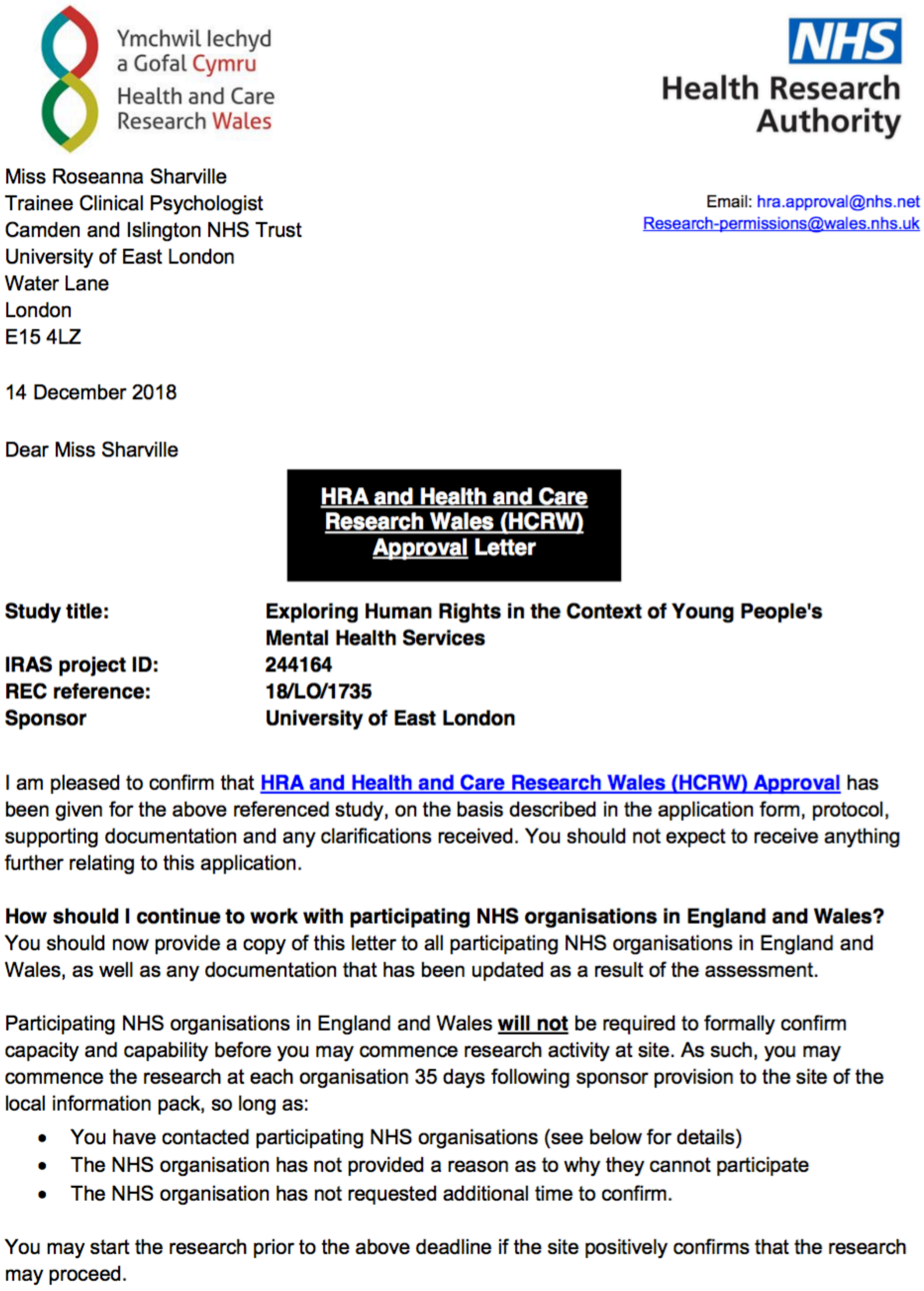
Yours sincerely

[redacted]

PP
Mr John Richardson
Chair

Email: nrescommittee.london-camberwellstgiles@nhs.net

6.19. APPENDIX S – Health Research Authority (HRA) Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Roseanna Sharville
Trainee Clinical Psychologist
Camden and Islington NHS Trust
University of East London
Water Lane
London
E15 4LZ

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

14 December 2018

Dear Miss Sharville

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring Human Rights in the Context of Young People's Mental Health Services**
IRAS project ID:	**244164**
REC reference:	**18/LO/1735**
Sponsor	**University of East London**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Participating NHS organisations in England and Wales **will not** be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation 35 days following sponsor provision to the site of the local information pack, so long as:

- You have contacted participating NHS organisations (see below for details)
- The NHS organisation has not provided a reason as to why they cannot participate
- The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. After entering your IRAS ID you will be able to access a password protected document (password: **Redhouse1**). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the "*summary of assessment*" section towards the end of this document.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Catherine Fieulleteau
Tel: [redacted]
Email: researchethics@uel.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **244164**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone [redacted]
Email: hra.approval@nhs.net