

HOW DO YOUNG PEOPLE WITH FIRST EPISODE PSYCHOSIS MAKE SENSE OF
HELP-SEEKING INTERACTIONS WITH PROFESSIONALS

by

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Thesis Overview

This thesis comprises four chapters. The first chapter is a meta-ethnography reviewing the experiences of adults being detained under the Mental Health Act in the UK. This included twelve papers and four themes were identified; interpersonal relationships, a loss of control and power, the use of restrictive practices, containment and medication, and the construction of disorder. The findings from the meta-ethnography have similarities to the principles of the trauma-informed care approach.

The second chapter is a qualitative empirical research project using Interpretive Phenomenological Analysis (IPA) to explore how young people with first episode psychosis (FEP) experience help-seeking with professionals. Six young people (aged between 17 and 21) were interviewed from the same early intervention psychosis service in an NHS trust in the midlands, UK. This paper provides experiences of what can be identified as barriers and facilitators to young people with FEP seeking support from professionals.

Finally, the third and fourth chapters of the thesis are the press releases for the meta-ethnography (chapter three) and the empirical research project (chapter 4).

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Patients' Direct Experiences of Detention Under the Mental Health Act in the United Kingdom

Abstract

Background: Previous research has reviewed the experiences of being detained in a hospital. However, these reviews often include studies across multiple countries that may follow different legal frameworks to the UK. Therefore, this may influence the experience people have whilst being in the hospital. Also, previous research has included data and information from professionals and family members, not exclusively the direct experiences of the individuals detained. Therefore, this review aimed to focus on the findings of direct experiences of being detained under the Mental Health Act in the UK.

Method: An online search was completed across five databases: Medline, PsycINFO, HMIC, Embase and the Social Sciences Citation Index database accessed via the Web of Knowledge. The studies were screened which left a total of twelve studies which met the inclusion and exclusion criteria.

Results: From the analysis, four themes (and subthemes) were identified: Interpersonal relationship; Loss of control and power; The use of restrictive practices; Medication and containment; and Construction of disorder.

Conclusion: The themes identified have overlapping concepts with the trauma-informed care approach. The findings from this review could influence conversations and services to support how to implement trauma-informed principles and improve the experience of people being detained under the MHA.

Introduction

In the United Kingdom, people who are unwell due to mental health difficulties and may be at risk to themselves or others can be detained under the Mental Health Act 1983 (Department of Health and Social Care, 2015). This means people can be treated without their consent and can be detained in hospital based on professionals making decisions in their best interest (Department of Health and Social Care, 2015). The Mental Health Act (MHA) was initially introduced in 1959, over 10 years after the National Health Service (NHS) was created. This was to ensure that people were being admitted and detained in hospital for medical rather than legal reasons (NICE, n.d.). The MHA was reviewed in 1983 to include consent, as people during this time were admitted to hospital under the MHA or voluntarily (NICE, n.d.). A description of the different Sections of the MHA can be found in Table 1.1 (Department of Health and Social Care, 2015). It has been reported that there has been an increase in the number of people being detained in hospitals to receive treatment in this manner over the years (Glover-Thomas, 2018; Keown et al., 2018). Keown et al. (2018) gathered data from national archives and NHS Digital and reported that from 1984 to 2016 there has been an increase of “295%” of people being detained under the MHA. This information was based on people being detained on longer sections, such as Section 2, Section 3 and court orders. This information did not include shorter detentions, such as being detained in a 136 detention suite or place of safety unless this resulted in a longer period of detention on a Section 2 or 3. The increase in detention has been larger for detention in hospitals (“331% increase”) over the 32 years compared to forensic detentions (“21% increase”) through court orders or prison transfers (Keown et al., 2018).

Table 1.1

Summary of some of the different detaining Sections under the Mental Health Act

Type of Section	Description
Section 2	Detained for 28 days for a period of assessment. The section will then end or people may be placed on a Section 3
Section 3	Detained for 6 months for treatment, this is reviewed for a further 6 months if it is still required to be in place. Following this the Section 3 is reviewed every 12 months.
Section 4	Detained for emergency assessment and lasts for only 72 hours. The section then will end or the person will be placed on a different type of section.
Section 37	The Crown Court or Magistrates Court can make a hospital order for a person who has committed an offence. This is similar to a Section 3 (but instructed from the court) being detained for treatment with 6 monthly reviews and then 12 monthly reviews.
Section 37/41	This is similar to a Section 37 with the hospital order being made by the court. However, there are additional restrictions (41) where any leave or transfer of hospital must be applied for and agreed by the Ministry of Justice. The clinical team in a hospital cannot make these decisions independently without permission from the Ministry of Justice.
Section 136	A police officer can take a person to a place of safety from the community if they think they may need an assessment under the MHA. The Section can last for a maximum of 72 hours from when they arrive at the place of safety for an assessment to take place and see if they may need treatment under a Section 2 or 3 and an admission into hospital.
Community Treatment Order (CTO)	This Section is for further supervised treatment when discharged from hospital, when previously being on a longer-term Section (e.g. Section 3 or Section 37). This is reviewed in the same way (6 monthly on two occasions, then 12 monthly). The CTO has conditions, this can include compliance with medication when discharged, not using substances if this increases the risk to themselves or others, and residing in the place they are discharged too. If the conditions are breached the individual can be recalled back to hospital.

Glover-Thomas (2018) also reported increases in detention rates from 2011 to 2016 based on data from NHS Digital. It was reported that a large increase is due to more people being detained under Section 2 of the MHA for a period of assessment and treatment. Glover-

Thomas (2018) reports that this increase could be possibly due to the introduction of community treatment orders (CTOs) in 2007, as well as funding implications. Glover-Thomas references the reduction of hospital beds and an associated need to increasingly rely on community teams and intensive support or crisis teams. Data is also provided from NHS Digital to suggest there has been an increase of individuals being transferred from Section 136 to Section 2 or 3 requiring treatment in the hospital.

The increase in detention rates is not only documented within the UK but in other countries in Europe (Keown et al., 2018). However, Keown et al. (2018) have acknowledged that how these statistics and the data are reported and collected may vary across different countries. This is important to acknowledge as previous meta-synthesis and literature reviews have included reviewing data from multiple countries (Akther et al., 2019; Seed et al., 2016b). While it is helpful to understand the rates of detention across different countries, the experiences of the individuals detained may be expected to vary according to the legal framework and its implementation in each country, alongside any cultural differences. When considering literature from multiple countries these experiences may therefore be somewhat diluted or homogenised across the literature and important findings may not be so readily identified or analysed (Smith et al., 2022). Therefore, the current research will be reviewing literature from the United Kingdom only.

Being detained under the Mental Health Act in the UK

There has been an increase in research on peoples' experiences of being detained, as well as family and professional perspectives of working and supporting individuals detained under the MHA (Dixon et al., 2022; Giacco et al., 2018; Loft & Lavendar, 2016; Mckeown et al., 2016). However, within these findings, the analysis often does not separate the direct experiences of the patient and the experiences of professionals and family. It has been noted

that the experience of being detained can be distressing for both family members and the individuals (Dixon et al., 2022). However, certain experiences of the process and rules to follow under the MHA, such as requesting leave, and reduced privacy in hospital are only directly experienced by the individuals themselves. Furthermore, staff may experience some of these processes differently when they are implementing rules and procedures, compared to individuals who have to follow these procedures implemented by the health care system. Given the data on the increased number of people being detained under the MHA, it is important to hear from those with direct experiences – particularly when considering what they feel works well and promotes recovery and what experiences they may find obstructive to their recovery.

The direct experience of being detained under the Mental Health Act

In 2019 Akther et al. conducted a meta-synthesis exploring “patients’ experiences of assessment and detention under mental health legislation”. The review included 56 papers and from the analysis five themes were identified. These included: “information and involvement in care”; “quality of the environment”; “quality of relationships”; “impact on self-worth” and “emotional impact of detention”. However, only 30 of the papers were from the UK, and several included family or carer perspectives that were not separated during the analysis of the interviews. Furthermore, a number of the papers included individual experiences of being on a CTO and the restrictions that can be included within a CTO when being discharged from the hospital. These restrictions and the increased level of freedom compared to being detained in a hospital may result in different experiences being discussed, particularly with regards to their relationships with professionals and others (family, friends or peers for those detained). The information and involvement in care experiences are also likely to be different, such as not having to request leave to go out of the hospital grounds and being able to have more

physical freedom. Some of the research papers also included a variety of different methods, such as focus groups or focus groups which led to individual interviews. This can affect what individuals disclose and share due to influence by wider group dynamics (Guest et al., 2017).

Therefore, there is a need to understand the lived experience of people detained under the UK mental health system. The present review therefore focused the analysis of the Akther et al. (2019) review by using only UK papers and interviews with patients (excluding family and professionals) to gain their direct experiences of being detained under the MHA. An updated search and literature review was also used to include any additional literature from January 2018, the date Akther et al. (2019) searched the literature databases.

Method

Epistemological position

A critical realist stance was taken in this meta-ethnography and there is an awareness that each individual's experiences being detained will be different. For example, individuals may experience a shared reality of being detained in hospital. However, their experience of this may also be different based on their interactions with others and how they make sense of being detained and these perceptions can influence that reality (Lyons & Coyle, 2021). It is acknowledged there is a reality that inpatient hospitals exist and within the healthcare system in the UK the MHA is a legal framework that is used to detain people when they are unwell. There is also the knowledge that multiple professionals will work in the hospital environment. However, from a critical realist perspective, this is knowledge and understanding that most people have, despite not having the experience of being detained. When having the direct experience of being detained under the MHA the knowledge and understanding of this process may be developed or modified, yet these experiences may vary depending on the interactions that happen within the hospital for each individual. A critical realist perspective means that

whilst there is a reality of objects and properties of the real world, our knowledge about these realities can change and develop (Haigh et al., 2019).

Critical realism describes that there is a social reality which includes three layers; the real domain, the actual domain and the empirical domain (Anderson, 2020; Stutchbury, 2022). The empirical domain is influenced by the other two domains, but it is what can be observed and measured based on people's experiences. The actual domain includes actions from people that can influence the experience others have (the empirical domain). For example, within a hospital setting the professionals within the team implement the ward routine of medication distribution, meal times, implementing the ward rules and policies. This can influence the social structure of roles and relationships within the hospital setting. The final layer is the real domain, which includes structures within social reality such as policies and procedures which are implemented or can be challenged in the actual domain (Anderson, 2020; Stutchbury, 2022).

Reflexivity and trustworthiness

As a researcher with prior experience working in mental health care inpatient settings (across rehabilitation and forensic wards), I am aware that my perspective on patient care might influence how I interpret the participants' accounts of detention under the MHA. This awareness was important, whilst also being aware that my experience is limited to the specific hospital and wards, I have worked in, with particular staff teams and services. It is important to capture the experiences of different individuals and be aware that there may be contrasting views from people detained under the MHA. Throughout the research to enhance trustworthiness, I reflected on my interpretations and decisions in discussions in supervision to ensure that my own experience did not influence the analysis and results through conscious or unconscious bias. I was also part of a meta-ethnography group, where developing ideas and

themes were shared with others and checked that this was grounded in the data. This was helpful to have the themes and data peer reviewed to ensure that the interpretations were relevant to the data.

Search strategy

Five databases were used to search for papers from January 2018 until April 2023. The databases were used to replicate the method of Akther et al. (2019): Medline, PsycINFO, HMIC and Embase, accessed via the Ovid platform and the Social Sciences Citation Index database accessed via the Web of Knowledge platform. The same search terms were used as Akther et al. (2019), which can be found in Table 1.2. However, the first set of search terms was amended by removing some of the search terms which related to research including family or carer's experiences (Appendix A). The search terms for "service users" which were removed included: carer* or famil* or caregiver* or caregiver or relative*.

Table 1.2

Search terms used, updated to ensure it is only direct experiences of service-users.

Key Words	Search Terms Used
Service-users	service-user* or patient* or consumer* or inpatient* or client* or ((lived or life) NEAR/0 experience*) or survivor*)
Compulsory admission	"mental health act" or section* or "mental treatment act" or (compuls* or involuntar* or coer* or forced or detention or detained or refusal or mandat* or civil or appeal* or advoc*) NEAR/2 (hospital* or admiss* or admit* or readmiss* or commit* or assess* or treat* or healthcare)
Mental health	mental disorders or ((mental* or psychologic* or psychiatr*) NEAR/2 (health or disorder* or disease* or deficien* or illness* or problem*))
Study design	qualitative research or interview or qualitative or (theme* or thematic) or "ethnological research" or (humanistic or existential or experiential or paradigm\$) or (field NEAR/0 (study or studies or research)) or ((purpos* NEAR/4 sampl*) or (focus NEAR/0 group*)) or "observational method*" or "content analysis" or ((discourse* or discurs*) NEAR/3 analys?s) or "narrative analys?s" or (grounded NEAR/0 (theor* or analys?s)) or "action research" or (account or accounts or unstructured or openended or "open ended" or narrative*) or (lived NEAR/0 experience*)

Systematic screening process

As illustrated in Figure 1.1, the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow diagram, the initial database search identified 2,421 records. EndNote was used to remove duplicate results. The remaining titles and abstracts were reviewed manually, this included reviewing the previous literature in the review from Akther et al. (2019). The remaining 56 studies of full texts were also reviewed manually. The final number of studies included in the meta-ethnography included 9 studies from the previous data search (Akther et al., 2019) and three studies identified from the database search from January 2018 to April 2023.

Data extraction

Table 1.3 includes the inclusion and exclusion criteria, with a rationale for these criteria. There was one study included where some individuals were detained on a Section 4

(Katsakou et al., 2012). This included a total of 59 participants, with seven who were detained under Section 4, whilst the remaining participants were describing their experiences of being detained on a section 2 (30 participants) or 3 (22 participants). Therefore, despite this being a shorter experience it was a small proportion of individuals, and the setting was on inpatient wards, so the experience was likely to be the same for a shorter time frame, compared to being detained in a place of safety. Table 1.4 provides the details of the study characteristics: author and year, country, sample size, and research method and analytical tool.

Table 1.3

Inclusion and exclusion criteria.

Inclusion	Exclusion	Rationale
Adults (18 years and over)	Children	Child services may have different ward rules, activities and physical environments compared to adult wards. Also, the relationships with individuals in the community is different as children may still live at home, compared to adults who have the choice to live independently. The loss of liberties may feel different as an adult who may have been employed, had freedom to choose when to go out and who they met. Children may still experience a level of monitoring from carers or family.
Detained under the MHA (including Section 2, 3, 37/41, 37(N))	Section 136 and place of safety, voluntary admissions and CTO.	The section 136 and places of safety are often not the same environment. It can be one or two rooms with specific staff, compared to a ward. It is also for 24 hours. Therefore, the experience may be very different to those detained on an inpatient ward. Voluntary admissions were excluded as the experience is likely to be different (e.g., knowing that they can leave the ward at any time, cannot be forced to take medication). Research with people on a CTO was excluded as they are not detained in a physical environment of a ward with staff. They still may have restrictions within the community but have more freedom and the contact with professionals is less frequent.
Service-users (patients)	Staff members,	The direct experiences of individuals who have been detained was aim of the research. Some previous research studies have included both or focus groups with both, however, this can

	family, carers	then influence the interviews of the individuals. A number of studies did not separate out the analysis of the of carer's and staff and were excluded due to this.
Interviews	Focus groups	Some studies facilitated focus groups, but these were excluded as discussion is not confidential and involves a group interpersonal dynamic, which may change the nature of the data collected.
United Kingdom	All other countries	It is important to consider the different legal frameworks across countries and how these are implemented. Therefore, only UK studies were included to represent being detained in the United Kingdom and the mental health act sections.
Qualitative studies	Quantitative studies	Studies had to include a qualitative component to gather the information of individuals experiences. Mixed method studies were considered if the qualitative aims were relevant to individuals experiences of being detained.

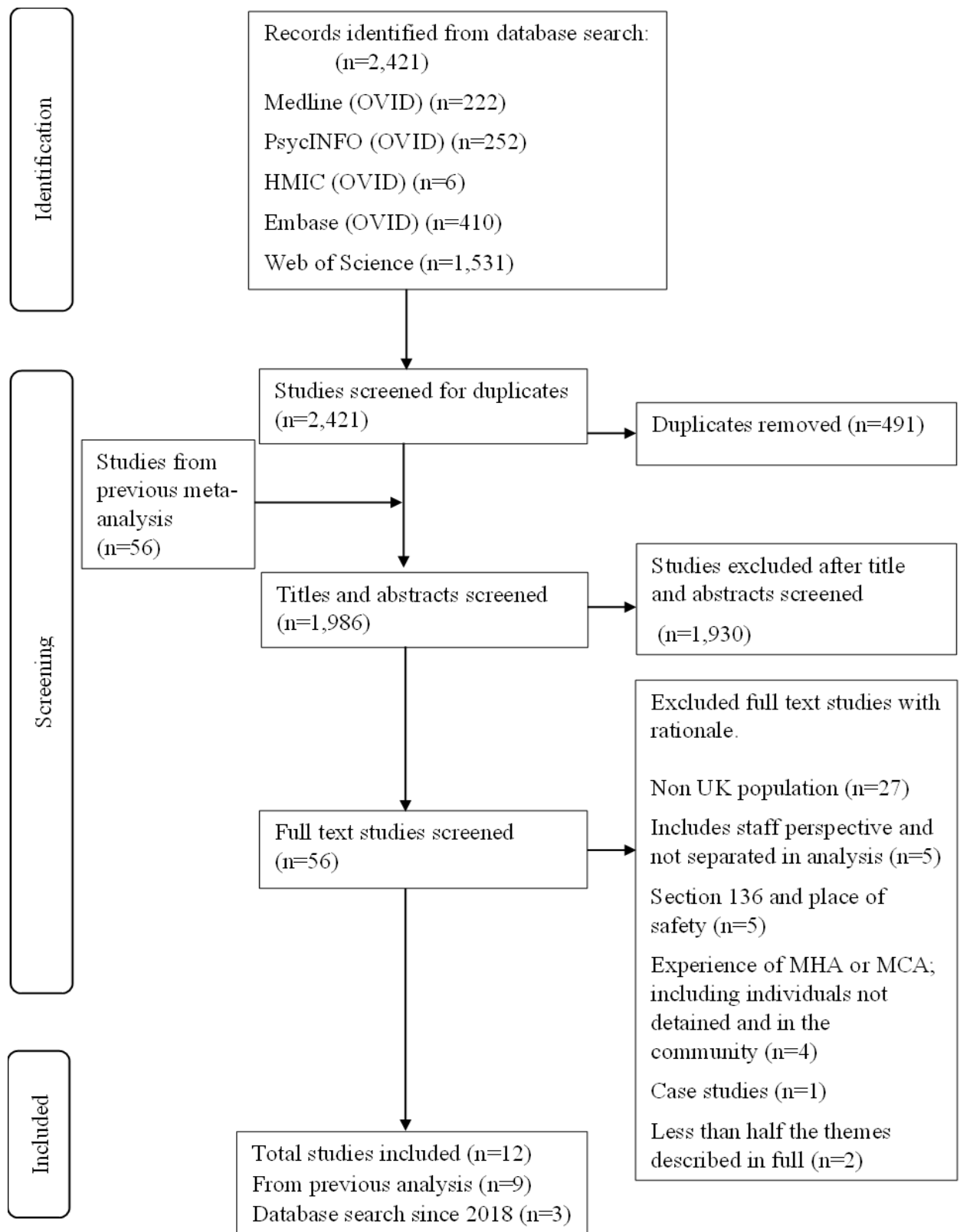
Figure 1.1*Prisma Flowchart illustrating the screening process of the literature*

Table 1.4*Study Characteristics*

Author and Year	Country	Sample Size	Method and Analytic Tool
Hughes et al. (2009)	UK	12	Qualitative: Thematic analysis (Braun & Clarke, 2006; Joffe & Yardley, 2004).
Haw et al. (2011)	UK	57	Mixed Methods: Thematic analysis (Braun & Clarke, 2006)
Gillard et al. (2012)	UK	19	Qualitative: Inductive thematic analysis (Ritchie & Lewis, 2003)
Katsakou et al. (2012)	UK	59	Qualitative: Thematic analysis and grounded theory
Tapp et al. (2013)	UK	12	Qualitative: Thematic analysis (Braun & Clarke, 2006)
Chambers et al. (2014)	UK	19	Qualitative: Inductive thematic analysis
Madders & George (2014)	UK	9	Qualitative: Thematic analysis (Braun & Clarke, 2006)
Valenti et al. (2014)	UK	59	Qualitative: Thematic analysis (Boyatzis, 1998)
Seed et al. (2016a)	UK	12	Qualitative: Grounded Theory
Sustere & Tarpey, (2019)	UK	12	Qualitative: Thematic analysis (Braun & Clarke, 2006) inductive approach
McDonnaugh, et al. (2020)	UK	7	Qualitative: Thematic analysis (Braun & Clarke, 2006)
Solanki et al. (2023)	UK	12	Qualitative: Thematic analysis (Terry et al., 2017) inductive approach

Participant characteristics

Table 1.5 includes the details provided from the research studies of the participant characteristics (age, gender and ethnicity when reported), mental health diagnosis and the type of Section. The combined sample size totals 230 participants, with 133 male participants and 97 female participants. The demographics of age and ethnicity were varied in how they were reported, meaning these cannot be accurately summarised across the 230 participants. Also, there are two research studies (Katsakou et al., 2012 and Valenti et al., 2014) that used the same participant group. Therefore, the demographic data for the summary has only included this population once to ensure it does not skew the data. Table 1.5 also demonstrates that there is variability in the level of detail of mental health diagnosis reported and the type of section individuals were detained under the MHA.

Table 1.5

Participant characteristics, mental health diagnosis and type of section under the Mental Health Act.

Author and Year	Age	Gender	Ethnicity	Diagnosis	Type of Section and ward/unit
Hughes et al. (2009)	19-62	5 male 7 female	Not reported	6 bipolar affective disorder 2 borderline personality disorder 2 schizophrenia, 2 depression	"involuntary inpatient care" Ward or Section not stated.
Haw et al. (2011)	19-52	27 male 30 female	Not reported	10 alcohol or drug-related disorders	27 Section 3 11 Section 37 19 section 37/41 and other

Tapp et al. (2013)	Average age 44.6	12 male	8 white participants 4 black or black British participants	7 schizophrenia, schizotypal and delusional disorders 4 disorders of adult personality and behaviour 1 not reported	High secure patients ready for discharge to medium secure requiring permission from the Ministry of Justice Section 3
Chambers et al. (2014)	19-53	12 male 7 female	7 black British participants 10 white British participants 2 other ethnic origin	Not stated; Acute ward, PICU ward and forensic rehabilitation ward	Acute admission wards, psychiatric intensive care wards and forensic wards.
Madders & George (2014)	Not stated	8 male 1 female	Not stated	Reports "mental health and personality disorder"	Not stated. Transitioning from high secure to medium secure
Valenti et al. (2014)	Mean age 37	34 male 25 female	37 white participants 14 black participants 6 Asian participants 2 "other"	27 schizophrenia (or other psychosis) 20 affective disorder 8 other	30 Section 2 22 Section 3 7 Section 4 Acute wards
Seed et al. (2016a)	18-55	12 female	Not stated	12 anorexia nervosa	Section 2 or Section 3 Ward states inpatient only.
Sustere & Tarpey, (2019)	Not stated	12 male	Not stated	Not stated	Section not stated

McDonnaugh et al. (2020)	28-54	7 male	6 white British 1 black Caribbean British	"MDOs under the care of the FCTs tend to have a primary diagnosis of paranoid or treatment resistant schizophrenia and a long-standing history of mental health problems prior to the index offence." Not included if IQ<70	Medium secure wards Section 37/41 Forensic wards
Solanki et al. (2023)	18-60	4 male 8 female	2 black African 1 black African/black Caribbean/black other 3 black British 2 black other 1 Caribbean 1 Caribbean and African 1 mixed race 1 black British/black African	1 acute stress disorder 4 don't know, 1 paranoid schizophrenia 4 psychosis 1 schizophrenia 1 split personality	Section not stated, "detained as inpatients under the MHA" Acute wards

Quality appraisal

A 19-item checklist was used based on the NICE quality appraisal checklist for qualitative studies (NICE, 2012) with an additional four items created to include in the trustworthiness subsection of NICE guideline criteria. The additional criteria included if the studies reported whether the type of Section or detention of the MHA was documented, the

type of ward the study collected research from (for example, an acute ward, rehabilitation, high secure ward), the diagnosis of participants and the demographic details of participants. The criteria of “is the context clearly described” then focused on specifically if context bias was considered.

All 12 studies met or partially met a considerable number of the quality appraisal items. Areas of strength across all the studies included: the theoretical approach, study design, and three out of five areas of the analysis (having rich data, the findings being convincing and the findings being relevant to the aims of the study). The quality varied across most areas of trustworthiness (six out of 8 criteria items), two analysis items (the reliability of the analysis and the conclusions) and the overall assessment. Most studies did not fully meet the criteria of data collection, two trustworthiness items (the role of the researcher being clearly described and the data analysis being sufficiently rigorous) and ethical considerations. These areas were often due to limited information to replicate the data collection, analysis or ethical process and limited information on the role of the researcher in relation to the ward, participants and recruitment. The quality appraisal checklist is illustrated in Figure 1.2 according to whether the criteria were met (green), partially met (orange) or not met (red).

Figure 1.2***Quality Appraisal Criteria***

Study	Theoretical Approach		Study Design	Data Collection	Trustworthiness									Analysis					Ethics	Overall Assessment
	Is a qualitative approach appropriate?	Is the study clear in what it seeks to do?			How defensible/rigorous is the research design/methodology?	How well was the data collection carried out?	Is the role of the researcher clearly described?	Type of section/detention of MHA documented?	Type of ward documented?	Diagnosis Documented	Demographic details documented?	Is the context bias considered?		Were the methods reliable?	Is the data analysis sufficiently rigorous?	Is the data 'rich'?	Is the analysis reliable?	Are the findings convincing?		
Hughes et al., 2009																				
Haw et al., 2011																				
Gillard et al., 2012																				
Katsakou et al., 2012																				
Tapp et al., 2013																				
Chambers et al., 2014																				
Madders & George, 2014																				
Valenti et al., 2014																				
Seed et al., 2016																				
Sustere & Tarpey, 2019																				
McDonnaugh et al., 2020																				
Solanki et al., 2023																				

Theme extraction: Data analysis and synthesis

Noblit and Hare's (1988) approach to meta-ethnography was used, which includes seven "phases". Phase 1 ("getting started") and Phase 2 ("deciding what is relevant to the initial interest") were completed when creating the research question. This includes the process of updating and reviewing previous meta-analysis criteria to narrow the question further to specific settings (being detained under the MHA in a hospital setting in the UK). Phase 3 ("reading the studies") was included as part of the screening process to determine the final 12 papers to be included. This phase is a repeated phase where the final papers are read to identify the themes, along with first-order quotes (from participants) and second-order quotes (authors interpretations of the data) (Sattar et al., 2021). Phase 4 ("determining how the studies are related") and Phase 5 ("translating the studies into one another") include developing an understanding of relationships and similarities within themes of a paper and across different papers. Phase 4 included reviewing all concepts from the twelve papers and

reviewing similarities within and across themes from first-order and second-order quotes when placed into a table (Appendix B). In Phase 5 the concepts are moved around within each of the papers, such as merging themes that could have similar concepts or be poles of the same theme (Appendix C). Phase 6 (“synthesizing translations”) is where reciprocal translations (multiple papers considering similar concepts) and line of argument synthesis (different concepts can be considered and understood as a wider concept that had not been considered until the different concepts were combined) have been considered. Phase 6 includes creating new themes, as well as subthemes, across all the papers when the quotes and concepts are combined (Appendix D).

Results

Table 1.6 displays the four themes and subthemes developed from the twelve studies included in the analysis.

Table 1.6

Meta-ethnography themes and subthemes identified from the analysis

Theme	Subthemes
1. Interpersonal relationships	1.1 Effect of other people's attitudes and approach 1.2 Being heard and collaboration 1.3 Treated with respect and dignity
2. Loss of control and power	2.1 Impersonal clinical environment 2.2. Power dynamics with staff and the system 2.3 Survival responses to the system
3. Use of restrictive practices, containment and medication	None
4. Construction of disorder	4.1 Reification of disorder through a traumatising environment 4.2 Disorder through labelling and misattribution

Theme 1: Interpersonal relationships

When being detained under the MHA the interpersonal relationships individuals had were crucial and discussed across all twelve studies. This included participants' relationships with family, peers, staff and professionals involved in their care. Whilst being detained in hospital participants reported their interpersonal relationships were affected by other people's attitudes and approaches towards them whilst in hospital. Two other key aspects of interpersonal relationships, particularly related to staff and peers whilst detained, included being heard and collaboratively involved in their care, and whether they were being treated with dignity and respect.

Subtheme 1.1 The effect of other people's attitudes and approach

Throughout the studies, there were varied perspectives of the attitudes and approaches to people who were detained which impacted their own experience and perception of themselves. The non-judgemental stance regarding participants' distress and talking about this was perceived as a positive interaction (McDonnaugh et al., 2020, p64; Sustere & Tarpey, 2019, p618). Sustere and Tarpey (2019, p618) illustrate this in their findings: "when patients self-harmed staff helped patients to express how they felt rather than imposing restrictions through the removal of risk items or seclusion". However, others reported that positive relationships and having the opportunity to talk to professionals about life stressors in the community enhanced the support for the future, reducing their worries about this (Katsakou et al., 2012, p1173; Solanki et al., 2023, p17). Positive attitudes included experiences of being part of their own meetings or ward rounds and being able to relate to peers:

"P2: In a ward round it gives the whole MDT [multidisciplinary team] a chance to give you some positive feedback and that keeps you motivated and gives you some more

confidence and self belief. It helps you recognise what you ought to know, and that kind of support you want to keep it going." (Madders & George, 2014, p29).

"You can be around other people who are going through the same stuff as you, so you don't feel::: awkward about saying, "Oh I felt like killing myself" or "I had these thoughts yesterday." So you got people who's going through the same experience. (Participant 6)" (Solanki et al., 2023, p17).

However, some participants described staff as doing their job, with little care and support: "Some of them are very human but the impression they give is that they're too busy to do it. That's the impression." (Gillard et al., 2012, p248). It felt to those participants that the staff team were carrying out a role, not a genuine level of support and care within the relationship they had with patients on the ward. Other participants felt that the staff were uncaring: "Three other participants perceived staff as custodial, regimented, and devoid of care." (Hughes et al., 2009, p156). Some participants found certain peer relationships unhelpful due to their attitudes and behaviours on the ward:

"there was patients on there [ward] that were smoking dope and that, and I never connected my drug and alcohol problem to my criminal history ... I used to sit round smoking dope and all that, well of course my paranoia got worse. (p. 6)" (Tapp et al., 2013, p170).

Individuals reflected on how the attitudes and behaviours of peers may influence their peer relationships within a hospital setting. For example, hearing the attitudes supportive of continuing to use drugs and alcohol, which were understood to contribute to a deterioration in mental health for others. Whilst trying to not associate with peers who demonstrate these attitudes and behaviours it can be difficult to avoid them when there is the physical limit of a

ward environment, impacting the peer support and connections people can have whilst detained under the MHA.

Subtheme 1.2 Being heard and collaboration

Feeling heard and working collaboratively within relationships was important for participants. This was particularly evident with staff relationships: “63% declared that they had been involved to some extent in decisions in the hospital and that they felt their freedom was respected.” (Valenti et al., 2014, p834). It was also acknowledged by some participants that having family or a close relationship involved in their care was important to increasing that feeling of collaboration and support: “I think it helps your cause if your family is involved in your care, ... It just shows you that someone cares for you, ... and you are not alone. (p. 9)” (Tapp et al., 2013, p169). Supportive relationships had the influence to empower collaboration. They could reduce feelings of isolation whilst being detained, increase feeling able share emotions with others involved in their care, including feeling able to be honest if they had a difference of opinion with professionals (Tapp et al., 2013, p169). Some participants identified changes in their experiences where they did feel heard and adjustments were made to approaches used when they felt distressed:

“. . .like if you was self-harming. . .you get things locked up in your bedroom then you could lose it for a week. . .now they give me half an hour to calm me self down and give me some pen and paper and that way. . .I could draw how I feel. . .(P1)” (Sustere & Tarpey, 2019, p618)

Adapting approaches, reinforced being heard and establishing the therapeutic relationship with professionals. It was also reported by increasing the collaboration of how individuals were supported when they felt distressed also increased autonomy (Sustere &

Tarpey, 2019, p618). However, other participants felt that they were not involved in the decision-making of their care plans (Seed et al., 2016a, p357), ward rounds and meetings (Solanki et al., 2023, p17) or medication (Solanki et al., 2023, p17; Valenti et al., 2014, p833-834). This can be illustrated by Sophie describing care plans which were “technical and impersonal” about “how they can restrain you” (Seed et al., 2016a, p357). During these experiences where participants do not feel involved there are references of being told to comply with professional decisions made, this reinforces the power dynamics (Theme 2: Loss of Control and Power).

Subtheme 1.3 Being treated with respect and dignity

Throughout this subtheme, being treated with respect and dignity was critical to the interpersonal relationships developed with staff when being detained in hospital. Valenti et al. (2014, p834) stated “Respect was consistently linked with the quality of the relationship between patients and staff.” Throughout the papers there were clear references to not being treated as a human being, but an animal or a criminal (Haw et al., 2011, p577; Solanki et al., 2023, p17). Participant 27 (Haw et al., 2011, p577) stated: “We are human beings, not animals, dogs, lions or tigers”. Being detained under the MHA and the power difference of role (Chambers et al., 2014, p4) meant that some participants felt within certain relationships they were not treated with respect or dignity, using the power difference to establish control: “You’re here, you’re under our control, and you’ll do as you’re told or you’ll be restrained’, you know? It was very cut and dried” (Gillard et al., 2012, p245).

In contrast, when participants referred to being treated with respect, this was often noted that they felt being treated as an equal: “I respected him and he respected me as well...they are just more on the level with you ... not like they are treating you like a kind of

nurse patient relationship (participant 21, male, aged 35).” (Valenti et al., 2014, p835). During these positive interactions, there were no comparisons to animals, power differences, control or roles.

Being treated with respect and dignity was identified across papers as essential to interpersonal relationships that were developed. This indicates the effects of attitudes and approaches towards others and how these link with whether participants are treated with respect. The previous subtheme (Being Heard and Collaboration) discussed how participants need to be able to develop trust within a relationship to then feel heard and be able to be open; Chambers et al. (2014) describe how this can then in turn influence collaborative discussions about care:

"In some way or another all interviewee spoke of a sense of powerlessness and lack of autonomy whilst detained, which was deemed to diminish their sense of self-worth. This alongside reported poor relationships with staff and staff attitudes led to the feeling that they were being marginalised for having a mental illness by staff and society." (Chambers et al., 2014, p4)

Theme 2: A loss of control and power

The loss of power and control when being detained under the MHA was not only based on power dynamics with staff and the system, but impersonal clinical environments and the survival responses participants engaged in as a result of this loss of control and power. This theme describes the manifestations through which power was exerted and control felt lost. The impersonal clinical environments were often compared to being in a prison, and having limited freedom (Chambers et al., 2014, p6; Gillard et al., 2012, p246). Sustere and Tarpey (2019, p619, p623) also reported that the expressed limitations of freedom within the

hospital settings and socialising with others could increase feelings of isolation. This is likely to impact the interpersonal relationships (Theme 1) people develop with peers and professionals due to the system and professionals enforcing these rules. As a result of these feelings of isolation, loss of freedom and control, participants described different survival responses they used. This included being compliant due to fear, fighting the system (non-compliance with medication, absconding from hospital) or playing the game of the system to enable discharge even if they did not agree with the treatment or discharge plan (Gillard et al., 2012, p248; p62; Seed et al., 2016a, p356-358).

Subtheme 2.1 An impersonal clinical environment

The impersonal clinical environment was described by participants as being surreal and not representative of their lives outside of hospital. This can be illustrated from a participant's quote: "You're sort of plucked out and suspended in time out of society, and society doesn't work like that, you know? ... You couldn't describe it as a progressive time at all" (Gillard et al., 2012, p247). Often participants also compared the clinical environment to a prison: "There's less, uh, restrictions in prison, you know? Like, we feel like we're in prison but they call it a hospital (Participant 3)" (Chambers et al., 2014, p6). The physical restrictions and clinical environment compared to the freedom and experiences of living in society reinforced the loss of power through being detained under the MHA. This was summarised by Gillard et al. (2012, p246):

"Service user researchers felt that the often unfavourable comparison that many interviewees drew between being detained in hospital and being in prison was important, articulating the impact of the withdrawal of freedom, without the rationale of punishment through the criminal justice system, on the sense of self"

The physical restrictions that were in place also reinforced separation between different individuals based on their diagnosis or the type of ward they may have been on. Participants reflected on how the physical environment reinforced stigmatisation and separation between individuals, reinforcing the power and control dynamic within hospitals:

“...you can’t mix with them because they got learning disabilities you can’t mix with them because they’ve got erm severe mental illness. . .it. . .stigmatises even in the place. . . they must feel you know how are we different to them. . .it must play on their minds (P5)”

(Sustere & Tarpey, 2019, p620)

These physical barriers in the environment were also reflected on when trying to build relationships within the ward. Participants described how the restrictions increased isolation and did not reflect society and being able to socialise with others in the same way they would be able to in the community: “...talking in corridors. . .you’re not allowed to yet we live together. . .(P7)” (Sustere & Tarpey, 2019, p620). The impersonal clinical environment, often compared to as a prison, and the separation participants experienced between different individuals based on their diagnosis may strengthen beliefs of other people’s attitudes towards them being detained under the MHA (Theme 1: Interpersonal Relationships). This may also emphasise the power dynamics that the system holds and the staff can reinforce (Theme 2: Loss of Control and Power).

Some participants reported that having some ownership and autonomy within the environment, such as a room key increased a sense of control: “...now people can lock their own bedroom. . .just like if you had a key to your house. . .now majority of patients can actually give themselves their own medication people got control. . .(P5)” (Sustere & Tarpey, 2019, p621). Participants reflected on increased feelings of autonomy when the environment feels more reflective of living in society.

Subtheme 2.2 Power dynamics with staff and the system

There was an awareness of the power dynamics created through staff and patients' roles within the ward, and that interpersonal power was used to control: "Well, it's the way the staff...they sort of overpower you...they tell you what to do all the time (participant 2, male, aged 24)" (Valenti et al., 2014, p834). Seed et al., (2016a, p357) reported that the participants also noted a power difference between the power dynamic of how staff interacted with individuals who were detained under the MHA compared to those who had gone into hospital voluntarily: "Participants believed that when they were under the MHA, the decision to impose restrictive interventions was made easier than when they were not under the MHA.". However, there was an understanding that the wider system (the legal framework and other multi-agency professionals) impacted and reinforced these power dynamics in favour of the staff team as well: "I think it's too much power. I think power comes in that the police are called and the nurses restrain you, and it seems to me as though you're very much at the bottom of the pile." (Gillard et al., 2012, p247). This reinforces the perception and attitudes (Theme 1.1) others may have towards people being detained under the MHA (being at the "bottom" of the system), which can impact if people feel as though they are being treated with dignity and respect (Theme 1.3).

The power dynamics between people were often reinforced by routines and boundaries within hospital settings, which may not reflect choices they would make when living in the community, such as meal times, or what time they would go to sleep (Katsakou et al., 2012, p1173). Participants expressed having no control in changing these routines and feeling as though they had to comply due to being detained under the MHA: "All your rights are taken away, it's horrible, you are not in control anymore (participant 27, male, aged 29)" (Valenti et

al., 2014, p833). Some participants expressed that the systems in place on the ward further removed their ability to gain independence and autonomy in daily tasks they would have previously maintained themselves, such as cooking and cleaning (Sustere & Tarpey, 2019, p620, P10).

The loss of power and control participants felt was also in relation to recovery and progress to discharge from being detained on a Section or discharge from hospital. The length of time and the process resulted in some participants stating that it increased feelings of institutionalisation: “P1: [It] can have a negative effect if you get too engrossed with the system” and “[it] makes it harder to leave”. (Madders & George, 2014, p32). Other participants described the type of section they were on made it difficult to think about discharge due to the level of restrictions which can be implicated by the wider system: “P4. on this section 37/41 I was there for a long time and sometimes you couldn’t see, like, freedom.” (McDonnaugh et al., 2020, p61). These processes of the wider system may increase feeling powerless about discharge from hospital. This may be associated with changes in the relationships participants have with staff as the process of moving on is likely to feel less collaborative (see Theme 1.2: Being Heard and Collaboration). There is an awareness from participants that this is a system process, where delays can be due to bed capacity, funding approvals or professional reports (Madders & George, 2014, p31). Increased hopelessness or frustration with the processes and reliance on others may be associated with participants’ responses to the system, for example being compliant due to fear of not getting discharged, not engaging with staff or treatment plans, or playing the game to move on by being compliant to get discharged. This is explored further in the next subtheme.

Subtheme 2.3 Survival responses to the system

In response to the loss of control and power participants experienced from the environment, staff and systems, there appeared to be three types of responses. Participants appeared to respond by being compliant due to fear: “I’m pretty sure I could refuse medication, but I just wouldn’t get out of here” (Gillard et al., 2012, p248), or trying to fight the system to gain some control back: “hide the medication or purge it (Kathy), hide... to like try and avoid’ staff and wait for the ‘opportunity to run away’ (Seed et al, 2016a, p356). However, most participants who tried to retain control, often reported that this became tiring so their approach changed to the third response of “play the game” and appear in a compliant way or as a perfect patient: “You play the game, don’t you? If you don’t play the game, you don’t get what you want” (Gillard et al., 2012, p248). Seed et al. (2016a, p358) also suggested that participants realised over time that by trying to regain control or “dig their heels in” in response to some of the rules or treatment options on the ward that they found this was not effective in meeting their needs, gaining more independence and working towards discharge. Madders and George (2014, p31) also reported a participant (P5) described feeling they had to “compromise” throughout their hospital admission to be able to progress through the system. Throughout the participant described feeling they had to do what they were “told” in order to be discharged from hospital. This reinforces the importance of the therapeutic relationships developed with professionals (Theme 1: Interpersonal Relationships) and how this relationship may influence people’s responses to the system when they are detained.

Due to the loss of power and control, participants’ survival responses resulted in two initial responses of being compliant due to fear of the response if they were not or fighting back by being non-compliant to ward rules and treatment. Often over time, this resulted in a third response of “playing the game” and presenting in a compliant way even if those detained

did not agree with it to increase the likelihood of discharge from the Section or hospital. This is summarised by Gillard et al. (2012, p250): “The patient’s decision to ‘play the game’ is taken in order to address a position of powerlessness, in spite of the injustice the patient feels, and as a strategy to have the ‘life sentence’ of detained care revoked”. It was reported that these responses could include masking how individuals felt or not sharing emotional distress with stress (McDonnaugh et al., 2020, p62; Seed et al. 2016a, p358), and being compliant with treatment expectations (Gillard et al., 2012, p248; Madders & George, 2014, p31, P5; McDonnaugh et al., 2020, p62; Seed et al. 2016a, p358). However, this final response may be observed by professionals as engaging, but for those detained it may reinforce not feeling heard and a lack of collaboration (Theme 1.2) due to the power dynamics experienced with the staff, the system and the environment.

Theme 3: The use of restrictive practices, containment and medication

The use of restrictive practices in this theme includes intramuscular medication, restraint and seclusion. These practices are used when individuals are detained under the MHA and should only be considered when all other de-escalation techniques and other interventions have been considered. Some participants described these interventions as beneficial and containing for their emotional distress (Haw et al., 2011, p572, p574), whereas others described them as distressing (Chambers et al., 2014, p5; Gillard et al., 2012, p246; Haw et al., 2011, p574-576; Seed et al., 2016a, p367). The use of restrictive practices and medication varied in the experiences different participants had. Some described medication as helpful and supportive: “without the medication I wouldn’t have become well again (Cherie)” (Hughes et al., 2009, p157), whilst others described medication as distressing: “I became weak, paralysed [P27]” (Haw et al., 2011, p576). Some participants reported feeling unheard

regarding their medication and felt this was forced, and dismissive of their emotional distress (Hughes et al., 2009, p157; Katsakou et al., 2012, p1173, P23; Seed et al., 2016a, p357).

Katsakou et al. (2012, p1173) stated: “The majority of the participants (68%) also reported being exposed to coercive measures, such as restraint, seclusion or forced medication”. When experiencing restrictive practices some participants described feeling overwhelmed and fearful at the time, but noticed feeling angry after (Seed et al., 2016a, p357). Other participants described feeling fearful they may die: “They injected me and I thought I was going to die. I was physically restrained for that injection! (participant 47, “positive” group)” (Katsakou et al., 2012, p1173) and “If my asthma comes (when I am being restrained) I will be dead. It worries me [P27].” (Haw et al., 2011, p576). It is reported that restrictive practices could result in increasing distress, rather than supporting recovery (Hughes et al., 2009, p159). This emphasises the loss of control and power (Theme 2) that can be experienced (fearing death, being injected by others whilst being restrained) and the importance of establishing therapeutic interpersonal relationships (Theme 1) to reduce this power dynamic, increase collaboration in treatment plans and implement these with dignity and respect. This is further evidenced by a quote from Participant 12 when they were being taken to seclusion whilst others witnessed this:

“When they dragged me forward, one of them had to drag me by my trousers... And they pulled them down, and left them. That’s out of order. It depends how it happens, some of them can be really embarrassing. Like me, I was getting dragged along in my underpants” (Chambers et al., 2014, p5)

Medication was perceived by some participants as a positive experience, increasing feelings of being relaxed, reducing feelings of distress, increasing the ability to engage in therapy and activities (Tapp et al., 2013, p170). This is illustrated by Participant 9: “At the

moment I am on Clozapine and it is probably the best I have ever been. It makes me feel relaxed, my thinking is a bit slower, so I can think better, and I feel quite happy.” (Tapp et al., 2013, p170). Similar reports were described regarding intramuscular medication: “It helps get your mental state get back on top again [P52]” (Haw et al., 2011, p574), and seclusion where the environment can feel calmer: “Sometimes it’s nice to be on your own and not to have people around when you are feeling upset [P32]” Haw et al. (2011, p572).

There are clear differences in how medication and restrictive practices can feel containing to some people and restrictive or punishing to others. It is reported the increased feeling of fear and distress from the implementation of restrictive practices can strengthen past negative views that individuals had of themselves (Seed et al., 2016a, p357). These views may also link to past traumatic experiences which the restrictive practice may trigger memories of (Theme 4.1: Disorder Through a Traumatising Environment), which could also include how this approached by staff (Theme 1.1: Effects of Other People’s Attitudes and Approaches). An example that illustrates this is from Sarah (Hughes et al., 2009, p157) who describes receiving intramuscular medication: “I was fighting and fighting. And they were saying, um, go on, pull her trousers down and stick it in her arse. I thought they were raping me.” Increasing collaboration in care and treatment plans to understand the right approach for individuals is crucial to develop therapeutic relationships (Theme 1: Interpersonal Relationships). This collaboration can also reduce the power dynamic between patients and staff (Theme 2: Loss of Control and Power) so that medication and interventions can be containing for people, rather than restrictive (Theme 3).

Theme 4: Construction of disorder

The construction of the disorder theme includes two areas which were taken to contribute to the experience of mental disorder described by participants. The nature of the environment was identified as a way in which memories of past trauma can be re-elicited: “Seclusion when accompanied by being stripped of normal clothing and being forced to wear rip proof gowns was particularly difficult for those who had been sexually abused” (Haw et al., 2011, p575). The second subtheme identified how the physical ward environment and loss of control and power (Theme 2) could reinforce labels being used or stigmatisation for human emotional responses: “Most participants described clinicians as attributing patients’ feelings and behaviours to having a ‘mental illness’. Grace described her identity being reduced to an illness ‘like someone who was just a person with anorexia’” (Seed et al., 2016a, p357). Both of these subthemes illustrate processes that can individually or in combination contribute to the construction of disorder. The environment (including experiences of restrictive practice and medication), or interpersonal relationships experienced by staff, peers, family and those in the community can reinforce memories of how participants perceived themselves previously. In addition, the current experience of being detained can reinforce these beliefs through the environment, or by labels or misattributing behaviours and emotions expressed.

Subtheme 4.1 The reification of disorder through a traumatising environment

Participants reported that experiences within hospital which can take place when people are detained under the MHA, such as restrictive practices, can trigger childhood memories or past trauma memories: “When they strip you off even if you have a history of self harm they will strip you off. If you have had sexual abuse this is not very good [P29]” (Haw et al., 2011, p575). Haw et al. (2011, p575) reported that physical restraint and IM

medication could also trigger memories and trauma and abuse increasing the distress of participants.

The construction of the disorder through a traumatising environment was not only based on physical interventions but also interpersonal relationships, interactions with staff, and how this shaped their view of themselves. Interpersonal relationships, approaches and attitudes towards participants could trigger memories and influence the participants' sense of self: "I knew I was evil before I went into hospital, because of what happened in my childhood. But . . . but, they sort of, what do you say, they sort of exemplified it [. . .] they sort of made it double that. (Annie)" (Hughes et al., 2009, p155). This emphasises the importance of the language used by professionals, the attitudes of staff (Theme 1: Interpersonal Relationships) and how this can influence how people perceive themselves when they are detained under the MHA, seen here with Annie describing her pre-existing belief of being "evil" as exemplified. Other participants reported experiencing triggers which were still current in their lives outside of hospital: "There's a few foes, few racists [unspecified] in there calling me "nigger," "monkey" and whatever, but, I get that every day anyway so it don't really bother me anymore. (Participant 6)" (Solanki et al., 2023, p17). Some experienced this as direct comments made to them, others described that there were assumptions based on their race, which can come with stereotypes and stigmatisation they experience: "Being black, you are treated as if you're superhuman, you've got superhuman powers... you just get treated differently because you're black. They [staff] assume because you're black that you're stronger... you can take it. (Participant 2)" (Solanki et al., 2023, p17). The traumatising environment through the power dynamics of the system and staff (Theme 2: Loss of Control and Power) can replicate people's experiences in society, with power differences and their experiences from individuals who may express stereotypes and stigma. This is based on

individual attitudes within systems and whether they treat others with respect and dignity (Theme 1: Interpersonal Relationships).

Subtheme 4.2 Disorder through labelling and misattribution

Whilst being detained in hospital participants described human emotional responses as being misattributed to mental health, and as a result being penalised: “If you lost your temper or got upset, you were a risk then, like that was your, well you know you’ve blown it now because you know you wouldn’t be allowed out now anyway, not in that state. (Marie)” (Seed et al., 2016a, p358). Becoming angry, frustrated or upset are human emotional states that everyone experiences and outside of hospital this would not prevent individuals from going out in the community. Seed et al. (2016a, p357) reported that it was not only emotional responses that could be misattributed to mental health, but also behaviours: “When under the MHA, normal requests were pathologised as a symptom of illness (e.g., not wanting to watch the same communal programme and preferring to spend time in their bedrooms was viewed as withdrawal).”

The label of the diagnosis as well as being detained were something participants were aware of when having to leave hospital. The association of the label and how it impacted their identity when leaving hospital was identified as significant, for example: “P8: The label, “I’ve been at Rampton, I’ve been a patient at Rampton”, [I] didn’t like psychopath and stuff, which are labels that stick out, that are the sort of thing that are quite negative to have yourself” (Madders & George, 2014, p32). Participants were also aware of people in the community and how the label of a diagnosis may have impacted the perception others now have towards them: “To be that girl sectioned, [people in the Black community say] “She was sectioned,

she's mad." I'm not mad... I think in regards to being Black... and being sectioned, I think there's less understanding in our community. (Participant 7)" (Solanki et al., 2023, p17).

The construction of the disorder within the hospital environment was also described as influencing the participant's sense of identity. This appeared to be in conflict with how they may have perceived themselves prior to being detained in hospital, for example: "Upon discharge, participants like Marie found it a challenge not to 'lose herself' to the anorexia but conversely did not want to 'let it go'" (Seed et al., 2016a, p359). The stigmatisation and attribution of behaviour and emotional responses as being experiences of mental ill-health may reinforce that this is now part of their identity. This appeared to make it difficult for individuals when they were ready for discharge as it may be conflicting to understand these experiences as derived from the rules and structure of the hospital ward and others may respond to these in different environments.

Discussion

The review aimed to gain an understanding of patient's direct experiences of being detained under the MHA in the United Kingdom. The analysis of the twelve papers identified four themes: interpersonal relationships, loss of control and power, use of restrictive practices, containment and medication and the construction of disorder. The theme that was identified in all papers was the significance of the experiences of interpersonal relationships. Other's attitudes and approaches towards people whilst detained may influence how they view themselves and the stigmatisation they experience. If the approach was a positive interaction it was more likely for individuals to feel heard and when they were included in their care, meetings, and care plans, these increased feelings of collaboration. The approach and inclusivity participants felt within their decision-making also influenced their perception of themselves and if they were treated with respect and dignity. For example, reducing the power

dynamic and being treated as a human being, compared to some experiences where participants described being treated as prisoners or animals. Henderson et al. (2012) have reported that the attitudes of other people can increase the stigma associated with mental health and help-seeking treatment. Telephone interviews were conducted with people accessing mental health services in the NHS (Brohan et al., 2013) to explore people's experiences over the last year. They found that between 2008-2009 stigma reduced from family, friends, employers and individuals in the community, however, there was no significant change in attitudes and stigmatisation from professionals. Henderson et al. (2013) suggested this could influence individuals in seeking help for their mental health.

Professional therapeutic relationships

The interpersonal relationships established with professionals can reinforce the loss of power and control if the relationships are not seen as supportive, trusting and collaborative. The therapeutic alliance is essential and collaboration with staff can reinforce this relationship and trust (Stanhope et al., 2013). Gilbert et al. (2008) suggested that communication and trust are crucial factors to increase collaboration and therapeutic relationships. Coercion and control were found to negatively impact therapeutic relationships. Gilbert et al. (2008) reported that when staff used coercion and control (highlighting the power difference between staff and patients) this reduced trust, communication and collaboration. The use of power within relationships may influence the therapeutic alliance and how patients engage in the care they are offered (the response to the system due to loss of control and power). Coercion was described as the use of restraint, seclusion, IM medication, as well as being humiliated by staff in front of other patients or staff (Gilbert et al., 2008). Trying to minimise the power imbalance in relationships (by building trust, clear communication and collaborating with patients) could increase the therapeutic alliance, which has been found to be a predictor of

medication compliance (Tessier et al., 2017). This may then influence the experiences of restrictive practices, particularly IM medication, which can cause distress. Experiencing trauma through the environment of being detained or through forced medication has been associated with irregularities in compliance with medication and people were less likely to seek support for their mental health again compared to people who did not experience this distress (Tessier et al., 2017).

The construction of disorder in the context of detention

The first three themes (interpersonal relationships, loss of control and power, use of restrictive practices, containment and restrictive practices) can be understood to interconnect with the final theme of the construction of disorder. The construction of the disorder included two subthemes, through traumatising systems and through labelling and misattribution. Professionals may be more aware of past trauma and how to not trigger distress if a therapeutic relationship has been established and this information has been shared (Sweeney et al., 2018). This increases collaboration within care and where patients can share this information the use of restrictive practices and medication can be discussed to reduce further distress (Sweeney et al., 2018). Additionally, if relationships with professionals are perceived as supportive and caring, the power dynamics within the relationships can be reduced as much as possible within the environment (Sweeney et al., 2018). This is supported by the Power Threat Meaning Framework (Johnstone & Boyle, 2018). Understanding the power dynamics within past or current relationships and systems may help professionals understand the different threat responses from individuals (emotional threat, threats to the relationships with staff, feelings of safety, their sense of identity) and the meaning they make of the experience (Johnstone & Boyle, 2018). Stigmatisation may reinforce worries about others' perceptions and increase the length of admission if this impacts their mental health further or increases

feelings of being institutionalised and learned helplessness. Sweeney et al. (2018) described how the power imbalance in relationships can create dependency and reinforce individuals feeling helpless.

Throughout the analysis there appeared to be links between the themes and how they could interact with each other, or reinforce the experiences people had, for example, if attitudes towards the participants felt negative (subtheme of Theme 1) and they did not feel heard by others (subtheme of Theme 1) they may be more likely to feel they have lost power and control (Theme 2) within the hospital environment. This could impact their survival response (fighting against the system or fear and compliance) (subtheme of Theme 2) which can further influence whether they experienced medication or restrictive practice as containing or coercive (Theme 3). Overall, these experiences appear to be associated with the construction of disorder (Theme 4).

As the themes interconnect, the review highlights some key areas of trauma-informed care approaches: safety, trustworthiness, choice, collaboration, empowerment, and cultural consideration (Office for Health Improvement & Disparities, 2022). Trauma is a distressing experience, which can impact how individuals cope and their functioning. This can be one traumatic experience or multiple experiences that take place over time and can include neglect, physical abuse, racial trauma and discrimination. It can lead to emotional distress, sleep disturbance, flashbacks and dissociation (Mind, n.d.). Trauma-informed care is an approach which recognises the impact of past trauma on individuals. It emphasises the importance of creating a sense of safety within the environment for individuals, empowering them in interactions and relationships, reducing the risk of re-traumatisation and working with individuals collaboratively using a person-centred approach (NHS Education for Scotland, 2017). The UK government reported that safety includes physical, psychological and

emotional safety. This coincides with all the themes identified in the participants' experiences of being detained in the UK. Trustworthiness, choice, and collaboration all coincide with participant quotes of experiences of interpersonal relationships, use of medication and restrictive practices and power dynamics with staff and the system (a subtheme of loss of control and power), which all contribute to the construction of the disorder (by events triggering past trauma or labelling and stigmatising individuals detained in hospital). Empowerment and cultural considerations are represented by all four themes identified in the review of the papers.

There are potential barriers to embedding trauma-informed care approaches across inpatient settings. These can include the understanding of the model, which emphasises the need for regular mandatory training and supervision. If staff teams are not aware of trauma-informed care or confident in talking with individuals about trauma this may result in difficulties implementing the approach. However, if training is offered and education is provided this can improve the interpersonal relationships between teams and patients. There are also barriers in conflicting information in policies and legal frameworks, which focus on and emphasise the medical model, risk management and treatment. This contrasts with personalising care and empowering individuals. For example, blanket risk management protocols are not trauma-informed. Whereas integrating personalised care and individual trauma could be used to create best practice risk assessments which are personalised and tailored to individuals. Some of these barriers are significant and reflect the findings of the power dynamics of the staff and the system (Theme 2.2). Some of these potential barriers may need to be addressed by healthcare systems to support staff to feel confident to implement the approach and require financial support as well.

Comparisons of the current findings to Akther et al. (2019) review

Akther et al. (2019) identified five themes from their review. The identified themes included: “information and involvement in care; quality of the environment; quality of relationships; impact on self-worth; and emotional impact of detention”. These five themes overlap with the current reviews themes and subthemes included in Theme 1 (Interpersonal relationships) which included: the effects of other people’s attitudes and approach; being heard and collaboration, and treated with respect and dignity. Within Akther et al.’s review there was also an overlap with the current theme of use of restrictive practices, containment and medication. These areas were included in Akther et al.’s themes and how the use of these practices impacted on self-worth (such as feeling dehumanised) and the emotional impact of their detention when restrictive practices were used. When describing the emotional impact this included the fear of restrictive practices, as well as side effects of medication. The theme regarding “quality of the environment” also compared to the current Theme 2.1 of a clinical impersonal environment and there was some overlap of power dynamics with staff, but less focus on the system. This may be due to the systems being across multiple countries and different legal frameworks being implemented.

The current review also provided some different themes to the previous review, which included the Theme 2.2 (power dynamics with staff and the system). Within this theme there was references to the awareness of the MHA and legal framework which the staff have to implement. There was also an awareness of the process of requiring meetings to review their care, and discharge pathways, including the availability of beds, possible MOJ involvement and funding processes. The current review also identified Theme 2.3 (survival responses to the system) within the experiences of being detained in the UK under the MHA, which discussed patients’ responses to the loss of power and control. This included compliance

through fear, fighting the systems or “playing the game” by being compliant to be discharged from hospital. Finally, the current review identified the theme of the construction of the disorder. Through the language and experiences the patients had whilst detained in the UK this emphasised the re-traumatisation through the environment and interactions with staff, as well as labelling and misattributing behaviours and emotions to align with mental health diagnosis, rather than normalising these human responses. Therefore, by focusing this review specifically in the UK, this identified the following themes: of power dynamics with staff and the system (which emphasises patients’ awareness of the systems in place and the power they hold); survival responses to the system (how individuals respond to the loss of power and control in the UK); and the construction of the disorder (how the environment can be re-traumatising, and misattributing behaviours and emotions can occur in UK hospitals).

As a result, specific recommendations for UK policy holders include regular mandatory training for all staff regarding a trauma-informed care approach. Across different NHS Trusts, there is no consistency regarding the trauma-informed training offered and therefore this can be confusing for both staff and patients (Emsley et al., 2022; McNally et al., 2023). A national training which is regularly reviewed, at least annually could provide consistent training for staff teams and to refresh their knowledge. This could increase their awareness of trauma and how inpatient settings could be traumatising or triggering past trauma (based on the environment or interactions with others). This could include the language used and how information is shared, as well as collaborating with patients regarding their care. Recommendations could also include collaboratively facilitating and designing the training with individuals with lived experience of being detained under the MHA, to share the knowledge of their experience and the effects a trauma-informed approach could have. Additionally, it could be beneficial to review policies to ensure trauma-informed care

principles are articulated throughout the policies. For example, currently the policies regarding environmental safety and risk management may be conflicting with the trauma-informed care approach of creating personalised and soothing environments for individuals. This can become integrated within the system rather than a standalone model to introduce alongside policies and procedures already in place. However, there is an awareness there are limitations to this as this requires funding and a significant amount of time from professionals.

Strengths and limitations

This review included a total of 230 participants. It specifically reviewed participants in the UK detained under the MHA, which gives a unique perspective on the impact of UK specific factors such as local and institutional culture. Previous reviews have included participants from multiple countries, which have different legal frameworks, therefore, the experiences are not likely to be representative of each country as their experiences of being detained in hospital will be influenced by the legal frameworks professionals and systems reinforce. The present study also applied a thorough and transparent design and methodology. This facilitated an appreciation of the different perspectives that were included in the review. For example, the review of the twelve research studies included forensic, acute and rehabilitation wards, individuals detained under Sections 2, 3, 37 and 37/41, and females and males detained under the MHA. The papers included provided a range of perspectives which enabled the analysis to consider all of the data and the context of the experiences. This ensures the analysis is meaningful, reflects a range of experiences and could support how services provide care and improve the recovery and rehabilitation of individuals detained under the MHA.

However, not all participant demographics were reported across all papers, including ethnicity, mental health diagnosis and type of Section under the MHA. This limits the ability to extrapolate specific findings for specific groups. This highlights the importance for future research to document these demographics. Areas of weakness in the papers also identified through the quality appraisal included limited information to replicate how the data was collected and analysed. For example, papers may include semi-structured interviews but have no details regarding questions.

Therefore, the areas of weakness highlighted in the review emphasise important areas for future research to consider. First, future research should consider the importance of reporting demographic details so that the experiences and findings for specific groups can be extrapolated. Secondly, as this research specifically explored the experiences of being detained future research could consider the experiences of those admitted to hospital voluntarily in the UK, and differences between those detained and those with informal status could be compared. Finally, it provides the opportunity for future research to consider how different legal frameworks across countries may impact the experiences individuals have when they have been detained in hospital.

Conclusions

This meta-ethnography explored patients' direct experiences of detention under the MHA in the United Kingdom. The experiences described across the literature suggested that these were largely influenced by interpersonal relationships, particularly their experiences of losing control and power dynamics with staff and the system, the use of restrictive practices and medication, and the social construction of mental disorder. The themes identified within the analysis have several overlapping concepts of the trauma-informed approach which may

provide the initial steps to applying some of these findings clinically for future research to review and changes.

References

- Akther, S. F., Molyneaux, E., Stuart, R., Johnson, S., Simpson, A., & Oram, S. (2019). Patients' experiences of assessment and detention under mental health legislation: systematic review and qualitative meta-synthesis. *BJPsych Open*, 5(3), e37.
- Anderson, B. (2020). Critical Realism: A Framework to Understand Organizations. *B. C. Anderson, Developing Organizational and Managerial Wisdom*, 1.
- Brohan, E., Clement, S., Rose, D., Sartorius, N., Slade, M., & Thornicroft, G. (2013). Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). *Psychiatry Research*, 208(1), 33-40.
- Chambers, M., Gallagher, A., Borschmann, R., Gillard, S., Turner, K., & Kantaris, X. (2014). The experiences of detained mental health service users: issues of dignity in care. *BMC Medical Ethics*, 15(1), 1-8.
- Department of Health and Social Care. (2015). *Code of Practice: Mental Health Act 1983*. <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>
- Dixon, J., Stone, K., & Laing, J. (2022). Beyond the call of duty: A Qualitative study into the experiences of family members acting as a Nearest Relative in Mental Health Act assessments. *British Journal of Social Work*, 52(7), 3783-3801.
- Emsley, E., Smith, J., Martin, D., & Lewis, N. V. (2022). Trauma-informed care in the UK: where are we? A qualitative study of health policies and professional perspectives. *BMC Health Services Research*, 22(1), 1164.
- Giacco, D., Mavromara, L., Gamblen, J., Conneely, M., & Priebe, S. (2018). Shared decision-making with involuntary hospital patients: a qualitative study of barriers and facilitators. *BJPsych Open*, 4(3), 113-118.

- Gilburt, H., Rose, D., & Slade, M. (2008). The importance of relationships in mental health care: A qualitative study of service users' experiences of psychiatric hospital admission in the UK. *BMC Health Services Research*, 8(1), 1-12.
- Gillard, S., Borschmann, R., Turner, K., Goodrich-Purnell, N., Lovell, K., & Chambers, M. (2012). Producing different analytical narratives, coproducing integrated analytical narrative: a qualitative study of UK detained mental health patient experience involving service user researchers. *International Journal of Social Research Methodology*, 15(3), 239-254.
- Glover-Thomas, N. (2018). Decision-making behaviour under the Mental Health Act 1983 and its impact on mental health tribunals: an English perspective. *Laws*, 7(2), 12.
- Guest, G., Namey, E., Taylor, J., Eley, N., & McKenna, K. (2017). Comparing focus groups and individual interviews: findings from a randomized study. *International Journal of Social Research Methodology*, 20(6), 693-708.
- Haigh, F., Kemp, L., Bazeley, P., & Haigh, N. (2019). Developing a critical realist informed framework to explain how the human rights and social determinants of health relationship works. *BMC public health*, 19, 1-12.
- Haw, C., Stubbs, J., Bickle, A., & Stewart, I. (2011). Coercive treatments in forensic psychiatry: a study of patients' experiences and preferences. *The Journal of Forensic Psychiatry & Psychology*, 22(4), 564-585.
<https://doi.org/10.1080/14789949.2011.602097>
- Henderson, C., Corker, E., Lewis-Holmes, E., Hamilton, S., Flach, C., Rose, D., Williams, P., Pinfold, V., & Thornicroft, G. (2012). England's time to change antistigma campaign: one-year outcomes of service user-rated experiences of discrimination. *Psychiatric Services*, 63(5), 451-457.

- Henderson, C., Evans-Lacko, S., & Thornicroft, G. (2013). Mental illness stigma, help seeking, and public health programs. *American journal of public health, 103*(5), 777-780.
- Hughes, R., Hayward, M., & Finlay, W. (2009). Patients' perceptions of the impact of involuntary inpatient care on self, relationships and recovery. *Journal of Mental Health, 18*(2), 152-160.
- Johnstone, L. & Boyle, M. with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D., & Read, J. (2018). The power threat meaning framework: overview. Leicester: British Psychological Society.
- Katsakou, C., Rose, D., Amos, T., Bowers, L., McCabe, R., Oliver, D., Wykes, T., & Priebe, S. (2012). Psychiatric patients' views on why their involuntary hospitalisation was right or wrong: a qualitative study. *Social Psychiatry and Psychiatric Epidemiology, 47*, 1169-1179.
- Keown, P., Murphy, H., McKenna, D., & McKinnon, I. (2018). Changes in the use of the Mental Health Act 1983 in England 1984/85 to 2015/16. *The British journal of psychiatry, 213*(4), 595-599.
- Loft, N. O., & Lavender, T. (2016). Exploring compulsory admission experiences of adults with psychosis in the UK using Grounded Theory. *Journal of Mental Health, 25*(4), 297-302.
- Madders, S. A. S., & George, C. A. (2014). "I couldn't have done it on my own." Perspectives of patients preparing for discharge from a UK high secure hospital. *Mental Health Review Journal, 19*(1), 27-36.

- McDonnaugh, T., Underwood, A., & Williams, A. (2020). "Swimming against the tide": conditional discharge from medium secure care. *The Journal of Forensic Practice*, 22(2), 57-69.
- McKeown, M., Jones, F., Foy, P., Wright, K., Paxton, T., & Blackmon, M. (2016). Looking back, looking forward: Recovery journeys in a high secure hospital. *International Journal of Mental Health Nursing*, 25(3), 234-242.
- McNally, K., Ragan, K., Varese, F., & Lovell, K. (2023). The ongoing importance of the routine enquiry into trauma and abuse and trauma-informed care within mental health trusts in England. *Journal of psychiatric and mental health nursing*, 30(6), 1130-1136.
- Mind. (n.d.). *Trauma. What is trauma?*
<https://www.mind.org.uk/information-support/types-of-mental-health-problems/trauma/about-trauma/>
- National Institute for Health and Care Excellence. (n.d.). *Mental health and the NHS: What's changed and what's to come?*
<https://indepth.nice.org.uk/mental-health-and-the-nhs/index.html#group-Whats-changed-and-whats-to-come-B1LgC7Gm7I>
- National Institute for Health and Care Excellence. (2012). *Methods for the development of NICE public health guidance (third edition)* (NICE Process and Methods PMG4).
<https://www.nice.org.uk/process/pmg4/chapter/appendix-h-quality-appraisal-checklist-qualitative-studies>
- NHS Education for Scotland. (2017). *Transforming psychological trauma: A knowledge and skills framework for the Scottish workforce*.
<https://transformingpsychologicaltrauma.scot/media/x54hw43l/nationaltraumatrainingframework.pdf>

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). sage.

Office for Health Improvement and Disparities. (2022). *Working definition of trauma-informed practice*.

<https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice>

Sattar, R., Lawton, R., Panagioti, M., & Johnson, J. (2021). Meta-ethnography in healthcare research: a guide to using a meta-ethnographic approach for literature synthesis. *BMC Health Services Research*, 21, 1-13.

Seed, T., Fox, J., & Berry, K. (2016a). Experiences of detention under the mental health act for adults with anorexia nervosa. *Clinical Psychology & Psychotherapy*, 23(4), 352-362.

Seed, T., Fox, J. R., & Berry, K. (2016b). The experience of involuntary detention in acute psychiatric care. A review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 61, 82-94.

Smith, J. A., Flowers, P., Larkin, M. (2022). *Interpretative Phenomenological Analysis 2nd Edition: Theory, Method and Research*. United Kingdom: SAGE Publications.

Solanki, J., Wood, L., & McPherson, S. (2023). Experiences of adults from a Black ethnic background detained as inpatients under the Mental Health Act (1983). *Psychiatric Rehabilitation Journal*, 46(1), 14.

Stanhope, V., Barrenger, S. L., Salzer, M. S., & Marcus, S. C. (2013). Examining the relationship between choice, therapeutic alliance and outcomes in mental health services. *Journal of Personalized Medicine*, 3(3), 191-202.

- Stutchbury, K. (2022). Critical realism: an explanatory framework for small-scale qualitative studies or an ‘unhelpful edifice’? *International Journal of Research & Method in Education*, 45(2), 113-128.
- Sustere, E., & Tarpey, E. (2019). Least restrictive practice: its role in patient independence and recovery. *The Journal of Forensic Psychiatry & Psychology*, 30(4), 614-629.
- Sweeney, A., Filson, B., Kennedy, A., Collinson, L., & Gillard, S. (2018). A paradigm shift: relationships in trauma-informed mental health services. *BJPsych Advances*, 24(5), 319-333.
- Tapp, J., Warren, F., Fife-Schaw, C., Perkins, D., & Moore, E. (2013). What do the experts by experience tell us about ‘what works’ in high secure forensic inpatient hospital services? *The Journal of Forensic Psychiatry & Psychology*, 24(2), 160-178.
- Tessier, A., Boyer, L., Husky, M., Baylé, F., Llorca, P.-M., & Misdrahi, D. (2017). Medication adherence in schizophrenia: The role of insight, therapeutic alliance and perceived trauma associated with psychiatric care. *Psychiatry Research*, 257, 315-321.
- Valenti, E., Giacco, D., Katasakou, C., & Priebe, S. (2014). Which values are important for patients during involuntary treatment? A qualitative study with psychiatric inpatients. *Journal of medical ethics*, 40(12), 832-836.

How Do Young People with First Episode Psychosis Make Sense of Help-seeking Interactions with Professionals

Abstract

Background: Previous research has identified barriers which can cause young people to avoid help-seeking in mental health. Young people with first-episode psychosis can reach crises before seeking professional help. It is crucial to have an understanding of what can increase help-seeking in young people as the duration of untreated psychosis can impact their experiences of symptoms and their well-being.

Method: Six individuals from an early intervention psychosis service participated in semi-structured interviews about their experiences of help-seeking from professionals. The interviews were analysed using interpretative phenomenological analysis.

Results: From the analysis, five themes (and subthemes) were identified; Difficulties understanding experiences and pre-conceptions of help-seeking prior to receiving help; “Mental health is a rollercoaster”; Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency; Professionals provide connection and belonging through community groups, education and employment; and Professionals support the “whole person” and provide hope for the future.

Conclusion: The themes identified relate to findings with Social Identity Theory and the Social Identity Model of Identity Change. The importance of the therapeutic relationship established by professionals, normalising their mental health experiences can lead to further connections through groups and peer support. Clinical implications are considered and discussed based on the findings.

Introduction

Within the United Kingdom, there is an increase in children being referred to mental health services (Children's Commissioner, 2023). The Children's Commissioner (2023) reported that there has been a national increase across most clinical commissioning groups (CCGs) of "6% in 2021-2022" (Children's Commissioner, 2023, p12). However, it was also reported that "91%" of CCGs have an increase in discharges before the child or young person received accessing the service (Children's Commissioner, 2023, p15). This resulted in 32% of young people not receiving treatment or input from professional mental health services. From these reports it is not clear who the referral was made by (such as self-referral, schools, General Practitioners or family).

Research suggests accessing mental health services earlier can prevent or delay the progression of symptoms or illness, further increasing social inclusion, and educational and occupational opportunities (McGorry & Mei, 2018). However, research reviews have identified that there is a large proportion of young people with mental health difficulties who do not access services or seek professional help (Gulliver et al., 2010; Radez et al., 2021). Both systematic reviews identified similar critical barriers to seeking help; knowledge and understanding of their experiences being associated with mental health symptoms (therefore not recognising they may need further support), the stigma associated with mental health and worries about how they may be perceived by others, and establishing a therapeutic relationship with professions (building a trusting relationship where people were confident about confidentiality being maintained). Systemic factors have also been identified as a barrier (Radez et al., 2021), such as waiting times to access support and staff responses or attitudes, as identified within the Children's Commissioner report (2023) with the increased number of individuals being discharged without receiving treatment. Gulliver et al., (2010)

similarly identified staff approach and attitudes as a barrier, which included the approach of how professionals responded to the young person, such as having a judgemental response or feeling as though the professional may not be able to relate to them. It has been reported that if people have experienced a negative encounter with a professional whom they perceive as being judged or treated unfairly they are less likely to seek further support (Henderson et al., 2013). It has been noted that young people experiencing mental health difficulties are more likely to seek support from friends, family or support networks already in place, such as academic professionals (Rothì, & Leavey, 2006).

Delays in help-seeking in psychosis are critical as the evidence suggests longer periods of duration of untreated psychosis (DUP) affect people's treatment response (Albert et al., 2017; Howes et al., 2021). Both research papers reported that longer DUP was associated with increased negative symptoms of psychosis. Albert et al. (2017) reported treatment of negative symptoms was more effective when the intervention was initiated earlier to noticing the symptoms. Howes et al. (2021) reported that when analysing follow-up data DUP was also associated with positive symptoms of psychosis, negative symptoms and reduced probability of remission of the symptoms they were experiencing. Positive symptoms can include hallucinations and delusions (NICE, 2014). Negative symptoms can include reduced motivation, social isolation, reduced motivation to attend to personal care and their environment, and suppressed emotions (NICE, 2014). Increased isolation could reduce connections with peers and reduce a sense of belonging which can be important for social identity and social development (Newman et al., 2007; Tarrant, 2002). This is critical for adolescents and young adults due to life changes they experience (transitions in education and peer groups) (Tanti et al., 2011; Tarrant, 2002).

Perceived stigma is significantly associated with DUP (Mueser et al., 2020). It was reported that there was a significant difference between perceived rates of stigma comparing short DUP (less than 74 weeks) and long DUP (74 weeks or more). Mueser et al. (2020) stated that perceived stigma was correlated with reduced perceived recovery and reduced well-being scores. Therefore, perceived stigma may be contributing to young people with first-episode psychosis (FEP) not seeking support from professionals. Age of onset has been identified as a factor that is significantly associated with longer DUP (Apeldoorn et al., 2014; Fond et al., 2018). Fond et al. (2018) reported both age (19 years or younger) and cannabis use were significantly associated with longer DUP (classified as more than 2 years). Apeldoorn et al. (2014) reported that younger age of onset, immigration status, and male sex were significantly associated with longer DUP (classified as less than one month). This emphasises the importance of exploring barriers to help-seeking with young people experiencing FEP.

Also, cultural and religious factors are associated with DUP (Ghanem et al., 2023; Mirza et al., 2019). Mirza et al. (2019) found that White British young people (16-20 years) with psychosis were more likely to have sought help for psychosis from professionals in mental health services compared to South Asian young people (16-20 years) in the UK. It was reported that the delay in help-seeking may be due to attributing psychosis to spiritual beliefs and causes. Therefore, these young people and their families may initially seek spiritual support rather than medical support, compared to young people who are White British. Furthermore, it was reported that the stigma from the community due to the difference in attribution of psychosis may be higher if these symptoms are associated with mental health, which can lead to avoiding seeking help from professionals. Whereas in Western society a biopsychosocial model is used to understand psychosis, therefore mental health for some White British individuals may be less stigmatising when the understanding of the experience

includes social factors, stressors and biological explanations. Ghanem et al., 2023 also emphasised the importance of cultural beliefs and help-seeking. They reported that within Western society a biopsychosocial model can increase help-seeking and an increase in positive attitudes towards medication. However, Asian, Latino, Polish, and Māori individuals reported psychosis symptoms using religious-spiritual models and African individuals described this using bewitchment models. Both religious-spiritual and bewitchment models were associated with DUP and reduced help-seeking from mental health services. The incorporation of these cultural considerations is important for all mental health services to be aware of and try to and support the reduction of stigma associated with help-seeking. This could include communicating how professional support can be offered in the least stigmatising way, providing the opportunity to increase the trust of healthcare professionals and help-seeking.

Some of these barriers emphasise the importance of epistemic injustice, and how the stigma of experiences and behaviours that people display may result in individuals to delay seeking help. Epistemic injustice is critical for people who experience mental health difficulties, where they share their knowledge and understanding of their experiences, but this knowledge can be minimised or challenged by professionals (Crichton et al., 2017; Kurs & Grinshpoon, 2018). People who feel unheard, or who find themselves stereotyped or stigmatised by others (including professionals), may be less likely to seek help or isolate from others and not share their experiences, which can further delay the treatment and support they may require (Crichton et al., 2017). Additionally, young people may experience epistemic injustice based on their age as well as well as experiencing mental health difficulties, such as FEP. A study by Houlders et al., (2021) has shown when young people describe their experiences to professionals and try to explain their understanding this can be minimised or

dismissed increasing the experience of epistemic injustice. This may lead to feeling as though they are not being believed and reducing their agency and self-esteem to share further information (Houlders et al., 2021). This lack of belief and agency within young people with psychosis or other mental health disorders may impact the therapeutic relationship developed with professionals and how they use support if they do receive professional support (Brown & Parry, 2023). People with psychosis have reported the importance of feeling there is a “safe space” to talk with professionals, professionals taking a non-judgemental stance (none stigmatising language, acceptance and listening to individuals with psychosis) and the importance of trust (Brown & Parry, 2023). These three areas were reported as essential in developing a therapeutic relationship. This emphasises that increasing the therapeutic relationship, is likely to reduce epistemic injustice, with people feeling heard and listened to about their own experience.

Due to the delay in help-seeking from young people experiencing psychosis, families often seek this support for their family member (Connor et al., 2016; Rodell & Parry, 2023). In two major reviews, Rodell and Parry (2023) examined help-seeking from families who had been supporting or caring for a family member under the age of 18 years, and Connor et al. (2016) examined help-seeking for families where a young family member was experiencing psychosis. Both reviews reported that family members and young people with mental health difficulties experienced similar barriers to help-seeking (Gulliver et al., 2010; Radez et al., 2021). Families identified were not aware of symptoms and did not understand the experience of these symptoms (Connor et al., 2016; Rodell & Parry, 2023). This may be due to less awareness and lack of mental health literacy with regard to prodromal symptoms (such as social isolation, changes in mood, apathy) which are all associated with early onset of psychosis (Addington & Heinssen, 2012; NICE, 2021). It was reported that some of the

negative symptoms and/or withdrawal from family was attributed by parents to the young people's age and their psychological and emotional development. Therefore, whilst young people may isolate and withdraw as they experience symptoms of psychosis, family members may not interpret this as a response to mental health issues.

Another overlapping barrier identified by families (Connor et al., 2016; Rodell & Parry, 2023) was stigma. The stigma associated with young people's mental ill-health is a worry for families which may prevent and delay help-seeking in young people with psychosis. Rodell and Parry (2023) reported that this often led to young people reaching crisis and to increased symptoms of psychosis before help-seeking took place. Both Connor et al., (2016) and Rodell and Parry (2023) reported that families were unclear on where to seek support. Some individuals did seek professional support from their GP. However, the young people felt that the approach could sometimes lead to them being excluded from conversations and the focus of the GP could be to gather information from the family member instead (Connor et al., 2016). Rodell and Parry (2023) reported that some families did not feel the GP was the appropriate place to seek help or some families had previously had contact with mental health services which had resulted in experiences where they no longer trusted the service and wanted to seek help. These barriers from family members replicate similar barriers reported by young people with mental health (Henderson et al., 2013; Gulliver et al., 2010) and the importance of the therapeutic alliance and trusting relationships with health care services and professionals. From these findings young people often sought help once reaching crisis.

Therefore, given the understanding and awareness of research completed with family members of young people with FEP, it is crucial to explore this further with them directly to understand their experiences of help-seeking with professionals. It is evident that barriers have been researched more widely, but it would be valuable to understand what increases

help-seeking to avoid individuals reaching crisis. Therefore, it could be beneficial to understand the features of a positive therapeutic relationship as this has been recognised as an important experience of help-seeking. This will allow research to inform clinical practice to reduce barriers and increase facilitators of help-seeking in young people with psychosis. This is crucial based on the evidence of reduced help-seeking and increased DUP on young people's perceived recovery, experience of symptoms, and well-being (Albert et al., 2017; Howes et al., 2021; Mueser et al., 2020). The research aims to explore how young people with FEP make sense of help-seeking with their interactions with professionals, to consider barriers and facilitators in responses from professionals and how this may affect young people's experiences.

Method

Ethical approval and considerations

Ethical approval was gained by the NHS Research Ethics Committee (Appendix E). Participants were provided with an information sheet (Appendix F) before giving written consent. The information sheet included information that participants had the right to withdraw anytime during the interview, without providing a reason. If they had completed the interview, they could withdraw their recording within 14 days following the interview (before the interview was transcribed and anonymised for confidentiality). A debrief was arranged so that each participant could reflect on the interview process and how they had felt following this process. Participants were informed confidentiality would only be breached if there was a risk or concern regarding the participant's health or welfare which would require sharing with the clinical team. They were informed this would be discussed with them so they were aware of the information being shared. Researchers involved in the wider project were not employed by any of the services. Informed written consent was provided by all participants and this was

confirmed again before the interview. Participants who were 15 years old, were assessed to ensure they were Gillick-competent to participate. This was decided due to feedback from the young persons advisory group at the McPin Foundation, who suggested seeking parental consent would minimise the sense of agency. This was approved by the research ethics committee.

Design

I adopted a qualitative design, and collected data via one-to-one interviews. McCabe et al. (2023) have highlighted the importance of young people being directly involved in research and therefore young co-researchers from the McPin Foundation were involved in the design, interviews, documents provided to participants, and the different styles of interviews that could be chosen. The co-development group from the McPin Foundation were all young people (male and female), aged between 16 and 25 with lived experience of various mental health conditions. This increases epistemic justice by including expert-by-experience researchers and young people directly in the development of the research. The research is part of a wider research study (“Understanding the interactional context of young people's experiences of disclosure and help-seeking for mental health difficulties”) which includes young people’s experiences of help-seeking in multiple teams within mental health services. The different services involved within the wider research project include: an eating disorder service, EIP service, Pause (a well-being drop-in service for up to 25 years) and a personality and complex trauma pathway.

Participants were able to choose between different *styles* of interviews from a menu of five options (Appendix G); a talking interview, relational mapping interview, timelines interview, bring-your-own-photos interview, or a draw-and-talk interview. Allowing participants to choose their preferred style of interview, provided options of how they could

reflect on the experiences and have made meaning of their experiences. For the current participants from the EIP service only the talking interview and draw and talk interview were chosen. Participants reflected that often their preference was to talk and focus on the interview itself. The two individuals who selected the draw and talk interview also reflected that they did not draw as much as they expected as once they felt comfortable talking they were happy to articulate in this way. The options are to provide choice and increase accessibility for participants interested who may find it difficult to express their experience verbally. This was identified by the co-development group from the McPin Foundation. The methods of interview chosen may vary across the different mental health services in the wider research project.

For analysis, I drew upon Interpretative Phenomenological Analysis (IPA) as outlined by Smith et al. (2021). IPA aims to explore individual experiences people have and how they reflect on and understand these specific experiences (Smith et al., 2021).

Sampling strategy

IPA uses small sizes (often between six and ten) which are selected to analyse the accounts of individuals who have had similar experiences, whilst considering their understanding and how they have made sense of the experience (Smith et al., 2021). A homogenous sample is preferred, in order to analyse in depth a specific occurrence, often in a particular context (Smith et al., 2021) - for example, young people seeking help for psychosis in the same service. The inclusion criteria were: young people aged 15-24, and accessing the EIP service. Convenience sampling was used for participants meeting the inclusion criteria, there was no restriction to how long they had been accessing the service for.

Recruitment procedure

Participants were recruited through an early intervention for psychosis (EIP) service in an NHS trust in the midlands. Service users were informed of the research by being provided with a poster from the EIP service. The service users could then use an email address on the poster or pass their email on for staff to give the study coordinator to gain further information if they were interested. A consent form (Appendix H) and information sheet (Appendix F) were sent by email for the participant to read with the opportunity to ask any questions.

Participants

There was a total of 6 participants, 4 male and 2 female, aged between 17 and 21 years old. Five of the participants requested interviews in person and all chose to have these interviews at their EIP service bases (a university site was also offered), one participant chose to take part in the interview online. Two of the participants opted in to complete a draw and talk interview (Debra and Hannah), and the other four participants requested a talking interview. Demographic details for each participant can be found in Table 2.1.

Table 2.1

Participant demographic data

Name	Age	Gender	Ethnicity	Age at onset of psychosis
Debra	17	Female	Black British Caribbean	14/15
Clarence	19	Male	Bangladeshi	16/17
Hasan	19	Male	Bangladeshi	19
Alexander	20	Male	Mixed – White and Asian	20
Emmanuel	19	Male	Black African	16-19
Hannah	21	Female	White British	18

Data collection procedure

Semi-structured interviews were arranged for up to 90 minutes (ranging from 46 to 72 minutes), and verbal consent was confirmed again before the interview. Participants were provided a summary sheet of different styles of interviews (Appendix G) so they could choose which style they would like to engage in; a talking interview, relational mapping interview, timelining interview, bring-your-own-photos interview, or a draw-and-talk interview. The participants had a choice of interviews being remote or face-to-face. The semi-structured interview guide can be seen in Appendix I. The interviews were audio recorded using an encrypted dictaphone. Interviews were transcribed after fourteen days to provide the opportunity for participants to withdraw. Following this, the transcripts were anonymised using pseudonyms and details were changed for any other identifiable information in the transcript (such as other individuals named or identifiable places which could be associated with participants).

Data analysis

The transcribed interviews were analysed using the guidelines of IPA (Smith et al., 2021). Initially the transcripts were read through before re-reading and making exploratory notes on the side of the transcripts. The exploratory noting was completed line by line and included descriptive, linguistic and conceptual noting (Smith et al., 2021). The descriptive notes could include participants describing an experience they have had whilst help seeking and how they felt during this time. The linguistic notes focused on the use of language, how this may change or shift when talking about certain situations, noticing emotive language or repeated phrases and words. The conceptual noting included questions, reflections or considerations from the researcher at the first stages of analysing the transcript. After the exploratory notes were completed, the experiential statements were constructed (Smith et al.,

2021). These statements are created by reviewing the initial notes from the transcript and creating a concise summary of the detail that has been noted in the exploratory noting. These notes were then cut out and reviewed to assess if there were connections across the different statements. By reviewing the statements and any connections personal experiential themes (PETS) (Smith et al., 2021) were identified for each participant (Appendix J).

During the analysis each participant's transcript was analysed individually (exploratory noting, experiential statements and PETS), before starting the process again for the next transcript. Once the PETS were completed for each individual these were reviewed across all the participants. The process including considering similarities and differences across the individual experiences (Appendix K) to gather group experiential themes (GETS). Each participant was allocated a colour so it could be clearly established which participants were contributing to each group theme.

Reflections

I am a female white British trainee clinical psychologist. Professionally I have an awareness of the processes of how to seek help, but I was surprised how this knowledge may not be accessible for people who need to access these services. After each interview a debrief was completed with another member of the research team, where initial reflections were discussed to become aware of any content that had stood out to the researcher, being aware of this and remaining neutral when analysing the transcripts, following the IPA process. Also, to ensure that the PETs were plausible, the PETS for each participant were reviewed and discussed with another member of the research team. The process was repeated for the GETS.

From a researcher's perspective, I was aware when starting the interviews that this was not a clinical interaction, so I had to shift away from formulation and towards a more neutral role, to allow the interviewees to tell their stories. Initially, this felt unusual but

discussions and support from the research team prior were helpful to maintain this stance. Reflecting on the process from a researcher's perspective it felt empowering to allow the interviewees to talk freely and tell their story. I was also aware of myself as a female researcher interviewing four males and two females, and not knowing how my identity might impact what they might feel comfortable sharing within the interviews. A couple of individuals did make reference to feeling more comfortable when talking to people from the same gender (from a family and professional perspective). I was aware that my ethnicity is White British and the sample was representative of the service users who access the service, which included participants from Black, Asian and Minority Ethnic backgrounds. This was not directly stated in any of the interviews and no discussions were observed to be closed down or stopped by the participants. However, I am aware that my ethnicity may result in certain statements or comments not being initiated or being filtered which may have felt been discussed with a researcher with the same ethnicity. This may be due to an increased shared understanding of possible experiences within power dynamics with others and cultural sensitivity which as a White British researcher I may be less likely to be exposed to. Throughout the interviews I wanted to ensure the participants felt as comfortable as possible when talking, with the hope of them feeling more relaxed and feel able to be open. I was also aware of creating an environment that felt psychologically safe to share their experiences and explore these in the interview in a respectful way.

One of the interviews included using a translator¹. Within different languages, there are not always direct translations for words or phrasing (Tribe & Lane, 2009), which means there is a level of interpretation of the information from the translator to the interviewee and possibly back to the researcher. Within the usual interview process there is the double

¹ The translator was used in the interview and the transcript included transcribing the translator's speech. Therefore, the quotes have been reframed in the first person to ensure confidentiality has been maintained.

hermeneutic process of interpreting meaning (Smith et al., 2021), the addition of the interpreter could add another layer of interpretation which is in then transcribed and part of the analysis.

Results

Table 2.2 displays the five themes and subthemes developed from the six interviews and includes which participants contributed to each theme.

Table 2.2

IPA themes and subthemes identified from the analysis

Group Experiential Theme	Subtheme	Participants contributing to theme
1. Difficulties understanding experiences and pre-conceptions of help-seeking prior to receiving help		All participants
2. "Mental health is a rollercoaster"	2.1 Help-seeking can be anxiety-provoking initially	All participants, apart from Emmanuel
	2.2 Professionals are understanding and collaborative, which creates a sense of safety	All participants
3. Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency		Debra, Clarence, Alexander, Hannah
4. Professionals provide connection and belonging through community groups, education and employment		All participants, apart from Hasan

5. Professionals support the
“whole person” and provide
hope for the future

All participants, apart
from Emmanuel

Theme 1: Difficulties understanding experiences and pre-conceptions of help-seeking prior to receiving help

An important aspect of help-seeking that all participants discussed was their understanding of their experiences when they started to experience changes in behaviours, emotions and positive symptoms of psychosis. This was articulated in several ways across the participants, based on their own experiences of psychosis. For example, Hasan acknowledged that seeking help initially was difficult because he could not determine what was real. This made it difficult to ask for help: “I couldn’t tell the difference between reality, so I couldn’t really tell anyone. Eventually I did.” (lines 250-251). Hasan’s use of “eventually” here provides a sense that he had endured these experiences for some time before seeking help. Similarly, Clarence described trying to continue as long as he could without help-seeking (“[I] just tried to get on with it I suppose”) (line 94), despite feeling “scared” and “confused”.

There was also a sense of isolation at times, prior to help-seeking, when participants had tried to understand what was happening. Hannah described how when she returned home from university: “I was ill, and kind of locked myself away a bit. Quite- felt quite lonely as well.” (lines 1300-1301). The phrasing of being “locked away” sounds final in its description. The initial process of isolating herself may have increased her feelings of loneliness. At this time in her life, she might have expected to be growing more independent, experiencing a sense of freedom, and moving out of the family home. Instead, Hannah ‘locked herself away’ and it seems plausible that she did so because she felt that this was the safest thing to do at the

time (perhaps protecting her from stigma or fear), but of course this also prevented her from receiving support.

Similarly, Debra described not seeking help initially and coping on her own, due to perceptions that others “wouldn’t understand”. She described being unwell “emotionally, socially and physically” which created a feeling of being overwhelmed while trying to understand her experiences. Similar to Hannah and Clarence she described not talking to others. Debra emphasised the difficulty in help-seeking from “anyone”. Similar to Clarence, she described the emotional distress associated with trying to cope with the number of changes she was experiencing. Debra expressed these concepts below:

“Emotionally, socially and physically unwell because like sometimes I just- well I couldn’t like speak to anyone, like I said it was hard to speak to anyone and hard to like tell them about how I was feeling because I had all these thoughts in my head and I was like I can’t tell anyone these thoughts because I feel like they wouldn’t understand me anyway, so yeah, and then like physically unwell because I wasn’t eating much because I usually do eat a lot but sometimes I just didn’t eat much and like I’d leave the plate or sometimes I’d eat a lot and like people will be wondering what’s going on and they’ll be like yeah, so that just made me feel like I was physically unwell and then emotionally I was like always crying, I was always upset, I was always isolating myself from like friends and family and they’d be like wondering what’s going on, so yeah.” (lines 485-496).

This extract is a good illustration of how of other people’s perceptions were a focus of concern for a number of the participants. Here Debra repeats the idea of others “wondering what’s going on”. There was also an expectation and understanding being unwell would result in stereotypes and stigma. Hasan described isolating himself from others, “acting weird”, and

stated: “I went a bit crazy, and then I ended up with the psychosis” (line 229). Hannah referred to her experience in terms of difference: “I just thought what was happening was real and there was nothing wrong with me.” (lines 694-695). Hannah’s experience, like Hasan’s, felt like reality. However, the use of the wording “wrong with me” feels like she anticipated a negative connotation to being unwell. Alexander also expressed “fears” about how his relationships and interactions would be affected, if he was “open” about his mental health:

“The fear of losing some, some people or what actions they're going to do after... Er... feel like they won't talk to me no more, not get along with me or see me, hate me, just basic stuff like that” (lines 273-277).

Given the challenges of anticipating other people’s perceptions and stigma, and the young people’s worries about how to explain or describe their experiences, it is not surprising that half of the participants received help only once their families had contacted emergency services. Two participants sought help by talking to someone they felt comfortable with, but even then, there was some delay in approaching others. For example, Emmanuel sought help, yet described “living with this illness [for] weeks and months” (line 535) and how he “stopped going to college for about 2 months” (lines 100-101). The delay that Emmanuel described was “weeks and months” and he was not attending college for some time.

In summary, initially help-seeking was difficult for participants, often resulting in family or others seeking help on their behalf. All participants described difficulties explaining their experiences to others. There was an additional layer of complexity when their experiences felt like reality, so they didn’t feel the need to seek help. Also, those who were distressed by their experiences also expressed not knowing how to articulate their experiences, and worrying about stigma and how others may respond.

Theme 2: “Mental health is a rollercoaster”

Mental health was described as a “rollercoaster” by Alexander. Across the participants this metaphor appeared to fit well. The rollercoaster could be interpreted in multiple ways, and this included in Alexander's own descriptions within the interview. The theme includes the idea that mental health is dynamic, across the longer-term engagement with services, and also directly before and after appointments. It was experienced as a rollercoaster of emotion, which included feeling anxious prior to appointments and a sense of relief or reassurance after. The subthemes included 'help-seeking can be anxiety-provoking initially' and 'professionals are understanding and collaborative, which creates a sense of safety'.

Theme 2.1: Help-seeking can be anxiety-provoking initially

A number of the participants described feeling anxious initially about the intentions of professionals. There was an uncertainty about why professionals may ask certain questions. Clarence described feeling worried about being “tricked or trapped” when he initially received support at home:

“I wasn’t really sure why they were here, they was explaining it to me, but I wasn’t quite sure why they were here, what they were going to do, and sometimes they wanted to ask me questions, and I didn’t know whether it’s to like trap me or trick me, I couldn’t make sense of it all, why are they asking me that?” (lines 166-170).

Clarence's doubt and uncertainty here is conveyed in the repeated phrase, “I wasn’t sure.” Similarly, other respondents described how they felt overwhelmed during their initial interactions, “couldn’t make sense” of what was happening, and felt unsure of professionals' intentions, even if they explained them. This uncertainty was shared by most individuals and reported in their experiences of initial interactions with professionals both in the community and in hospital. For example, Debra expressed feeling scared when being admitted to hospital:

“It was scary because I was very young and I was on the ward and I’m like I don’t know what these people think of me” (lines 390-391). Similarly to Clarence, Debra described her fear and uncertainty of what professionals may think of her. Debra also referenced her age which may be an important factor for young people seeking help. Often young people are encouraged to see their youth as a source of vulnerability (e.g. not to talk to strange people or go to unfamiliar environments), but when people require support for their mental health, there are a number of new people to interact with. Hannah initially described the professionals as “strangers”: “It felt weird, like having strangers in my house I guess” (line 172). Hannah provided some advice on how to help reduce the anxiety and uncertainty of meeting new professionals:

“Maybe like information sheets on like the different people that work here, and what their job is, and stuff about them. Or like a photo, so you know who you’re meeting, if you can’t remember. Because when you’re really ill you can’t really remember people and you don’t know who they are.” (line 1204-1211).

This anxiety remained for a number of the participants, even when relationships had developed with professionals, maintaining that rollercoaster metaphor around their appointments. The anxiety prior to appointments was described as arising while travelling to the appointment, waiting for the appointment, being in the waiting rooms, anticipating the questions that may be asked, or sounding “silly” to professionals. Participants described the strong physical presence of their anxiety:

“I get really anxious, thinking people might... before the appointments, because when I have to go there, I don’t like leaving my house, when I do, I think people are going to come attack me and that, attack my family. Yeah, I start sweating and all that and my heart starts racing.” Hasan (lines 425-431).

“Normally I feel quite good, quite prepared, but obviously when you come here you forget what you were going to say. Normally quite relaxed, you know, but it’s only until I get here, I don’t know why I get nervous, I shouldn’t really because, you know, there’s nothing to be nervous about, it’s just one of those things, you know, I get like butterflies in my stomach and such.” Clarence (lines 279-284).

This kind of anxiety before appointments appeared to be sustained throughout the help-seeking process for young adults. However, as relationships with professionals and services continued, the participants described a contrast in how professionals also provided a safe environment for them to be open about their experiences of psychosis.

Theme 2.2: Professionals are understanding and collaborative which creates a sense of safety

Being listened to, and feeling heard, were shared experiences that were important to all participants. For example Hannah emphasised how important it was that staff were, “supportive, yeah because the staff were supportive and understanding and listened to you” (lines 1425-1426). Clarence reiterated the importance of being listened to and emphasised that he had this experience “all the time” by repeating that phrase: “All the time, I think all the time. All the time, they seem to pay close attention to what I was saying, and how I was feeling” (lines 416-417). The description of “close attention” underlines the idea of fine details being heard about what was said, but also about how he felt emotionally. Debra similarly described feeling heard and understood, but also emphasised the importance of this interaction being *collaborative*:

“I feel like it’s a two way conversation, I think... I don’t really plan what I’m going to say, I remember like someone asked me questions and then I answer them, stuff like that and then they can put their input in as well, once they’ve like listened to you and understood what I’ve said” (lines 568-576).

Debra acknowledged that collaboration is important “once they’ve listened”.

Collaborative working may increase the value of being heard. Clarence emphasises the importance of collaboration, but he described preferring directive feedback from professionals. He compared professionals to a tutor where he could learn more about his mental health experiences, placing them in an expert position:

“I’d say it’s like a tutor teaching a student, like they go there, they tell you if you’re getting better or getting worse, and what you need to work on, and what you need to improve, and what you have to look forward to, and if you don’t do this you’ll be like this, if you don’t do this your life will be like this. I think it’s more, it’s like a learning curve, like I know where I am I’d say, so that helps. Because sometimes you’re in the dark, are you improving, are you going back, trying to do this, trying to do that, but they let you know and reassure you that either you’re on the right track, or you need to do this to get better.” (lines 802-810).

The feedback and collaboration provided reassurance for Clarence. Prior to help-seeking this feedback of being “on the right track” wasn’t present for the participants. They were trying to make sense of their experiences on their own so this collaboration and shared understanding appeared to be valued. Being able to talk openly about their mental health with a non-judgemental approach, and while receiving reassurance, was a positive experience that was shared by the participants: “They always reassure me. They’re always, you know, asking me things that I would like to do” (Emmanuel, lines 405-406)”. The advice from all the

participants to other young people was that it was a positive experience receiving help, despite the initial worry and fear: “Sometimes you've just got to be, open up and be brave to talk about it, even if it's scary or terrified, because after you've talked about it it'll make you relieved and joyful” (Alexander, lines 256-258). The contrast in emotions before and after appointments reiterated the emotional rollercoaster of appointments with professionals.

There were times when professional support could feel less collaborative, becoming more transactional. The transactional experiences were often based on medical appointments, such as blood tests and prescribed medication. Debra described not feeling included in those discussions initially:

“Like my medication, because at the start, they had like a very high dosage of the tablets that I got, so I feel if they like listened to me first and said like oh, what do you think would help, what do you think a dose is that you think it would take” (lines 1098-1101).

In contrast, Hasan felt “at ease” that professionals led these discussions. This was because of their professional knowledge and expertise, as well as them “understanding” his experiences and emotions:

“It makes me feel at ease, because they know what they’re doing, they know what medication to give me, what’s best for me and that. Because they have the experience... And they understand what I’m going through more, like the mental illness, how I’m feeling and that.” (lines 686-695).

In summary, the process of help-seeking can be both anxiety-provoking and reassuring. These contrasting feelings before and after appointments continue once relationships have established with professionals. There is an awareness of the young people describing a power imbalance with professionals which is aligned with their feelings of anxiety. It is important to be aware of these anxieties and what can increase feelings of safety,

such as reassurance, being listened to and collaboration. Increasing these positive interactions may also increase a sense of agency for young people.

Theme 3: Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency

Normalising young people's experiences and collaborating with them on their care increased their sense of agency and enabled them to share their thoughts more openly. This in turn influenced the nuance of identity and mental health becoming a part of their identity. This positive experience was described as being unexpected. Young people had anticipated that professional support would be more "cold and clinical," rather than collaborative and supportive of their voice:

"I'd expect it to be like more clinical and like less about you, but it's like here it's more about you, and like what your goals are, and what your life's like, and how you want it to be... I don't know why I thought of that, because they're there to help you." (Hannah, lines 248-250).

The repeated use of "you" and "your" provides insight into the sense of autonomy developed when working with professionals. It implies the level of influence she had in her care compared to her expectation that it would be "clinical" and "less about you", suggesting the expectation that young people may anticipate to have a more passive role in their care. Participants also expressed how professionals normalised the experiences they shared, making them feel less isolated. This normalisation may also increase their confidence to contribute to their care. Hannah reported that professionals normalising her experiences has been meaningful: "I kind of thought I was the only one going through this and stuff like that" (line 1072).

Clarence also described developing his agency over time whilst receiving support from professionals. At the first appointment, professionals spoke with his family first, which he stated he “wanted”. This also felt similar to interactions with other health professionals as he has grown up and was his expectation: “I mean when we go to the doctor obviously they talk to my dad first, but now I’m older they talk to me now, so what’s the problem?” (lines 254-255). Clarence later compared how his confidence had developed whilst working with professionals, which he was described as positive: “sometimes I think to myself, you know, ten years ago whatever, the past to now, it’s completely different me, yeah, I like it, it’s not bad.” (lines 342-344). Also having their experiences normalised and increasing their confidence, created a shift in the nuance of their identity. For participants this was described in different ways, such as regaining their sense of identity after help-seeking, noticing a change in identity during their initial experiences of psychosis, and feeling a change in their identity as they become more understanding of their experiences. For Alexander, similar to Clarence he described his confidence building going out of the house after help-seeking and feeling as though he was regaining his identity by feeling happier. He contrasts this with when he isolated himself prior to seeking help from professionals:

“Before, I didn't used to laugh, and that was at the start, and after going out a lot I've just started laughing again, slowly becoming myself. It takes time, but it feels good, yeah, it feels calm, nice and calm.” (lines 482-484).

Clarence acknowledged it can take time to feel himself again. Debra described having the support as a positive experience, having her experiences normalised and increasing conversations about her mental health with other people she can trust. As the agency increased in young people with professionals, this appeared to translate to being able to talk with family

members as well. In turn, the more people they can be open with about their mental health, the more this may influence the nuance of their identity:

“My mental health like makes me feel better about myself because I know that if I have struggles I can just go to professionals, speak through it, speak to them and like they’ll help me and I can speak to my mum about finding people that I can trust, that I could speak to, so that makes me feel better.” (Debra, lines 1310-1314).

However, this was in stark contrast to how Debra felt initially prior to seeking help from professionals. She described a sense of being “different” to others initially:

“I didn’t like myself because I just didn’t want to have like a mental health problem what made me different, I just want to be the same as everyone else but then I was like I’ll just take it in like little steps, I just understand that not everyone’s like born the same, like we’re not born twins, like we’re not the same people, we’re not the same mind, so everyone like deals with things differently” (lines 281-286).


Debra initially described not liking herself or her experiences of psychosis. She described wanting to be the same as others. Having her experiences normalised by professionals, increased her confidence to be open with professionals. She described initiating these conversations eventually, and later she described that everyone is different. This change and importance of mental health being an important part of her identity is illustrated in Table 2.3. The participants describe adjusting to the changes in their mental health and identity. This process takes time, then there is a sense of acceptance and what they have learnt through their experiences:

“I think it’s like because of psychosis, like I feel like I’m different, as a person, and think different things now to before. Makes me feel a bit annoyed, but I think it’s for the better, and you can’t change it now, so it’s who I am.” (Hannah, lines 1112-1118).

Similar to Debra, Hannah described conflicting feelings about her mental health and how she viewed her identity. They both used the word “better” as the positive aspect of their experiences of their mental health and identity. They also both expand on how their experiences of psychosis have increased their understanding and empathy of other people’s difficulties: “Just being more understanding, and more thoughtful” (Hannah, line 1122), “like I can understand their stories as well because I’ve got something to relate to with them as well” (Debra, lines 1317-1318).

Table 2.3

Debra’s Poster – “Mental Health Matters”

Description and analysis of image	Image of Poster
<p>The title of the poster states “mental health matters”. This has been put in different colours and capital letters to signify the importance to her. She has also used exclamation marks either side of the word “matters”. This is reflected in her quote, where she describes initially not wanting to be “different”, but later reflects that people are “not the same”. This aspect of her identity does “matter” to her.</p> <p>There is also an image of herself with a thought bubble that states “at different stages in my life my mental health has improved”. This again reflects on adjusting to the changes she has experienced which has been described by other participants as well. The use of the word “stages” emphasises the importance of the time it has taken for her to possibly feel more confident about this. That may be reflected by her being on her own in the picture and how initially she may have felt “different”, alone or isolated from others.</p>	 <p>The poster features the title "MENTAL HEALTH MATTERS!" written in large, bold, capital letters. "MENTAL HEALTH" is in red and purple, while "MATTERS!" is in blue with exclamation marks. Below the title is a thought bubble with the text "At different stages in my life I feel like my mental health has improved." and a small stick figure of a person.</p>

In summary, positive support and interactions from professionals can normalise young people's distressing experiences. This provides space for them to process those experiences and talk to professionals, adjusting to how mental health can influence the nuance of their identity. This process feels almost like another part of the “rollercoaster” of help-seeking. At the same time participants described how their encounters with professionals increased their confidence and sense of agency.

Theme 4: Professionals provide connection and belonging through community groups, education and employment

In the interviews, there was an emphasis on professionals providing connections to the community. This was described as happening through various arrangements including; attending activity groups with peers who also access the EIP service, accessing the community during their appointments rather than them being based in rooms on site, and supporting participants to look for employment and attend college courses of interest. Clarence described how the activities provided him with a sense of purpose describing it “almost like a job”, as well as connecting with his peers and this being something to look forward to:

“it gives you something to look forward to, you know, it certainly gives me, like tomorrow if everything goes well and the others join in, we’ll do it again for an hour. So I’d say it’s great fun, you get a chance to meet new people, and I mean if you love the game I’d say, if you love the game, it gives you a sense of almost like a job” (lines 967-971).

Clarence also described how this experience and support from professionals was “fun” and provided him with the opportunity to meet with his peers. When explaining this he changed his use of language from “I” and “you” to “we”, which implied that the community

groups were associated with a sense of belonging and a shared identity. Meeting peers with similar experiences was described by Debra as comforting: “it’s good to like know there’s other people that are like me, not like big celebrities or like that but like me” (lines 357-359). The importance of the connection through her peer groups is valued, she repeated the phrase “like me” to emphasise this. Professionals through the EIP service provide this space to create friendships with shared experiences. However, at the same time, it created space for them to have “fun” and connect as young people with shared interests as well as shared experiences of mental health: “they take us on trips, they make us go to like laser tag, bowling or picnics or simple stuff like baking, which you have fun and not worrying about mental health problems” (Debra, lines 363-365). The open environment creates space where they can be open with peers and professionals whilst enjoying activities. As described in Theme 3 (Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency) a sense of agency can be created when the participants choose when they want to use these activities as their time to connect through enjoyment or conversations with peers sharing their experiences.

As well as the peer connection that can be promoted through professional support, there was an emphasis on connecting back into society after isolating and prior to help-seeking. The encouragement and adapting appointments to be in the community can promote happiness, by feeling more connected to the outdoors. Alexander described feeling “free” when going out with professionals. He repeated the phrase and how this can impact his mood, along with his connection with professionals (smiling, greeting him) and noticing the change of environment (“fresh air”):

“the mental health associates greeting you, being happy to see you, or going out and getting fresh air with them, because when you're outside you feel free and once you've felt

free you can feel happy, joyful, grateful, you're feeling grateful to be outside, leaving the house every once in a while or every, once a week” (lines 569-573).

The participants described that they would recommend engaging in the activities to other young people who may need to support for their mental health. The participants also described receiving support for trying to find work as well as educational courses, which can be avoided due to isolation prior to seeking professional support:

“Continue to do the social groups, because that gets them doing something, and finding out things for them to do, in like public, so like education courses, and stuff like that.

Supporting to work, that was good when I was looking at that... Yeah, I think our intervention's quite good at that, because it's all about like getting you back into society and stuff, when you like are trying to keep yourself away kind of when you're ill. (Hannah, lines 1274-1289).

Hannah presents the professionals' support here as a way of “getting you back into society”. This provides an insight into how participants described themselves as feeling isolated, prior to receiving support. Professionals' support and encouragement can increase the social connection again, initially with professionals, and later peers and the wider community:

“They do help me to find job and... They help me to register, you know, in the gym somewhere not far from here. They are looking for a...Places where I can join like gym, football, basketball as well.” (Emmanuel, lines 225-231). However, Emmanuel also reported the importance of medication and professional support he received initially which may have contributed to his increased confidence and motivation to connect with peers and activities he enjoys: “After taking the medication I did have that desire to do things like going playing with friends, like PlayStations and do things in my life.” (lines 304-305).

In summary, professionals create a sense of belonging and connection with the community and peers with shared experiences. This approach is valued by participants and creates an environment where they can be open, but also show different aspects of themselves as a whole person, linking into Theme 5. It also creates further collaboration and being heard (Theme 2.2) as the activities, employment opportunities or courses recommended by professionals are guided by the participant's interests and hobbies.

Theme 5: Professionals support the “whole person” and provide hope for the future

An important aspect of help-seeking to the participants was being supported by professionals as an individual. They did not only focus on the young people's experiences of mental health, but considered their interests and what was important to them as individuals as well. Hannah described the support as person-centred: “They're really helpful, and they listen to you, and they tailor the support to you, and your goals” (lines 1337-1338). It was a shared view that professionals considered the interests of individuals to engage them (likes, dislikes, family stories) and considered what their goals would be for the future (interests, education, employment). They also used these shared interests to build relationships initially: “Asking me how my day is, how I am, how my family is, and that makes me feel comfortable around them” (Hasan, lines 523-524), “they've watched YouTube a lot, just like me, in their spare time and talked about what I always feel like doing, like watching TV or drawing or, or, in general, like fashion” (Alexander, lines 222-224).

Some participants described how professionals supported other systems associated with the individual, such as school. This was perceived as helpful to increase the school's knowledge of psychosis and maintain their attendance at school. This included challenging the stigma that young people with psychosis would be a “danger” to others:

“I feel like once the professionals told them about how my diagnosis was, how I act or how I’m not like a danger to like the school, I feel like it was better because the school, like they didn’t fully understand it but they just said like, oh yeah, she can still go to school so it’s fine and then that would just work, so no-one had to really know about things” (Debra, lines 1273-1278).

Debra described how professionals “told them”, sharing their knowledge and expertise about Debra’s mental health. She reported how the school “didn’t fully understand” which feels like a contrast to the support she has received from the professionals, but was relieved that she could return to school. Missing education when isolating and feeling unwell was critical for the participants, and something that professionals did provide support to ensure they returned to college, school or employment. This promoted being heard and hope so that the participants could still work towards their future goals.

However, one area that Hannah described based on her personal experiences was not included as part of a holistic approach was the link between physical and mental health. She described feeling frustrated that this was disconnected and that there was limited communication between the services. When unsure of side effects this would leave her feeling uncertain about if it was related to medication for physical health or mental health:

“I know with children there’s like paediatric nurses and they like collate all the information together, and like focus on the person as a whole and all the different things that are going on with them, but there’s not really that for adults” (Hannah, lines 649-652).

When participants reflected on being treated as a “whole person” they were able to share their future goals with professionals. This provided space to talk about how to work towards the goals that were important to the participants, consider coping strategies and receive reassurance:

“What I’m experiencing is normal, and I’m not like, I’m not, just because I have this condition, it doesn’t mean there’s certain things I can do, and certain things I can’t, it’s just learning about how to deal with it, I’d say, in a different way, compared to how normal people would deal with it” (Clarence, lines 769-773).

Clarence described the importance of his experiences being normalised by professionals and how he can still achieve his goals when “learning” coping strategies for his experiences of mental health. This hope and normalisation was critical as there appeared to be an underlying expectation of him being different compared to others (“normal people”), which may impact his perception that his future goals could change. The future also included short-term goals for participants, thinking about the next appointment and the additional professional support that could be offered. Professionals normalising participants experiences and building connections instilled hope. Hasan described this with a metaphor of feeling “brighter”:

“like there’s a future ahead. A lot of people are on the way to help you, such as doctors... makes me feel like brighter now. Before I was like down and that, I didn’t like it, there was nothing to look forward to.” (lines 886-894).

Here, Hasan compares prior times when he was “down” and had less hope for the future with the newer feeling that the future is brighter. Professional support and the approach used were seen as critical by some participants for feeling this kind of hope for their future. Hasan also stated that it was reassuring to know that he would be supported by the EIP service during in the medium term: “they’re going to have me for three years, to check me... Really confident for the future, that there is a future there” (lines 328-332). The repeated phrase about his confidence for the future demonstrates how professionals can instil hope in

participants and the value of this. The importance of the time (“three years”) creates a sense of safety that the professional support will remain for some time.

In summary, receiving care for the “whole person” increases person-centred care and collaboration in working towards the individual’s goals. Having a shared understanding of goals to work towards provides hope for the future for young adults with psychosis. Professionals appear to provide reassurance, validation and normalise that they can still reach goals with some support through coping strategies or adaptations made. It was also acknowledged by the participants having support for up to three years instilled some hope for the future. This may be due to feeling reassured the support is there if they require it, using the agency they have developed with professionals (Theme 3).

Discussion

The aim of the paper was to explore how young people with first-episode psychosis make sense of help-seeking in their interactions with professionals. Using IPA, five themes were identified from the six participants' accounts: 1. *Difficulties understanding experiences and pre-conceptions of help-seeking prior to receiving help*; 2. *“Mental health is a rollercoaster”*; 3. *Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency*; 4. *Professionals provide connection and belonging through community groups, education and employment*; and 5. *Professionals support the “whole person” and provide hope for the future*. The first theme identified that initially help-seeking was difficult for young adults. They described concerns about explaining their experiences due to worries about stigma or how others may respond. However, some individuals also reported the complexity of their experiences feeling as though it was reality so didn’t know they needed to seek help. This is consistent with the findings of Gulliver et al. (2010) and Radez et al. (2021) who identified these factors as

barriers to help-seeking for children, adolescents and young adults. Research has found that the awareness and understanding from society about psychosis is more limited compared to other mental health disorders such as anxiety and depression. Significant differences were found in stigmatising attitudes and increased withdrawal from individuals with psychosis compared to individuals with depression (Svensson & Hansson, 2016). Wood et al., (2014) found that people with schizophrenia were significantly more likely to be associated with negative stereotypes (“a danger to others”, “unpredictable” and “hard to talk to”) and the belief that with treatment the individuals would “never fully recover” or “not improve”. These findings were based on The Office of National Statistics survey from the public. The stigma of mental health still appears to be varied and the education of increasing awareness of understanding of psychosis within society may help reduce this stigma.

However, once the participants had received support, they described professionals created a safe space, actively listened to them, and normalised and validated their experiences. These characteristics were identified by Barr et al. (2015) and Brown and Parry (2023) as critical characteristics professionals should develop with individuals accessing FEP services to build a therapeutic relationship. Similarly to what was expressed by the participants, Brown and Parry (2023) stated that from the systematic review of EIP services across different countries, these characteristics increased the feeling of safety for individuals to be open with professionals about their experiences (Theme 3). A positive therapeutic alliance between professionals and young people may increase their autonomy in their care as they become more comfortable and the care becomes more collaborative (Dimic et al., 2023). Dimic et al. (2023) reported that prior to developing a positive therapeutic alliance between professionals and young people (10-24 years) individuals reported feeling anxious before appointments due to not knowing what to expect in their first appointment. This reflects similar experiences

from participants and Theme 2.1 (help-seeking can be anxiety-provoking initially). However, some of the participants described the anxiety remaining prior to appointments throughout their contact with professionals. Positive experiences of help-seeking and having their experiences normalised may also reduce internalised stigma. Moriarty et al. (2012) reported that internalised stigma and worries about how others perceive them significantly correlate with reduced activity. This may help understand why several participants described initially isolating from others. Moriarty et al. (2012) also suggested that social inclusion and activity is an important intervention for people with psychosis. Therefore, if the therapeutic alliance and trust with professionals, as well as normalisation of their experience can reduce their internalised stigma, it may increase the possibility of attending groups in the community and peers with similar activities (Theme 4). Berry and Greenwood (2015) have reported that based on findings of dyads of professionals and young people with psychosis, positive therapeutical alliance increased activity and social connection, which predicted increased young people's hope (Theme 5). Therefore, these findings replicate what the participants reported in Theme 4 and Theme 5. This emphasises the importance of the therapeutic relationship between young people and professionals in EIP services and the additional gains this can lead to, such as social inclusion, connection, and increased hope.

Social identity theory

The five themes identified in the analysis and how they interlink with each other and the evidence from other research correspond with social identity theory (Tajfel & Turner, 1978) and the Social Identity Model of Identity Change (SIMIC) (Haslam et al., 2021). Social identity theory suggests that individuals categorise people, which can create certain social groups (in-groups and out-groups). This could include people identifying with peers over similar interests or hobbies, socialising with other peers due to similar life experiences or

shared understanding of mental health. These social identities connect individuals within groups. SIMIC emphasises the importance of maintaining or creating new group membership, particularly when going through life changes (this could be health related, migrating to a different country, change in job roles, or education). During life changes and stressors when experiencing these transitions, the social support can be important for people's well-being and maintaining a sense of belonging and meaning. Losing these connections can increase feelings of distress and confusion regarding identity. Theme 1 (Difficulties understanding experiences and pre-conceptions of help-seeking prior to receiving help) emphasises some barriers to young people seeking help from professionals. Included within this theme is the fear of stigma and others' perceptions. In theme 3 (Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency) there were comparisons to their identity, "before" and "after" seeking professional support. This reflects the initial expressions of feeling "different" to others within their current social groups (friends and family) and all participants described isolating. Social identity is based on the connection with others in their "social groups", when feeling disconnected from the group it is reported that this can increase feelings of loneliness and disconnection (Haslam et al., 2022). This sense of disconnection and isolation may explain the anxiety of worry when initially seeking help (Theme 2.1) as they are unsure how professionals will perceive them with their new nuance of identity. However, when the experience is positive and a therapeutic relationship is developed where they feel safe and understood (Theme 2.2) and their experiences are normalised by professionals (Theme 3) this can increase a sense of connection. The importance of professionals developing relationships where they support the "whole person" (Theme 5) is critical as it can create an understanding of the young person's own personal identity and wider interests as well. This understanding of young people then

provides professionals to increase their social connections with community groups and college or employment (Theme 4). This increases people's sense of connection and belonging as they become part of another social group and develop their social identity again (Haslam et al., 2021; Tajfel & Turner, 1978). This may explain how in Theme 3 (Normalising can influence the acceptance of a 'mental health' identity, and help professionals to support the development of a sense of agency) the importance of hearing professionals normalise their experiences can lead to a shift in nuance of their identity where their mental health can be accepted or sometimes valued. The SIMIC model (Haslam et al., 2021) emphasises the importance of feeling connected and belonging to multiple groups when a significant life change occurs. Professionals being aware of the "whole person" (Theme 5) and being able to promote connections in the community associated with their interests as well as their mental health reflects the development of this social connection and their social identities.

Strengths and limitations

The demographics of the participants included different ethnicities and genders who represent individuals who access EIP services. Also, there was an in-depth analysis which was quality checked by researchers who did not conduct the interviews. The study follows a number of the standards for reporting qualitative research (Levitt et al., 2018) such as transparency in the methodology and analysis process and contextualisation of evidence in the researcher's reflections.

However, some of these experiences may vary for individuals who are older and accessing the EIP services. Consequently, these results may not be transferable to those individuals. This could be a consideration for future research to interview individuals aged 25 and over and their experiences of help-seeking. This could provide insight into possible similarities and differences in their experiences of help-seeking.

Clinical implications

Several clinical implications can be considered based on the findings. Participants and previous reviews (Gulliver et al., 2010; Radez et al., 2021) identified delays in recognising needing support and help-seeking. Therefore, focused interventions for specific communities to increase mental health literacy and reduce stigma could improve the knowledge of where to seek help and understand the experiences of mental health. This could include different public health campaigns targeted at young people and parents. This could also be an area of future research to ask young people and their families where this information could be displayed to increase awareness.

The EIP team increased social connections for the participants accessing the service and viewed them as a “whole person” when building relationships (Brown & Parry, 2023). Professionals listened, established trust, supported agency through a “tuition” styled approach, encouraged young people to build social connections and incorporate their mental health experiences into their identities, supported by social identity theory (Haslam et al., 2021; Tajfel & Turner, 1978). Social inclusion was critical to reduce stigma, increase connection and provide hope for the future (Berry & Greenwood, 2015). This was valued by participants and remains an essential part of interventions, outlined by the NICE guidelines (NICE, 2013; NICE, 2014). There is evidence to suggest the approach used by early intervention services is cost-effective, reducing hospital admissions and increasing access to education and employment, as well as improving health outcomes (NHS England, 2023; Tsiachristas et al., 2016). Using this approach across other services for young people could increase social inclusion rather than exclusion (Haslam et al., 2021; Tajfel & Turner, 1978). Sharing this approach across organisations to implement similar practices could be considered

by using an identity-informed leadership approach (Haslam & Platow, 2001), emphasising the shared NHS values, improving health outcomes and applying this in a cost-effective way.

The findings from the individual analysis of these data will be prepared for publication in a paper where they will be integrated with the analysis conducted by the young co-researchers from the wider project. This co-analytic perspective is especially important for practice implications. For example, the individual analysis highlights many positive features of young people's help-seeking and care-receiving experience in Early Intervention services. There are more nuanced points from which service providers can learn, but the overarching message for EI teams might well be 'keep doing what you're doing.' In the context of service pressures to 'dilute' the outreach and wider engagement commitments of EI, this is an important message. However, the young co-analysts from the wider project read the accounts of the EI participants in light of their own personal experiences of help-seeking from less specialist services, for a broad range of mental health difficulties. Their own experiences were generally less positive, and the data they had seen elsewhere in the project was also much less positive. For them, the key message for service improvement is pitched at a higher level than EI teams: 'why can't all services for young people provide this level of care?' Thus, what might help services most is an understanding communicated to commissioners and policy-makers: a) that young people deserve better care from mental health services and b) that we already have good models of better care on which to build. The features of these models are clearly evident in the themes reported here.

Conclusions

The findings of this study highlight some of the barriers young people experience when seeking professional support. These include worries about people's perceptions and stigma, limited understanding of their own experiences which impacts the awareness they

may need to seek help, and complications of their experiences feeling like reality so not seeking help. It highlights the importance of therapeutic relationships that can be built between young people and professionals through normalising their experiences, feeling heard, promoting agency and increasing social connections and hope for the future.

References

- Addington, J., & Heinssen, R. (2012). Prediction and prevention of psychosis in youth at clinical high risk. *Annual review of clinical psychology*, 8, 269-289.
- Albert, N., Melau, M., Jensen, H., Hastrup, L. H., Hjorthøj, C., & Nordentoft, M. (2017). The effect of duration of untreated psychosis and treatment delay on the outcomes of prolonged early intervention in psychotic disorders. *NPJ schizophrenia*, 3(1), 34.
- Apeldoorn, S. Y., Sterk, B., van den Heuvel, E. R., Schoevers, R. A., Islam, M. A., Bruggeman, R., Cahn, W., de Haan, L., Kahn, R., & Meijer, C. J. (2014). Factors contributing to the duration of untreated psychosis. *Schizophrenia Research*, 158(1-3), 76-81.
- Barr, K., Ormrod, J., & Dudley, R. (2015). An exploration of what service users value about early intervention in psychosis services. *Psychology and psychotherapy: Theory, research and practice*, 88(4), 468-480.
- Berry, C., & Greenwood, K. (2015). Hope-inspiring therapeutic relationships, professional expectations and social inclusion for young people with psychosis. *Schizophrenia Research*, 168(1-2), 153-160.
- Brown, K., & Parry, S. (2023). How do people with first episode psychosis experience therapeutic relationships with mental health practitioners? A narrative review. *Psychosis*, 1-12.
- Children's Commissioner. (2023). *Children's Mental Health Services 2021-22*
<https://assets.childrenscommissioner.gov.uk/wpuploads/2023/03/Childrens-Mental-Health-Services-2021-2022-2.pdf>

- Connor, C., Greenfield, S., Lester, H., Channa, S., Palmer, C., Barker, C., Lavis, A., & Birchwood, M. (2016). Seeking help for first-episode psychosis: a family narrative. *Early Intervention in Psychiatry*, 10(4), 334-345.
- Crichton, P., Carel, H., & Kidd, I. J. (2017). Epistemic injustice in psychiatry. *BJPsych bulletin*, 41(2), 65-70.
- Dimic, T., Farrell, A., Ahern, E., & Houghton, S. (2023). Young people's experience of the therapeutic alliance: A systematic review. *Clinical Psychology & Psychotherapy*, 30(6), 1482-1511.
- Fond, G., Boyer, L., Andrianarisoa, M., Godin, O., Brunel, L., Bulzacka, E., Coulon, N., Llorca, P., Berna, F., & Aouizerate, B. (2018). Risk factors for increased duration of untreated psychosis. Results from the FACE-SZ dataset. *Schizophrenia Research*, 195, 529-533.
- Ghanem, M., Evangeliki-Dawson, C., & Georgiades, A. (2023). The role of culture on the phenomenology of hallucinations and delusions, explanatory models, and help-seeking attitudes: A narrative review. *Early Intervention in Psychiatry*, 17(9), 843-863.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*, 10, 1-9.
- Haslam, C., Haslam, S. A., Jetten, J., Cruwys, T., & Steffens, N. K. (2021). Life change, social identity, and health. *Annual Review of Psychology*, 72(1), 635-661.
- Haslam, S. A., Haslam, C., Cruwys, T., Jetten, J., Bentley, S. V., Fong, P., & Steffens, N. K. (2022). Social identity makes group-based social connection possible: Implications for loneliness and mental health. *Current opinion in psychology*, 43, 161-165.

- Haslam, S. A., & Platow, M. J. (2001). The link between leadership and followership: How affirming social identity translates vision into action. *Personality and Social Psychology Bulletin*, 27(11), 1469-1479.
- Henderson, C., Evans-Lacko, S., & Thornicroft, G. (2013). Mental illness stigma, help seeking, and public health programs. *American journal of public health*, 103(5), 777-780.
- Houlders, J. W., Bortolotti, L., & Broome, M. R. (2021). Threats to epistemic agency in young people with unusual experiences and beliefs. *Synthese*, 199(3), 7689-7704.
- Howes, O. D., Whitehurst, T., Shatalina, E., Townsend, L., Onwordi, E. C., Mak, T. L. A., Arumuham, A., O'Brien, O., Lobo, M., & Vano, L. (2021). The clinical significance of duration of untreated psychosis: an umbrella review and random-effects meta-analysis. *World Psychiatry*, 20(1), 75-95.
- Kurs, R., & Grinshpoon, A. (2018). Vulnerability of individuals with mental disorders to epistemic injustice in both clinical and social domains. *Ethics & Behavior*, 28(4), 336-346.
- Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist*, 73(1), 26-46.
<https://doi.org/10.1037/amp0000151>
- McCabe, E., Amarbayan, M., Rabi, S., Mendoza, J., Naqvi, S. F., Thapa Bajgain, K., Zwicker, J. D., & Santana, M. (2023). Youth engagement in mental health research: a systematic review. *Health Expectations*, 26(1), 30-50.

- McGorry, P. D., & Mei, C. (2018). Early intervention in youth mental health: progress and future directions. *BMJ Ment Health*, 21(4), 182-184.
- Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural differences in psychosis: The role of causal beliefs and stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, 50(3), 441-459.
- Moriarty, A., Jolley, S., Callanan, M. M., & Garety, P. (2012). Understanding reduced activity in psychosis: the roles of stigma and illness appraisals. *Social Psychiatry and Psychiatric Epidemiology*, 47, 1685-1693.
- Mueser, K. T., DeTore, N. R., Kredlow, M. A., Bourgeois, M. L., Penn, D. L., & Hintz, K. (2020). Clinical and demographic correlates of stigma in first-episode psychosis: The impact of duration of untreated psychosis. *Acta Psychiatrica Scandinavica*, 141(2), 157-166.
- National Institute for Health and Care Excellence. (2013). *Psychosis and schizophrenia in children and young people: recognition and management*. (Clinical Guideline CG115) <https://www.nice.org.uk/guidance/cg155/resources/psychosis-and-schizophrenia-in-children-and-young-people-recognition-and-management-pdf-35109632980933>
- National Institute for Health and Care Excellence. (2014). *Psychosis and schizophrenia in adults: prevention and management*. (Clinical Guideline CG178). <https://www.nice.org.uk/guidance/cg178/resources/psychosis-and-schizophrenia-in-adults-prevention-and-management-pdf-35109758952133>
- National Institute for Health and Care Excellence. (2021). *How do I identify a person at risk of developing a psychotic disorder or experiencing psychosis?* <https://cks.nice.org.uk/topics/psychosis-schizophrenia/diagnosis/identifying-someone-at-risk-of-a-psychotic-disorder-or-experiencing-their-first-episode-of-psychosis/>

- Newman, B. M., Lohman, B. J., & Newman, P. R. (2007). Peer group membership and a sense of belonging: their relationship to adolescent behavior problems. *Adolescence*, 42(166).
- NHS England. (2023). *Implementing the early intervention in psychosis access and waiting time standard*.
<https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/04/eip-guidance.pdf>
- Radez, J., Reardon, T., Creswell, C., Lawrence, P. J., Evdoka-Burton, G., & Waite, P. (2021). Why do children and adolescents (not) seek and access professional help for their mental health problems? A systematic review of quantitative and qualitative studies. *European Child & Adolescent Psychiatry*, 30(2), 183-211.
- Rodell, S., & Parry, S. (2023). Family members' experiences of seeking help for a young person with symptoms associated with the psychosis spectrum: A narrative review and synthesis. *Clinical Child Psychology and Psychiatry*, 13591045231176701.
- Roth, D. M., & Leavey, G. (2006). Mental health help-seeking and young people: A review. *Pastoral Care in Education*, 24(3), 4-13.
- Smith, J. A., Flowers, P., & Larkin, M. (2021). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE Publications.
https://books.google.co.uk/books?id=_-46EAAAQBAJ
- Svensson, B., & Hansson, L. (2016). How mental health literacy and experience of mental illness relate to stigmatizing attitudes and social distance towards people with depression or psychosis: A cross-sectional study. *Nordic Journal of Psychiatry*, 70(4), 309-313.

- Tajfel, H., & Turner, J. C. (1978). Intergroup behavior. *Introducing social psychology*, 401(466), 149-178.
- Tanti, C., Stukas, A. A., Halloran, M. J., & Foddy, M. (2011). Social identity change: Shifts in social identity during adolescence. *Journal of Adolescence*, 34(3), 555-567.
- Tarrant, M. (2002). Adolescent peer groups and social identity. *Social Development*, 11(1), 110-123.
- Tribe, R., & Lane, P. (2009). Working with interpreters across language and culture in mental health. *Journal of Mental Health*, 18(3), 233-241.
- Tsiachristas, A., Thomas, T., Leal, J., & Lennox, B. R. (2016). Economic impact of early intervention in psychosis services: results from a longitudinal retrospective controlled study in England. *BMJ open*, 6(10), e012611.
- Wood, L., Birtel, M., Alsawy, S., Pyle, M., & Morrison, A. (2014). Public perceptions of stigma towards people with schizophrenia, depression, and anxiety. *Psychiatry Research*, 220(1-2), 604-608.

We need more progress in tackling mental health stigma and poor attitudes - including inside mental health hospitals

Mental health patients detained in hospital may find recovery tougher if the environment triggers previous trauma and their behaviours are misinterpreted as symptoms.

According to research carried out at the University of Birmingham, patients who are detained under the Mental Health Act (MHA) may benefit from trauma-informed care approaches that are better suited to their needs. A meta-ethnography reviewed the findings of 12 studies based on people's experience of being detained under the MHA in the UK. Four themes were identified that influence the experience people have whilst detained under the MHA in the UK:

- The relationships they form with others, both professionals and peers within the hospital (including other people's attitudes towards them, feeling heard, being treated with dignity and respect, and being involved in the decision-making of their care and treatment).
- The loss of control and power they feel when they are detained under the MHA. The impersonal clinical environment was more often compared to prison, not representative of living in the community or the family home. The power dynamics of being an adult who had independence previously, but may now have restrictions and require legal permission on when they can leave the building or visit family. Through this loss of power and control, people described responding in different ways to cope with the loss of independence and autonomy.
- The experiences of taking medication, being restrained or in seclusion. There were mixed results from people's experiences regarding whether they found this distressing or containing. This often was linked with the collaboration and relationships they had

with staff and if their preferences of intervention were being considered. This was critical for individuals who had distressing past experiences where restraint or forced medication may trigger these memories.

- The construction of the mental health disorder was experienced whilst detained by two types of processes. This included the environment which could trigger past distressing memories (through physically restrictive practices or how they were treated by others, including feeling stigmatised). This was also experienced by general human responses being stigmatised as symptoms of mental health, such as becoming upset or angry being defined as someone being “unwell”.

Previous literature reviews have included research from across countries, however, the current review aimed to understand the experiences of being detained in the UK as the legal frameworks are not the same across different countries.

Sophie Tilston, Trainee Clinical Psychologist at the University of Birmingham stated, “The findings from the research overlap with the model of trauma-informed care. The themes reported and understanding people’s experiences directly can support hospitals to collaboratively work with people detained in hospital to support their recovery using a trauma-informed approach”.

Future research could also be considered to compare the experiences of adults who are in hospital voluntarily. This could also result in future research comparing differences and similarities of the hospital experience of being detained under the MHA or being voluntarily admitted in the UK.

ENDS

People are more than their mental health diagnosis in early intervention psychosis services. More knowledge and understanding are needed to ensure people can access these services.

Support by professionals in early intervention psychosis teams is non-judgemental, understanding and can increase social inclusion, however, to know this the anxiety and worries of help-seeking need to be reduced and normalised.

According to research carried out at the University of Birmingham, young people experiencing first-episode psychosis benefit from professionals' knowledge and expertise, but also the value of the therapeutic relationship and social inclusion with peers and in the community. Interviews with six people (aged 17-21) were interviewed about their experiences of help-seeking when experiencing psychosis. Five themes were identified that influence the experience young people have when seeking help:

- Difficulties seeking professional help due to worries about others, stigma, and the complexity of understanding their experiences when it feels like reality can make it difficult to seek support.
- Mental health was described using the metaphor of a “rollercoaster”. This reflected the experiences that mental health is dynamic, but also the process of seeking help can feel like an emotional rollercoaster. Initiating help-seeking and meeting professionals could be anxiety-provoking, scary and fearful. However, as professional relationships developed and trust was built this was described as a positive experience of being heard, supported, and it felt safe to talk.
- Young people having their experiences heard and normalised influenced a level of acceptance of their ‘mental health’ identity. Some of this was contrasted with how they felt about this prior to seeking help and worries about what others may think.

Young people had a voice in their care, goals and worked collaboratively with professionals becoming more autonomous with professionals.

- Once a therapeutic relationship has been built between young people and professionals, promoting connection and belonging with others is valued. This included peer connections with activities and supporting young people to access education and employment opportunities, working towards their goals.
- The young people described a positive experience was that they were seen as a whole person and the support they received was holistic, not focused only on diagnosis. The experiences they had provided hope for the future and some of this was knowing ongoing support was available from the early intervention psychosis teams.

Sophie Tilston, Trainee Clinical Psychologist at the University of Birmingham stated, “The findings suggest the experience of help-seeking can be a positive experience for young people, particularly with the holistic care and promoting social inclusion. There are significant similarities between these findings and social inclusion theory. However, delays in seeking help are an ongoing barrier. Increasing mental health knowledge and where to seek help could have a crucial impact if health campaigns target young people and families”.

Future research could also be considered about where it would be effective for these campaigns to be promoted. Some research could focus on parents/families and some on young people to ensure this knowledge is known.

ENDS

Appendix

Appendix A

Exact search terms used for each database. Search terms updated to ensure it is only direct experiences of service-users.

Database	Key Words	Search Terms Used
Medline (OVID) PsycINFO (OVID) HMIC (OVID) Embase (OVID)	Service-users	service-user* or patient* or consumer*, or inpatient* or client* or ((lived or life) adj experience*) or survivor*
	Compulsory admission	"mental health act" or section* or 'mental treatment act' or (compuls* or involuntar* or coer* or forced or detention or detained or refusal or mandat* or civil or appeal* or advoc*) adj2 (hospital* or admiss* or admit* or readmiss* or commit* or assess* or treat* or healthcare)
	Mental health	mental disorders/ or (mental* or psychologic* or psychiatr*) adj2 (health or disorder* or disease* or deficient* or illness* or problem*)
	Study design	qualitative research/ or interview/ or qualitative or (theme\$ or thematic) or 'ethnological research' or (humanistic or existential or experiential or paradigm\$) or (field adj (study or studies or research)) or ((purpos\$ adj4 sampl\$) or (focus adj group\$)) or 'observational method\$' or 'content analysis' or ((discourse\$ or discurs\$) adj3 analys?s) or 'narrative analys?s' or (grounded adj (theor\$ or analys?s)) or 'action research' or (account or accounts or unstructured or openended or open ended or narrative\$) or (lived adj experience\$)
Social Sciences Citation Index (Web of Science)	Service-users	service-user* or patient* or consumer* or inpatient* or client* or ((lived or life) NEAR/0 experience*) or survivor*)
	Compulsory admission	"mental health act" or section* or "mental treatment act" or (compuls* or involuntar* or coer* or forced or detention or detained or refusal or mandat* or civil or appeal* or advoc*) NEAR/2 (hospital* or admiss* or admit* or readmiss* or commit* or assess* or treat* or healthcare)
	Mental health	mental disorders or ((mental* or psychologic* or psychiatr*) NEAR/2 (health or disorder* or disease* or deficient* or illness* or problem*))
	Study design	

qualitative research or interview or qualitative or
(theme* or thematic) or “ethnological research” or
(humanistic or existential or experiential or paradigm\$)
or (field NEAR/0 (study or studies or research)) or
((purpos* NEAR/4 sampl*) or (focus NEAR/0
group*)) or “observational method*” or “content
analysis” or ((discourse* or discurs*) NEAR/3
analys?s) or “narrative analys?s” or (grounded NEAR/0
(theor* or analys?s)) or “action research” or (account or
accounts or unstructured or openended or "open ended"
or narrative*) or (lived NEAR/0 experience*)

Appendix B

Extract of the table for Phase 4 of the data analysis and synthesis. The yellow box has been highlighted as it overlaps with another theme within the same paper.

A	B	C	D
Concept 1		Concept 2	Concept 3
	<p>Views of self</p> <p>"My illness has affected me, but I wouldn't say being sectioned has affected me. (Cherie)" "About half the participants said they had retained their sense of self during their time in hospital... These participants generally had a positive or indifferent experience of involuntary hospitalization."</p> <p>"I knew I was evil before I went into hospital, because of what happened in my childhood. But . . . but, they sort of, what do you say, they sort of exemplified it [. . .] they sort of made it double that. (Annie)" "The remaining participants experienced negative changes in self-concept and loss of identity, which they ascribed to their experiences of involuntary hospitalization."</p> <p>"I had no self-respect when I left there whatsoever. (Sarah)" "Feeling ignored by staff, and the frequent use of physical restraint were seen as leading to a loss of dignity and self-respect"</p> <p>"there wasn't much to demonstrate your confidence through. Um, you didn't have the opportunity to do anything, so you didn't know if you were competent or not. (Jake)" "Reduced self-efficacy was described by over half the participants in relation to involuntary hospitalization. Physical restrictions such as not being allowed to leave the ward, and having nothing to do, were significant factors associated with reduced self efficacy"</p> <p>Factors that impacted the view of self included relationships with staff, physical restraint, reduced self-efficacy and physical restrictions within inpatient environments.</p>	<p>Experience of relationships and interactions</p> <p>"talking to my mum [. . .] convinced me that I needed help (Jake)" "Partners and family could have a significant impact on participants' attitudes to involuntary hospitalization and receiving compulsory treatment."</p> <p>"whole social life had fallen apart (Sarah)" "Other participants believed that their relationships were negatively affected during involuntary hospitalization." "However, approximately another half of the participants saw their relationships with family and friends as unaffected by the experience"</p> <p>Three of the participants had clearly positive perceptions about their relationships with ward staff, describing them as "caring people" (Felicity), who provided a "really high standard of care" (Cherie). "Relationships with ward staff were also reported as variable."</p> <p>"Three other participants perceived staff as custodial, regimented, and devoid of care." "Just doing their job (Ian)" "They used to take away my furniture, so I was left with a mattress on the floor. And, no sheets, no bedding [. . .] So those were the ways that they used to punish me. (Annie)" "Four participants described very negative aspects to relationships with ward staff, some of whom they experienced as punitive, violating, and abusive. Safety procedures such as removing furniture and personal items to reduce risk were experienced by these participants as punishment"</p> <p>"I was very aggressive, I was very abusive. That was probably in this environment that I was in [. . .] I did say to them, if you treat me like an animal, then I'll act like an animal. Why are you doing this, to me? You know, because I was acting, totally out of character. (Sarah)" "Three participants believed that their aggressive or pathological behaviour during involuntary hospitalization was part of a cycle of conflict in their relationships with ward staff and professionals"</p> <p>Includes poles e.g. reports that half did not find relationships with family and friends were effected no direct quote. Also different relationships- professional, friends and family.</p>	<p>Medication</p> <p>"without the medication I wouldn't have been instrumental in their recovery" "I interviewed did not like having strongly negative views and I couldn't talk, my mouth was dry. And I couldn't talk to let them know where to turn, I didn't know where to turn. I knew I was going to be medicated. (Annie)" "Forced medication distress. This relates to the cycle of distress. medication can be experienced as distress. Includes views of medication of side effects of medication restraints medication distress"</p>
<p>Hughes et al., 2009</p>	<p>A time for quiet reflection (Subthemes = 1.Helpful isolation 2.Chill out – calm down 3.Get peace of mind 4.Reflect back on what happened 5.Learn a lesson)</p> <p>"Sometimes it's nice to be on your own and not to have people around when you are feeling upset [P32]". "Some participants spoke of seclusion as providing helpful isolation."</p> <p>"You can chill out, like get peace of mind. It's quiet [P18]" "Seclusion could also have a positive effect on thoughts and emotions, through its calming influence or by providing time to think and reflect on actions".</p> <p>"It helps de-escalate the situation and helps me reflect on my behaviour [P35]" "Physical restraint could also have a calming effect and aid reflection on ones' actions."</p> <p>"It (seclusion) teaches you not to do it again [P2]". "All three types of coercive treatment could result in participants feeling the incident had taught them a lesson."</p>		
<p>Haw et al., 2011</p> <p>The subthemes are part of the quotes included</p>	<p>Particularly strong theme for seclusion - having the space and time to think. Also a reference to restraint physically stopping someone. Then medication providing the same effect. Possible link to control or physical environment? - the removal of choice/control providing a response or forcing a change of environment and removing stimulation possibly?</p>	<p>Prevents violence to self and others (Subthemes = 1.Prevents self-harm 2.Prevents injury to others)</p> <p>Participants recognised that seclusion, physical restraint and emergency medication could all prevent violence to ones' self and others.</p> <p>"In a way it stopped me from hurting myself and other's [P51]" - seclusion & medication</p> <p>"It stops you causing more damage to yourself [P32]" - physical restraint</p>	<p>Positive effects of IM medication</p> <p>"you feel better"</p> <p>"The last one was a good experience. I calmed down in its sedative effect of medication over the following day".</p> <p>"It (haloperidol) calms me down" "emergent theme about the positive calming effect."</p> <p>"It makes you really sleepy a quicker and seems to last longer" "medication was more effective"</p> <p>"It helps get your mental state [P52]"</p> <p>"It's good. It works. It makes it helped them to feel better"</p>

Appendix C

Extract of the table for Phase 5 of the data analysis and synthesis

A	B
	<p>Concept 1 - Interpersonal relationships</p> <p>Experience of relationships and interactions</p> <p>"talking to my mum [. . .] convinced me that I needed help (Jake)" "Partners and family could have a significant impact on participants' attitudes to involuntary hospitalization and receiving compulsory treatment."</p> <p>"whole social life had fallen apart (Sarah)" "Other participants believed that their relationships were negatively affected during involuntary hospitalization." "However, approximately another half of the participants saw their relationships with family and friends as unaffected by the experience"</p> <p>Three of the participants had clearly positive perceptions about their relationships with ward staff, describing them as "caring people" (Felicity), who provided a "really high standard of care" (Cherie). "Relationships with ward staff were also reported as variable."</p> <p>"Three other participants perceived staff as custodial, regimented, and devoid of care." "Just doing their job (Ian)" "They used to take away my furniture, so I was left with a mattress on the floor. And, no sheets, no bedding [. . .] So those were the ways that they used to punish me. (Annie)" "Four participants described very negative aspects to relationships with ward staff, some of whom they experienced as punitive, violating, and abusive. Safety procedures such as removing furniture and personal items to reduce risk were experienced by these participants as punishment".</p> <p>"I was very aggressive, I was very abusive. That was probably in this environment that I was in [. . .] I did say to them, if you treat me like an animal, then I'll act like an animal. Why are you doing this, to me? You know, because I was acting, totally out of character. (Sarah)" "Three participants believed that their aggressive or pathological behaviour during involuntary hospitalization was part of a cycle of conflict in their relationships with ward staff and professionals"</p> <p>Includes poles e.g. reports that half did not find relationships with family and friends were affected - no direct quote. Also different relationships- professional, friends and family.</p>
Hughes et al., 2009	<p>Attitudes of staff conducting coercive treatments - merged themes within paper.</p> <p>Positive attitudes and experience of staff conducting coercive treatments (Subtheme = 1. Just doing their job 2. Caring attitude)</p> <p>"In my case the nurses feel they have the expertise. They have the grades. They are doing their required job." "Five participants perceived staff as just doing their job."</p> <p>"The staff are so caring and they want to look after you [P20] and I can see why they have to do it. It shows staff care and they don't want you to hurt yourself." "Others felt that staff had a caring attitude even when using a coercive treatment."</p> <p>Negative attitudes and experience of staff conducting coercive treatments (Subtheme = 1. They treat you like an animal 2. Staff deliberately punishing patients 3. Staff acting unprofessionally 4. Staff touch you 5. Use of undue force 6. Staff need proper training 7. Loss of trust)</p> <p>"A very wide range of opinions was expressed about staff conducting coercive treatments, though negative views predominated." "We are human beings, not animals, dogs, lions or tigers [P27]." - in relation to IM medication.</p> <p>"They treat you like criminals. They hurt you to get their own way [P41]". "When they twist your arms and legs back it feels like they hate you [P43]". "Other participants expressed the view that staff were deliberately punishing patients and exerting power over them"</p> <p>"When you are being restrained you feel some staff take the mickey out of you. They say things like you are bad and talk down to you [P39]" "They abuse you. They say I am stupid [P25]". "Some participants described how staff could act unprofessionally... These attitudes could lead to patients losing trust in staff and not wanting to confide in them anymore." "It's assault. I hate it. I don't like people touching me anyway. I would rather be injected than have anyone put their hands on me [P31]."</p> <p>"People that restrain should get properly trained [P4]" "On this ward a lot of patients get restrained aggressively without proper techniques [P22]"</p> <p>Physical pain, injury and fear of death (Subtheme = 1. Physical pain 2. Injury 3. Paralysis 4. Can't breathe 5. Fear of death 6. Damage to clothes 7. Unpleasant drowsiness 8. Problems with injection site)</p> <p>"They twist your wrists hard and dig their nails to put your face on the ground. They hold you down hard. You are screaming. They say calm down. It is harsh on us. [P42]"</p> <p>"One very common emergent theme about physical restraint concerned unpleasant bodily sensations. Physical pain associated with being restrained was the commonest sensation reported."</p> <p>"If my asthma comes (when I am being restrained) I will be dead. It worries me [P27]." "Not only did some participants report not being able to move, some said they were held so tightly they could not breathe properly. This was particularly distressing for those with asthma."</p> <p>"It knocked me out. I was really drowsy for three days [P57]." "Many participants complained about the physical effects of IM medication. Some participants complained it left them tired and drowsy for days." "I couldn't move [P22]" "I became weak, paralysed [P27]" "Some complained of paralysis, while others complained that it was painful".</p>
Haw et al., 2011	
	<p>Concept 3 - Use of restrictive practices and medication</p> <p>Medication</p> <p>"without the medication I wouldn't have become well again (Cherie)" "Two participants had positive attitudes towards medication, and believed that it had been instrumental in their recovery. However, the majority of participants interviewed did not like having to take medication, and five participants expressed strongly negative views and experiences in relation to it."</p> <p>"I couldn't talk, my mouth was locking, my mouth was like twisting, it really hurt [. . .] And I couldn't talk to let them know what was wrong. (Ian)" "Side effects were described by some participants as frightening and physically painful". Some side effects were experienced as life-threatening.</p> <p>"I used to plead with them and plead with them (tearful), please don't give me that [medication]. And of course that used to make me more crazy, because I didn't know where to turn, I didn't know what to do (crying) [. . .] the more bad I was, the more I knew I was going to be medicated, so the more crazy I got, because I was terrified. (Annie)" "Forced medication was seen by some participants as worsening their distress. This relates to the cycle of conflict described earlier, and suggests that forced medication can be experienced as impeding, rather than fostering, recovery."</p> <p>Includes views of medication that helped, quotes are included regarding experiences of side effects of medication. Also provides quotes for those who found forced restraint medication distressing.</p> <p>Effects or understanding of how restrictive practices may be used in certain situations? - merged themes</p> <p>Prevents violence to self and others (Subthemes = 1. Prevents self-harm 2. Prevents injury to others)</p> <p>Participants recognised that seclusion, physical restraint and emergency medication could all prevent violence to ones' self and others. "In a way it stopped me from hurting myself and other's [P51]" - seclusion & medication</p> <p>"It stops you causing more damage to yourself [P32]" - physical restraint</p> <p>Positive effects of IM medication (Subthemes = 1. Calming, sleep-inducing 2. Makes you feel better)</p> <p>"The last one was a good experience. I wasn't dopey the next day and it didn't affect my sight. I calmed down in half an hour. [P19]" "A number of participants found the sedative effect of medication helpful, provided this did not leave them feeling hung-over the following day".</p> <p>"It (haloperidol) calms me down and helps me relax [P39]" "The most common emergent theme about the positive effects of IM medication was its beneficial calming effect."</p> <p>"It makes you really sleepy and you just sleep [P49]." "Using IM gets in there quicker and seems to last longer [P46]." "Several participants said that IM medication was more effective than oral medication"</p> <p>"It helps get your mental state get back on top again [P52]". "It's good. It works. It makes me feel better [P53]." "Three female participants said it helped them to feel better"</p> <p>A time for quiet reflection (Subthemes = 1. Helpful isolation 2. Chill out - calm down 3. Get peace of mind 4. Reflect back on what happened 5. Learn a lesson) - Particularly strong theme for seclusion - having the space and time to think.</p> <p>"Sometimes it's nice to be on your own and not to have people around when you are feeling upset [P32]". "Some participants spoke of seclusion as providing helpful isolation."</p> <p>"You can chill out, like get peace of mind. It's quiet [P18]" "Seclusion could also have a positive effect on thoughts and emotions, through its calming influence or by providing time to think and reflect on actions".</p> <p>"It helps de-escalate the situation and helps me reflect on my behaviour [P35]" "Physical restraint could also have a calming effect and aid reflection on ones' actions."</p> <p>"It (seclusion) teaches you not to do it again [P2]". "All three types of coercive treatment could result in participants feeling the incident had taught them a lesson."</p> <p>Unpleasant physical environment (Subthemes = 1. Uncomfortable 2. It's worse than a prison 3. Claustrophobic 4. You don't know how long you will be in there)</p> <p>"It was horrible in there, like rough sleeping for five days [P16]". "You spend hours and hours on your own looking at four walls [P18]." "One emergent negative theme about seclusion concerned the unpleasant physical environment. Participants complained about the seclusion room being cold, claustrophobic and uncomfortable"</p> <p>"It can be weeks and weeks. In prison you're only in a cell for 23 hours of the day [P9]"</p> <p>"It's worse than a prison. It's cold. You feel left out, lonely and empty. They treat you like criminals [P42]". "Being locked in a room made some participants feel as though they were in something worse than a prison."</p> <p>Indifference (Subtheme = 1. It didn't bother me 2. Both good and bad experience)</p> <p>"I think it was OK regardless of who was guilty. I don't mind being secluded [P3]" "It didn't bother me [P 18]". "Several participants said that seclusion had been a 'neutral' experience for them"</p> <p>"I've not thought anything of it [P1]" = physical restraint</p> <p>If indifferent about experiences does that not merge within rest of the themes.</p>
Haw et al., 2011	

Appendix D

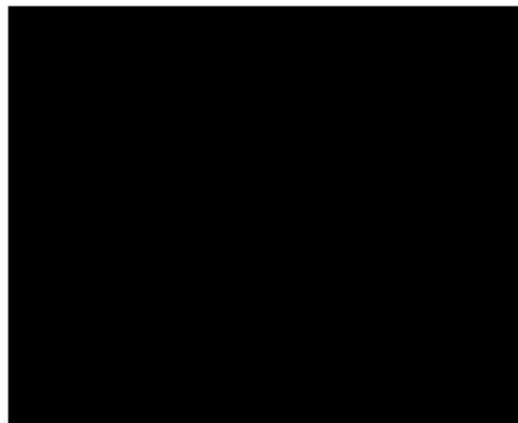
Extract of the table for Phase 6 of the data analysis and synthesis

A	B	C	D
		Theme 1 - Interpersonal relationships	
Subthemes	Effect of other people's attitudes and approach	Being heard and collaboration	Treated with respect and dignity
Hughes et al., 2009	<p>"talking to my mum [...] convinced me that I needed help (Jake)"</p> <p>"Partners and family could have a significant impact on participants' attitudes to involuntary hospitalization and receiving compulsory treatment."</p> <p>Three of the participants had clearly positive perceptions about their relationships with ward staff, describing them as "caring people" (Felicity), who provided a "really high standard of care" (Cherie).</p> <p>"Relationships with ward staff were also reported as variable."</p> <p>"Three other participants perceived staff as custodial, regimented, and devoid of care." "Just doing their job (Ian)" "They used to take away my furniture, so I was left with a mattress on the floor. And, no sheets, no bedding [...] So those were the ways that they used to punish me. (Annie)" "Four participants described very negative aspects to relationships with ward staff, some of whom they experienced as punitive, violating, and abusive. Safety procedures such as removing furniture and personal items to reduce risk were experienced by these participants as punishment".</p>		<p>"I was very aggressive, I was very abusive. That was probably in this environment that I was in [...] I did say to them, if you treat me like an animal, then I'll act like an animal. Why are you doing this, to me? You know, because I was acting, totally out of character. (Sarah)" "Three participants believed that their aggressive orpathological behaviour during involuntary hospitalization was part of a cycle of conflict in their relationships with ward staff and professionals"</p>
Haw et al., 2011	<p>"In my case the nurses feel they have the expertise. They have the grades. They are doing their required job." "Five participants perceived staff as just doing their job."</p> <p>"The staff are so caring and they want to look after you [P20] and I can see why they have to do it. It shows staff care and they don't want you to hurt yourself." "Others felt that staff had a caring attitude even when using a coercive treatment."</p>		<p>"A very wide range of opinions was expressed about staff conducting coercive treatments, though negative views predominated." "We are human beings, not animals, dogs, lions or tigers [P27]." - in relation to IM medication. .</p> <p>"They treat you like criminals. They hurt you to get their own way [P41]."</p> <p>"When they twist your arms and legs back it feels like they hate you [P43]."</p> <p>"Other participants expressed the view that staff were deliberately punishing patients and exerting power over them"</p> <p>" When you are being restrained you feel some staff take the mickey out of you. They say things like you are bad and talk down to you [P39]" "They abuse you. They say I am stupid [P25]". "Some participants described how staff could act unprofessionally... These attitudes could lead to patients losing trust in staff and not wanting to confide in them anymore."</p> <p>"People that restrain should get properly trained [P4]" "On this ward a lot of patients get restrained aggressively without proper techniques [P22]" "It's assault. I hate it. I don't like people touching me anyway. I would rather be injected than have anyone put their hands on me [P31]."</p>

A	H
	Theme 3 - Use of restrictive practices, containment and medication
Subthemes	
Hughes et al., 2009	<p>"without the medication I wouldn't have become well again (Cherie)" "Two participants had positive attitudes towards medication, and believed that it had been instrumental in their recovery. However, the majority of participants interviewed did not like having to take medication, and five participants expressed strongly negative views and experiences in relation to it."</p> <p>"I couldn't talk, my mouth was locking, my mouth was like twisting, it really hurt [...] And I couldn't talk to let them know what was wrong. (Ian)" "Side effects were described by some participants as frightening and physically painful". Some side effects were experienced as life-threatening.</p> <p>"I used to plead with them and plead with them (tearful), please don't give me that [medication]. And of course that used to make me more crazy, because I didn't know where to turn, I didn't know what to do (crying) [...] the more bad I was, the more I knew I was going to be medicated, so the more crazy I got, because I was terrified. (Annie)" "Forced medication was seen by some participants as worsening their distress. This relates to the cycle of conflict described earlier, and suggests that forced medication can be experienced as impeding, rather than fostering, recovery."</p> <p>Includes views of medication that helped, quotes are included regarding experiences of side effects of medication. Also provides quotes for those who found forced restraint medication distressing.</p>
Haw et al., 2011	<p>Participants recognised that seclusion, physical restraint and emergency medication could all prevent violence to ones' self and others.</p> <p>"In a way it stopped me from hurting myself and other's [P51]" - seclusion & medication</p> <p>"It stops you causing more damage to yourself [P32]" - physical restraint</p> <p>"The last one was a good experience. I wasn't doopey the next day and it didn't affect my sight. I calmed down in half an hour. [P19]" "A number of participants found the sedative effect of medication helpful, provided this did not leave them feeling hung-over the following day".</p> <p>"It (haloperidol) calms me down and helps me relax [P39]" "The most common emergent theme about the positive effects of IM medication was its beneficial calming effect."</p> <p>"It helps get your mental state get back on top again [P52]" "It's good. It works. It makes me feel better [P53]. " "Three female participants said it helped them to feel better" (IM medication)</p> <p>"Sometimes it's nice to be on your own and not to have people around when you are feeling upset [P32]" "Some participants spoke of seclusion as providing helpful isolation."</p> <p>"You can chill out, like get peace of mind. It's quiet [P18]" "Seclusion could also have a positive effect on thoughts and emotions, through its calming influence or by providing time to think and reflect on actions".</p> <p>"It helps de-escalate the situation and helps me reflect on my behaviour [P35]" "Physical restraint could also have a calming effect and aid reflection on ones' actions."</p> <p>"It (seclusion) teaches you not to do it again [P2]" " All three types of coercive treatment could result in participants feeling the incident had taught them a lesson."</p> <p>Particularlry strong theme for seclusion - having the space and time to think.</p> <p>"It was horrible in there, like rough sleeping for five days [P16]". "You spend hours and hours on your own looking at four walls [P18]." "One emergent negative theme about seclusion concerned the unpleasant physical environment. Participants complained about the seclusion room being cold, claustrophobic and uncomfortable"</p> <p>"It can be weeks and weeks. In prison you're only in a cell for 23 hours of the day [P9]" "It's worse than a prison. It's cold. You feel left out, lonely and empty. They treat you like criminals [P42]. " " Being locked in a room made some participants feel as though they were in something worse than a prison."</p> <p>" They twist your wrists hard and dig their nails to put your face on the ground. They hold you down hard. You are screaming. They say calm down. It is harsh on us. [P42]" "One very common emergent theme about physical restraint concerned unpleasant bodily sensations. Physical pain associated with being restrained was the commonest sensation reported."</p> <p>"If my asthma comes (when I am being restrained) I will be dead. It worries me [P27]." "Not only did some participants report not being able to move, some said they were held so tightly they could not breath properly. This was particularly distressing for those with asthma."</p> <p>"It knocked me out. I was really drowsy for three days [P57]." "Many participants complained about the physical effects of IM medication. Some participants complained it left them tired and drowsy for days."</p> <p>"I couldn't move [P22]" "I became weak, paralysed [P27]" "Some complained of paralysis, while others complained that it was painful,".</p>

Appendix E

Confirmation letter of NHS ethical approvals



Email: approvals@hra.nhs.uk

16 January 2024

Dear Dr Larkin

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

Study title:	Understanding the interactional context of young people's experiences of disclosure and help-seeking for mental health difficulties
IRAS project ID:	326506
Protocol number:	MR/X003108/1
REC reference:	23/YH/0278
Sponsor	Aston University

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.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

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 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) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

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 standard conditions 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

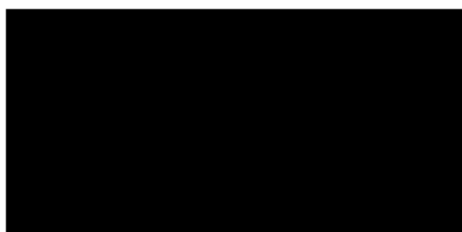
The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

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 **326506**. Please quote this on all correspondence.

Yours sincerely,



Copy to:



Appendix F

Participant information sheet



Study title: Young people's experiences of help-seeking for mental health

Participant Information Sheet

We'd like to invite you to take part in our research study. Taking part in this study is entirely up to you. Before you decide if you would like to take part, we would like to give you some information about why this research is being done and what it would involve for you. Please feel free to discuss the study with other people such as your family or friends. Please contact the study co-ordinator, Shioma-Lei Craythorne, whose contact details can be found at the end of this information sheet, if there is anything that is not clear, or if you would like to ask any questions before making your decision.

What is the purpose of this study?

In this study, we'd like to talk to 20-30 young people about what it's like to seek help from professionals for their mental health.

In this study, young people will be interviewed by a researcher to understand what was helpful and/or not helpful when talking to mental health professionals about their mental health. The information gathered will be used to inform mental health services and improve the experience of help-seeking for young people.

Why have I been invited to take part?

You have been invited to consider taking part because you are currently receiving support for your mental health from [REDACTED] and you are between 15-24 years of age. [REDACTED] is a community and mental health partnership, supporting young people aged 0-25 years.

Who is conducting the research study?

This research study is being carried out by a team of Psychology researchers at Aston University and the University of Birmingham.

What will happen to me if I take part?

You will meet with a member of the research team from Aston University or the University of Birmingham (their names can be found at the end of this information sheet) to talk about your experiences of seeking help for your mental health. **It will take a maximum of 90 minutes.** The interview can be done in person (on the same premises as your community team or in a private meeting room at Aston University) or online using a meeting platform of your choice (on Zoom, Google Meet, for example). You will be able to choose what type of

interview you'd like to have from a list of options: **a talking interview, relational mapping interview, timelining interview, bring-your-own-photos interview**, or a draw-and-talk interview. **A description of all of these interview types is provided separately in the 'Interview Options' document. You can ask the research team to explain the differences if needed.** The researcher will ask you if you would like to have a break during the interview every 20-25 minutes, and you will be able to tell the researcher you would like a break at any time.

After the interview, the same researcher will have a **debrief conversation** with you. This will involve the researcher asking how you are feeling after the interview, and you will be able to share any thoughts or feedback you might have. If any issues or concerns arise during this debrief, the researcher will talk to you about them contacting your clinical team at [REDACTED]. **The debrief conversation will not be recorded.** The researcher will also ask you to provide some demographic data to help with reporting the study findings, however, **you do not have to provide any information you do not wish to.** Some of the demographic information is classed as special category data (for example, being asked to describe your ethnicity).

Do I have to take part?

No. It is up to you to decide whether or not you would like to take part in this study. If you do decide to take part, you will be asked to provide informed consent by filling in a consent form. Your decision to participate or not participate in this study will in no way affect the care you receive from [REDACTED]. We will not inform your clinical team that you have chosen to (or chosen not to) take part, unless you tell us something that causes us to have concerns about your health and/or welfare.

You can stop participating in the research at any time by telling the researcher at any point during the interview and up to 14 days after the interview. If you decide to stop participating, any data collected up to that point will not be used. If you want to withdraw your data after the interview, you can do so by contacting the research team member who conducted your interview and giving your name.

Before the interview, the researcher will send you a consent form to fill in, which you can return via email or post (we can provide a pre-paid return envelope). If you have any questions about the consent form, you can reach out to ask the research team.

Will my taking part in this study be kept confidential?

Yes. A code will be attached to all the data you provide to keep you anonymous. Your real name will be replaced with a pseudonym (false name). We will also do this for any other names of people or places you might mention during the interview.

If we need to collect personal data (such as your real name and contact details) we will only use this for the purposes outlined in this information sheet e.g. to contact you to arrange an interview.

The data we collect from you (audio recordings of interviews and/or images of artwork/photographs you provide) will be stored electronically on a secure cloud storage device. This data may be shared with the research team and used in scientific journals and/or presented at conferences. If you have signed a paper consent form, this will be scanned and stored electronically and securely. You will receive a copy of the consent form by email once you and the researcher have both signed it. The paper version will then be destroyed.

How will the conversation during the interview be recorded and how will the information I provide be managed?

With your permission, the researcher will audio record the interview and take notes. If you choose to have an online interview, it will be done via video conferencing software (e.g. Zoom, Google Meet). You will have the option of having your camera on or off during the interview. We would only record the audio, not the accompanying video, using an encrypted digital voice recorder. If you choose an in-person interview, it will be audio recorded on an encrypted digital voice recorder.

During the interview, you are free to not answer any questions that are asked without giving a reason. For example, if you do not feel comfortable answering a certain question, you can simply say this to the interviewer and they will move on to the next question.

The recording will be typed into a document (transcribed) by an Aston University approved transcription service within 14 days of your interview taking place. It would then be anonymised (any information which could be used to identify people e.g. names of people, places etc. removed) by a member of the research team once they have received the transcript.

Audio recordings will be destroyed at the end of the project.

We will ensure that anything you have told us that is included in the reporting of the study will be anonymous.

Will you inform my healthcare practitioner(s)?

If you tell a member of the research team something that causes them to have concerns about your health and/or welfare, they may need to breach this confidentiality and inform your care coordinator or a member of your clinical team to follow up on any concerns. If this

does happen, the research team member will aim to discuss this with you first so that you are aware that they will be sharing this information.

What are the possible benefits of taking part?

You will have a chance to talk about your experiences and views with a researcher who is genuinely interested in what you have to say. Some people find this to be helpful. Some young people we have worked with also say that taking part in research is helpful, because they know they are helping to improve services for others.

Expenses and payments

If you take part in an interview, you will receive an online £20 Amazon voucher as a 'thank you' for helping with the study. You will receive this voucher via email within seven days of your interview. If you travel to have an in-person interview, you will also be able to have your travel expenses paid back by completing an online Aston University expenses form and submitting a receipt for your travel costs. Please allow up to 28 days to receive your expenses.

What are the possible risks and burdens of taking part?

We hope that you find the interview interesting, and we do not think there will be any disadvantages of you taking part. However, some people can find being asked about their mental health experiences difficult or upsetting. You can choose not to answer any questions and are also free to withdraw or stop the interview at any time without giving a reason. The researcher will end the interview if it is causing you distress. The interview may last up to 90 minutes. Please consider how long you would need to travel for if you wish to have your interview in person. If you decide to take part or do not wish to take part, this will not affect the care you receive from [REDACTED]

What will happen to the results of the study?

The results of this study may be published in scientific journals and/or presented at conferences. If the results of the study are published, your identity will remain anonymous.

A summary of the results can be sent to you when the study has been completed. If you would like a copy, please include your email address in the box at the end of the consent form.

Who is funding the research?

This study is being funded by the UKRI Medical Research Council
(<https://www.ukri.org/councils/mrc/>).

Who is organising this study and how is my data being used?

Aston University is organising this study and will be the data controller for this study. Research data will only be used for the purposes of the study or related uses identified in this information sheet or Appendix A (at the end of this information sheet).

Who has reviewed this study?

This study was reviewed and given a favourable opinion by the Yorkshire & The Humber – Leeds West Research Ethics Committee. Receiving approval from them means that our study follows the accepted ethical standards of a genuine research study.

What if I have a concern about my participation in this study?

If you have any concerns about your participation in this study, please speak to a member of the research team (study co-ordinator, Shioma-Lei Craythorne) and she will do her best to answer your questions. Her contact details can be found at the end of this information sheet.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted, you can contact the Aston University Research Integrity Office at research_governance@aston.ac.uk or via the University switchboard on +44 (0)121 204 3000.

Where can I obtain more information about participating in clinical research?

If you would like advice on any aspect of this study, please contact the [REDACTED] Trust PALS (Patient Advice and Liaison Service). You can also obtain further information from the NIHR (National Institute of Health Research): <https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-take-part-in-a-study.htm>

Research Team and Study Co-ordinator contact details

Shioma-Lei Craythorne – Study co-ordinator and Researcher
Email: [REDACTED]



Michael Larkin – Chief Investigator and Researcher

Sophie Tilston – Researcher

Frances Massey Duckworth - Researcher

Thank you for taking time to read this information sheet. If you have any questions about the study, please don't hesitate to ask the study co-ordinator.

Appendix A: Transparency statement

**Transparency Wording (NHS)****How will we use information about you?**

We will need to use information from you for this research project.

This information will include your name, contact details, age, self-described ethnicity and gender. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our webpage available at www.aston.ac.uk/dataprotection
- by asking one of the research team
- by sending an email to dp_officer@aston.ac.uk

Appendix G

Interview options handout



Study title: Young people's experiences of help-seeking for mental health

Interview options

If you choose to take part in this study, you will be able to choose what type of interview you'd like to have from the options on this sheet. If you would prefer to adapt any of these options, please speak to a member of the research team, and we will do our best to make your idea work. The interview can last up to **90 minutes**, and you can withdraw or stop the interview at any time or without giving a reason. **All options can be done online or in person.**

1. Talking interview

This involves answering questions and talking to a researcher either in person or online. If you choose an in person interview, it can be done on the same premises as your community team your or in a private room at Aston University. If you choose an online interview, this can be on Zoom, Google Meet etc.



Example interview room in Aston University's Institute of Health and Neurodevelopment (IHN)

2. Relational mapping interview

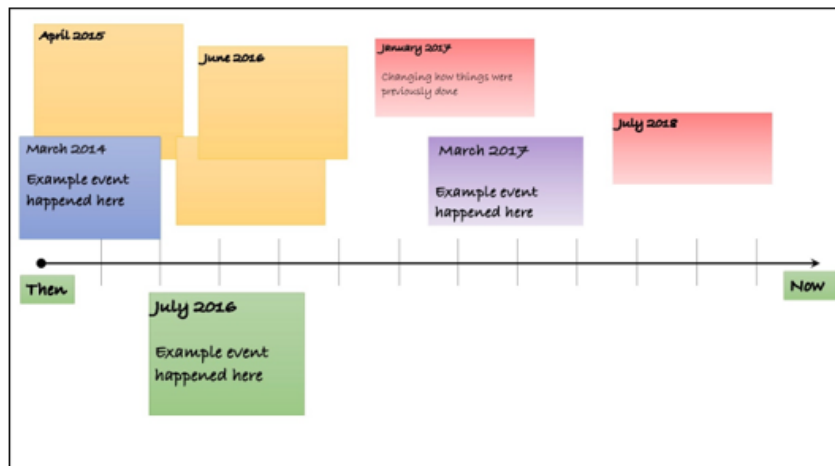
This involves creating a diagram or picture to represent people who you think have been involved in seeking help for your mental health. This could be family, friends, doctors, or counsellors, for example. You would talk to the researcher and answer questions as you are creating the relational map. If in person, all materials (such as paper and coloured pens) would be provided for you.



Example relational map created in a research interview. Katharine Slade©

3. Timelining interview


The researcher would provide you with a blank timeline (a straight line on a page), and you will be able to write or place sticky notes on the page to help you talk about your help-seeking experience. You don't have to remember any specific dates for this, and it doesn't matter if things are not in the exact order they happened.



Example timeline used in a research interview

4. Bring-your-own-photos interview

The researcher would ask you to send some photographs by email that you feel represent your help-seeking experience, and you would answer questions and talk to the researcher about them. The researcher will ask you to email your photographs to them at least 24 hours before your interview – this is so the researcher can print them for you to discuss, if you wish. The photographs could be of objects, or anything else that might represent your experience. Some examples might be a photograph of an item that was particularly important to you during your help seeking experience, a scene, or something abstract/artistic. We ask that the photographs are appropriate for discussion – for example, they cannot contain nudity or anything potentially offensive. If you include people in your photographs, please make sure they are not identifiable (for example, that their faces are not visible). The researcher will blur any other features or aspects of the photographs that might reveal who they are after the interview to protect their identity. There is no minimum or maximum amount of photographs needed, but please bear in mind the interview would



last no longer than 90 minutes and we want you to have the opportunity to discuss all of your photographs.

5. Draw-and-talk interview

You would be invited to draw parts of your experience of seeking help from a mental healthcare professional while answering questions and talking to the researcher. If in person, all materials (such as paper, pens, pencils) would be provided. If online, a digital whiteboard could be used, or you can use your own materials and either show the researcher [your](#) drawing via camera, or send a photograph of your drawing to the researcher via email or using the chat function. If you show your drawing on camera, the researcher will take a screenshot of your work, and will make sure that you are not visible in the image.

Appendix H

Participant consent form



Study title: Young people's experiences of help-seeking for mental health

Consent Form

Name of Chief Investigator: Dr Michael Larkin

Please write your
initials in the boxes
below to show you
agree

1.	I confirm that I have read and understand the Participant Information Sheet [Version 2, 3 January 2024] 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 during the study, without giving a reason and without my medical care or legal rights being affected.	
3.	I understand that I do not have to answer every interview question and I can stop any time I like without giving a reason.	
4.	I understand that I am able to withdraw my data up to 14 days after the interview by contacting a member of the research team using the contact details provided in the Participant Information Sheet [Version 2, 3 January 2024]. After this point, your data will have been included in our analysis and it will not be possible to withdraw it.	
5.	I agree to my personal data and data relating to me collected during the study being processed as described in the Participant Information Sheet.	
6.	I understand that if during the study I tell the research team something that causes them to have concerns in relation to my health and/or welfare they may need to breach my confidentiality.	
7.	I agree to my interview being audio recorded and to anonymised direct quotes from me being used in publications from the study.	
8.	If I choose to donate photographs and/or create artwork for the study, I agree to potentially identifiable information in them being removed or obscured and used in publications from the study.	
9.	I agree to take part in this study.	

Name of participant Date Signature

Name of Person receiving consent. Date Signature

If you wish to receive a lay summary of the research project upon its completion, please provide an email address to which the summary can be sent.

Email address:

Appendix I

Semi-structured interview guide

Study title: Young people's experiences of help-seeking for mental health

Interview Guide

Before the interview begins, the researcher will have a short conversation with the participant. They will then remind them what the study is about and ask if they have any questions or concerns before proceeding with the interview. The researcher will then answer any questions and address any concerns the participant may have. The researcher will remind the participant that the interview will be audio recorded and ask if they are willing to continue with the interview. The researcher will then remind the participant that they do not have to answer a question if they do not wish to and can end the interview at any time without giving a reason.

1. Can you tell me a bit about yourself and your experiences of mental health?

Possible prompts: When did you first start to experience challenges with your mental health? What was going on in your life at the time? What made you seek help for your mental health?

2. What type(s) of professionals have you spoken to about your mental health?

Possible prompts: For example: a GP, counsellor, psychologist, psychiatrist, teachers, religious leaders, social workers, any other members of your community? If so, what was that experience like for you?

3. How was your first experience of speaking to a professional about your mental health?


Possible prompts: Was it as you expected or was it different to how you envisioned it? If so, how?

4. Before you have a conversation with a mental healthcare professional, how do you usually feel? What thoughts run through your head?

Possible prompts: How do you usually feel the day before an appointment? Do you plan what you want to talk about before you arrive?

5. How do you think your mental health is understood by professionals?

Possible prompts: How confident did you feel that they were able to help you/had the knowledge to help you? Have there been times you felt listened to/understood by a professional? Have there been times you did not feel listened to/understood by a professional? Could you tell me what happened?



6. How do you feel after you've had a conversation with your mental healthcare professional?

Possible prompts: Do you feel the same as before you went, or different? What thoughts come up for you after the conversation?

7. When you are [in the room/talking online] with a professional, what do you feel?

Possible prompts: How would you describe the feeling to someone who has never spoken to a professional about their mental health before?

8. After meeting with your mental healthcare professional, how do you feel as soon as you leave the room or building/close the video call?

Possible prompts: What are the outdoor surroundings like? What do you usually do after you've left?

9. What do you think are the most helpful things that mental health professionals have said to you during your conversations with them?

Possible prompts: Has a professional ever given you advice that you thought was important or memorable? How did this make you feel?

10. Is there anything about your appointments more generally that you think is quite helpful?

Possible prompts: What do you usually take away or remember from your appointments?

11. What are your thoughts on the environment your conversations with mental health professionals take place in?

Possible prompts: What is the room like? How does it make you feel? Is there anything about it you'd change? If they take place online, how do you feel in the environment you are in? How about the environment the professional is in (if you can see them on a video call)?

12. What do you think are the least helpful things that your mental healthcare professional says or does?

Possible prompts: Is there anything you dislike about your appointments? Is there anything you disagree with?

13. What recommendations would you make if you had the opportunity to provide some advice to mental healthcare professionals?

Possible prompts: What would you suggest they should do in the future for other young people? What would you suggest they do differently? What do you think works well?

14. What advice or suggestions would you give other young people who might feel nervous about seeking help for their mental health?

Possible prompts: Thinking back to your first appointment, how did you feel before you went? Did you speak to anyone about it? If so, who? What made you decide to attend the appointment? Did you ever think about cancelling your appointment or not going? Why was this?

If the participant has chosen an interview option that involves **relational mapping**, **timelining**, **bring-your-own-photo**, or **draw-and-talk**, the researcher may ask specific questions tailored to these additional options and what the participant has produced. Example questions are provided below.

Relational mapping interview

- Could you talk me through how you have chosen to represent the people who have helped you with help-seeking?

Example prompts: I've noticed this section is smaller/larger than the others – could you talk about what this means to you? The people/images over here are quite close together – could you explain why you decided to group them like this?

- I can see you've drawn [x] on your map. Could you explain to me what this means to you and your help seeking experience?

Example prompts: Was there a particular reason you chose to use this colour/shape? Could you tell me how this section links with the images/shapes above it?

Timelining interview

- I can see you've placed this event in the middle of your timeline and it's quite large. Was this event significant to you?

Example prompts: If so, what were things like before and after this happened? Can you remember what else was going on in your life when this happened? Who were you in contact with? How did you feel when this particular event happened?

- I've noticed there are lots of events marked on this part of the timeline. Could you talk me through what was going on for you at this point in time?

Example prompts: How were you feeling when this was happening? Who did you think was most/least helpful during this, and why?

Bring-your-own photo interview

- Could you talk me through what this photo represents to you and your help seeking experience?

Example prompts: Can you remember when it was taken? What memories do you think of when you look at this photo? Could you explain the link between this photo and any mental health professionals you have spoken to?

- [Example – participant shows a photograph of a park] Which part(s) of the photo are the most important to you?

Example prompts: What was happening around you when you took this photo? Were you with anyone when you took this? If so, who? What does this park mean to you in relation to your mental health and help seeking? How do you feel now when looking at this photo?



Draw-and-talk interview

- In this part of your drawing, you've included an image of [x]. What does this represent to you and your experience of help seeking for your mental health?

*Example prompts: What were you thinking about when you drew this part?
Why did you choose to put it there? Is there anything important about its size?*

- This section here looks quite vibrant. Could you tell me why you chose to use these colours?

Example prompts: Do the colours mean anything to you and your experience of talking with a professional about your mental health? What do the colours represent?

- [At the end of the interview] How did you feel as you were drawing this piece?

*Example prompts: What was that like? Did it turn out as you had planned?
What did you enjoy most/least about it?*

Appendix J

An extract of some of the personal experiential themes being created from the experiential statements.

Section 1 (Top):

- Homely vibe – feels more comfortable to talk – compared to being really formal which feels less helpful. P18
- Homely vibe – feels comfortable to talk about difficult experiences “bad things”. P18
- Preference of environment at the base, not home – increases engagement. P21
- Feeling calm which is created by both Debra and professionals. Both taking part in the conversation P18
- Beneficial to be together in person P17
- Would make changes to the environment – not professional interactions. –Temperature is hot and more colour. P22
- Professional appearance – clothing can make professionals more relatable and human, compared to uniforms/tunics/ formal clothing P22
- Calm environment increases engagement, this includes professionals non-judgemental stance, creates the space to be open. P22
- Travelling to the appointment is an “adventure” – change of environment and actively travelling is a positive experience P21

Sticky Note 1 (Top Right):
The environment and non-verbal communication can influence engagement with professionals

Section 2 (Middle):

- Professionals have an understanding of Debra’s experiences, know of evidence about her experiences and can provide help/support P16
- Family didn’t know about mental health or friends.
- Professionals have experience of hearing about mental health, they have knowledge which can be helpful and want to help. P7
- Professionals have knowledge and expertise. Others that don’t have this knowledge are less able to understand P19
- Feeling understood builds the relationship, and makes Debra feel positive, but also relief/outlet. P24
- Professionals are the right people to talk to. – can provide support and seek help. P19

Sticky Note 2 (Middle Right):
Knowledge and expertise provided by professionals made for a positive experience

Section 3 (Bottom):

- Mum sits in appointments and this increases her understanding and their communication outside of them. P16
- Mum observing appointments increases her understanding of how Debra feels. P17
- Seeks reassurance from mum prior to appointments P14
- Medical appointments – blood tests that doesn’t like, mum reassures and treat after P25
- Professionals supported with systems who didn’t understand (school/stigma). P26
- Community support with other services was a positive interaction – supporting Debra’s understanding of her experiences. P4

Sticky Note 3 (Bottom Left):
Professionals provide support to develop others understanding (School, family etc)

Appendix k

An extract of the group experiential themes being created from the different personal experiential themes

<p>An extension of her hobbies and interests into other areas of her life</p>	<p>Professionals provide access to groups and peer support. This provides connection, understanding and empathy, whilst having fun in activities. P8 Ward – connecting with people during activities and hobbies P11 Interest and hobbies as a coping strategy, form of communication and sense of identity and self-understanding P13 After appointments treats self to something she enjoys. P29 Do more of: Tangleline items, creativity and physical plans/discussions to create a shared understanding. Inclusive of expression if difficult to articulate verbally P26</p>	<p>The importance of being seen as a "whole person" by professionals</p>	<p>Professionals "learn about" and get to know you as a person and use a person centred approach "tailor the support to you" P5 Positive experience with professionals and being able to "talk to them" which increases their understanding of her and her experiences. P14 Professionals provide connection and predictability ("know" each other and shared interests) when she knows them P7 Developed her understanding of how mental health is related to all aspects of her life – family, spare time etc. Initially didn't think this was related when talking to professionals P20 Advice to others – seeking help has been positive. Professionals they listen and provide person centred support "taller to you and your goals" P27 3 monthly reviews plans topics that are important to talk about (MEd, education, employment and how she feels). Monthly appointments are more informal P7 Feels less heard regarding side effects of medication... What is physical health and what is mental health? – disconnect which causes frustration and anxiety around her health. P21 Helpful to have "communication" between physical and mental health professionals. Increase being seen as a "whole person" by professionals, not fragmented parts. P15-16</p>
<p>Professionals provide social connection with peers and activities of interest</p>	<p>Professionals found the activity and clubs – wouldn't have known about these or how to access them without the support. P20 Peer clubs through professionals has provided social connection and an enjoyable activity. P6-7 Groups with peers and professionals are a positive experience – increasing confidence and socialising with peers P7 Professionals to keep offering support with activities – pool. Positive experience, loves the game, something to look forward to and sense of connection with peers P20 Professionals provide links to the pool club – enjoyable activity and a sense of purpose P16-P17 Always had limited social connections – worries about the wrong crowd (family narrative as well). Home feels safer than socialising. P7 Access and nerves regarding the social interactions – has limited social interactions. P6</p>	<p>Professionals have a positive impact on his mood following meetings and understand him as a person</p>	<p>First experience talking to professionals was happy – "wanted help", different people to talk to as well. P5 Advice to others "you versus you" seeking help is positive and receive support/help. P18 Talking to professionals creates an emotional change – shift in his mood P11 Relief after appointments to talk about his experiences and emotions P12 Felt listened to based on the help support he has received. Medication and taking him out to the community – accessing the community and connecting over activities is important. P8 Advice to professionals to be happy and confident in their approach – makes this more comfortable to talk. Their nervous – you feel nervous P17-18 Professionals have helped by providing medication and having someone who understands him and his mental health, but also understand his interests/hobbies (adult person). P7-8 Professionals understand mental health – practical understanding of medication which has been effective. P7 Professionals make it easier to talk by getting to know him as a person and share their interests – both collaborative. P6</p>
<p>Professionals provide connection through community access and activity</p>	<p>Most helpful support from professionals is appointments in the community. Sense of connection and reduced isolation from his room. P11 Prior to professional support was staying in the house "stuck", "boring", "laid" – due to worries he was experiencing. P14 Experience isolation – leaves the house with family other than professionals P15 Lots of different activities linked to his interests – sports/active tasks. P20 Professionals create an environment he feels more comfortable to – going out and engaging in activity. This creates a positive experience "smiling, laughing" P6 Professionals offer support – ask what he would like that support to look like and offer to go out places. Not just the talking but the experience of going places provided positive experiences. P9 Appointments in the community and doing activities create a calming environment where he is able to talk without this becoming too overwhelming. P20 Professionals provide support with social contact and visits in the community. Talking is the more difficult aspect of the contact P3 Professionals provide help with connection, positive relationships, but connection in the community, reducing isolation "feel free" positive emotions. P18 Appointments in the community are enjoyable – experiencing the physical sensations of the weather P15 Weather has a calming effect, feels happy being in the community. P15 Appointments feel fun – activities together, encouragement and competition. P14 "Noticed at home with family and activities in the community are positive for his mental health. P12</p>	<p>Professionals provide support to develop others understanding (about and family)</p>	<p>Mum sits in appointments and this increases her understanding and their communication outside of them. P16 Mum attending appointments increases her understanding of how Detox helps. P17 Seeks reassurance from mum prior to appointments P14 Medical appointments – based with that doesn't like, mum reassures and that after P25 Professionals supported with systems who didn't understand (school/night). P26 Community support with other services was a positive interaction – supporting Detox's understanding of her experiences. P4</p>
<p>Professionals can help change your experience through medication and accessing activities and employment</p>	<p>After help seeking was provided medication and has visits from professionals who also support access activities in the community e.g. gym. P2 Professionals support finding activities/ sports teams he is interested in. P4 Has ongoing support to look for employment. P10 Wanted the medication – removed the difficult experience he had and now he longer has these experiences. P5 Medication increased his motivation and engagement in activities, socialising again and accessing the community and shops he enjoys. P1 Finds this connection positive P7 No advice to professionals they are the experts. He wouldn't change anything about his care. P11 Help is free and it can change the situation "help to find a cure" – lots of help from professionals P11 Professional care – obvious through their actions and their "help" – takes notes, provide medication, actively look to find things he enjoys, including gym and employment. P5</p>	<p>Professionals normalise mental health and provide a sense of hope for future goals</p>	<p>Expressing how you feel is positive, creates a sense of a relief and space to think about the future. P21 Feels happier after speaking to professionals – focuses on the plans for the rest of the day. P16 Professionals normalise mental health – can still look forward to future plans and goals. P16 Reassurance from professional reduces anxiety (changes in physiology) like weight has been lifted. (relief) Can then focus on the rest of the day. P11 Professionals normalise mental health – he can still enjoy the things he wants to do. More helpful. P16</p>
<p>Activities and educational courses provide a sense of connection and meaning. Peer support in the community also provides connection (right time)</p>	<p>Courses and activities supported by professionals increase connection and access to the community. P8 Professionals provide support with college courses of interests which have been a positive experience P8 Peer support group activities have been critical in reducing isolation – "being involved" – creates a sense of belonging P27 Importance of continuing to offer social groups and support with employment – provides connection and a sense of purpose/achievement in the community. Makes the comparison to previously isolating herself. P26 Groups promoted through professionals create connections with own age group with similar experiences, similar age related focuses and feels safe to talk about "struggles" due to their understanding. P18 Professionals and peers from groups have a shared understanding, which other peers do not. Less relatable. P23 Social contacts in the community, meeting for coffee or attending range of social groups of activities of interest – connecting with peers with similar experiences. Positive experience. P17 OT on the ward provided "fun" activities and learning new activities – not available daily P11 Restrictions contributed to the boredom and limited activities which could increase frustration. P10 Being locked in restricted and no access to "fresh air", sunlight – focus on the weather and connection of outdoors – even if limitations to opening windows "mesh on them" P9 Unwell in hospital, which impacts recognition of this. Recalls medication, being tired, and the "impact" of peers – didn't like hospital P8 Environment – temperature can fluctuate. Medication could be more personalised – artwork from young people using the service P24</p>	<p>Professionals provide a stepped approach to care and facilitating hope for the future</p>	<p>Compares himself to "normal people" and how they would cope, using different coping styles. Professionals support the coping skills. P16 Professionals approach is a positive experience – talks to family but it isn't the same – not articulated in the same way P12 Mental health is "normal" to professionals. "Some what they are dealing with" – experience of mental health P8</p>
<p>Professionals provide connection through creating community groups, education + employment</p>	<p>Professionals provide support for future thinking and future focus – feels this helpful. P16 Professionals listen and remember things about you as a person. They are motivating, reassuring and "cheer you up". Provide positivity when it can be hard to see a horizon. P12 Professionals encourage Marnah to think about the future which is positive as she can find this challenging as she feels "different" P23 There's been a lot of change and professionals have supported with this and create new plans. P25</p>	<p>Professionals provide hope for the future and support future planning</p>	<p>Feels happy he is progressing which is symbolised by transitioning across teams and frequency of contact – home treatment to less visits from D. P7 "Released" from hospital – visits by home treatment team – 3 let days a week. Structured days for visits. P6 Professionals home visits were helpful to talk, but also practically to deliver medication. P5 (I service for three years feels reassuring and positive. Provides hope for the future. Feels confident for the future, that the future is there" P7 Receiving help has been positive – plan to seeking help, less hope about the future, "nothing to look forward to" P18 Keep trying to seek support as there is a "future" help seeking provides a hope for the future and support for the future. P18 Professional understand and offer support. This can be direct or through other professionals – activities and finding employment. This a positive experience P25</p>