

**Young people's narrative accounts of participation  
in the design and delivery of NHS mental health services**

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## Abstract

**Rationale and Aims:** Youth participation in the design and delivery of mental health services has continued to gain momentum both nationally and internationally over recent years. However, research in this area has largely focussed on discrete participatory projects and service outcomes, rather than the experiences of young people involved. This research looks at the ways in which young people story the experiences and meaning of participation in the design and delivery of mental health services within the NHS.

**Methods:** A qualitative approach was used in order to explore the accounts of six young people with experience of participating in mental health service design and delivery. Face-to-face semi-structured interviews were held with young people, each lasting approximately 60 minutes. Interviews were audio-recorded, transcribed, and analysed using narrative analysis. Narrative analysis was used to explore the content, performance, context and discursive elements of the accounts individually and collectively. Consideration was given to the social and political contexts that arguably shaped these accounts. A participatory research design was used at supervisory level and across different stages of the research. This allowed collaboration on areas such as identifying and prioritising interview questions, co-designing information material, input on analysing and interpreting data, and disseminating the findings.

**Analysis:** Transcripts were read multiple times as a way to develop individual summaries and construct an analysis across all of the accounts. Reflective notes were made noticing content, identity performance and context (Wells, 2011). Particular attention was paid to preferred identities around what kind of stories were told (Riessman, 2008) and the way in which narrators employed or challenged dominant societal discourses (Wells, 2011).

**Findings:** The findings demonstrate the ways in which the young people taking part construct rich, multi-layered narratives with the potential to enhance understanding of their experience of service participation in mental health service delivery. Four main storylines were observed across accounts. These were stories of 1. Moving into social spaces and holding out a helping hand; 2. Having to become the 'right fit' for participation; 3. Repositioning from patient to person; 4. Strengthening alternative identity stories through relationships. Strategies of resisting dominant narratives around 'patient' subjectivity and societal views of what it means to be a young person are highlighted, with survivor discourse key for constructing an alternative subjectivity.

**Implications:** The findings are discussed with reference to existing literature along with their potential bearing for clinical practice, strengths and limitations of the methodology are considered, and directions for future research, policy, and service delivery specified.

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Artwork by Nadia<sup>1</sup>

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<sup>1</sup> Pseudonym has been used to ensure anonymity

## Contents

Abstract .....	1
Acknowledgements .....	2
Chapter One: Introduction and Systematic Literature Review .....	7
1.1 Chapter Overview .....	7
1.2 What drew me to the area of research .....	7
1.3 Epistemological Position .....	8
1.4 A Reflexive Introduction to the Research .....	9
1.5 Participation .....	10
1.5.1 Defining Participation .....	10
1.5.2 Overview of Conceptual Frameworks of Participation .....	11
1.5.3 Political and Ideological Context of Participation in Mental Health Services .....	12
1.6 Young People and Participation in Mental Health Services .....	14
1.6.1 The Conceptualisation of Young People .....	14
1.6.2 Young People and Mental Health .....	15
1.6.3 Youth Participation in Mental Health Services .....	16
1.6.4 Youth Participation in Practice .....	17
1.6.5 The Impact of Youth Participation .....	18
1.7 Summary .....	19
1.8 Systematic Literature Review .....	20
1.8.1 The Aims and Scope of the Systematic Literature Review .....	21
1.8.2 Review Strategy .....	22
1.9 Literature Review .....	26
1.9.1 Participation through the Lens of Young People .....	27
1.9.2 Participation through the Lens of Researchers .....	38
1.9.3 Participation through the Lens of Clinicians and Managers .....	39
1.10 Quality Evaluation of the Literature .....	41
1.11 Limitations of Research and Critical Reflections .....	42
1.12 Conclusion .....	44
1.13 Rationale and Aims for the Study .....	45
1.13.1 Rationale for the Study .....	45
1.13.2 Aims of the Study .....	46
Chapter Two: Method .....	47
2.1 Overview .....	47
2.2 Qualitative Research .....	47

2.2.1 Epistemological Position.....	48
2.2.2 A Case for Narrative Inquiry .....	49
2.2.3 A Discursive Narrative Approach to Analysis.....	51
2.2.4 The Choice of a Narrative Approach .....	52
2.3 Design .....	53
2.3.1 Participatory Research Design .....	53
2.3.2 Sampling Strategy .....	58
2.4 Ethical Considerations .....	60
2.4.1 Process of Ethical Approval.....	60
2.4.2 Confidentiality and Consent.....	60
2.4.3 Potential Distress .....	61
2.4.4 Remuneration.....	61
2.5 Procedure .....	61
2.5.1 Recruitment.....	61
2.5.2 Young People Taking Part .....	62
2.5.3 The Interview Process: Collecting Stories .....	63
2.6 Analysing Young People's Stories .....	64
2.6.1 Interview Transcription.....	64
2.6.2 Framework for Guiding Analysis .....	65
2.6.3 Analytic Process.....	65
2.6.4 Gaining Alternative Perspectives.....	67
2.6.5 Representing the Narratives .....	69
2.7 Credibility, Rigour and Pragmatic Use .....	69
2.7.1 Reflexivity.....	70
Chapter Three: Findings .....	72
3.1 Overview.....	72
3.2 Introducing the Individual Accounts.....	73
3.2.1 Drew's Story .....	73
3.2.2 Ana's Story .....	75
3.2.3 Rowena's Story .....	77
3.2.4 Jordan's Story .....	80
3.2.5 Beth's Story .....	82
3.2.6 Nadia's Story .....	84
3.3 Storylines .....	87
3.3.1 Moving into social spaces and holding out a helping hand.....	88

3.3.1.1 Self as Social .....	89
3.3.1.2 “They kind of get me” .....	91
3.3.1.3 Self as Helping Others .....	93
3.3.2 Having to become the ‘right fit’ for participation .....	94
3.3.2.1 Youth participation offered to those “well enough” .....	94
3.3.2.2 Youth participation taken away: perpetuating power differentials .....	96
3.3.2.3 Self as Heard .....	97
3.3.3 Repositioning from Patient to Person .....	99
3.3.3.1 “We are both just people” .....	100
3.3.3.2 Stepping in and out of an illness narrative .....	101
3.3.3.3 Flipping the Power Imbalance .....	102
3.3.4 Strengthening alternative stories through relationships .....	104
3.3.4.1 Calling deeper on courage and stepping into new realms .....	104
3.3.4.2 “Wow, I can actually do stuff:” Empowerment and building confidence.....	106
3.3.4.3 A Message to You.....	108
3.4 Summary .....	109
Chapter Four: Discussion.....	111
4.1 Overview .....	111
4.2 Discussion .....	111
4.3 Clinical Relevance and Implications.....	126
4.3.1 Young people participating in mental health service design and delivery .....	126
4.3.2 Routes to Participation within Services .....	128
4.3.3 Practitioners currently involved in the shaping of service participation .....	129
4.3.4 Service Implications.....	131
4.3.5 Policy Level Implications .....	132
4.4 Methodological Reflections .....	134
4.4.1 The Use of Interviews .....	134
4.4.2 The Use of Narrative Analysis .....	136
4.4.3 The Use of Participatory Methods .....	138
4.4.4 A Reflexive Approach to the Research.....	139
4.5 Future Research Directions .....	140
4.6 Conclusions.....	142
References.....	144
Appendices.....	156
Appendix A: Literature Review Process.....	156

Appendix B: Framework for Quality Assessment (Elliott et al., 1999).....	159
Appendix C: Examples of Quality Evaluation of Literature Reviewed.....	161
Appendix D: Research Ethics Committee Approval Letter.....	164
Appendix E: Health Research Authority Approval Letter.....	168
Appendix F: NHS Trust Confirmation of Capacity and Capability.....	174
Appendix G: NHS Trust Right of Access Letter .....	175
Appendix H: University of Hertfordshire Sponsorship Letter.....	177
Appendix I: Project Summary Report Sent to REC & Trust R&D.....	178
Appendix J: Letter to GP .....	182
Appendix K: Information Sheet.....	183
Appendix L: Consent Form .....	188
Appendix M: Debrief Sheet.....	190
Appendix N: Research Invitation Letter and Email.....	192
Appendix O: Interview Guide.....	194
Appendix P: Extract from Interview .....	197
Appendix Q: Consent Form for Inclusion of Transcript.....	198
Appendix R: Extract of Data Analysis Process.....	199
Appendix S: Evaluation of the Present Study .....	201
Appendix T: Reflective Log Extract.....	204
Appendix U: Letter/Summary of Stories and Storylines for Young People Taking Part .....	206
Appendix V: Young People's Messages to Young People Accessing CAMHS .....	208

## List of Tables and Figures

### Tables

Table 1. <i>Summary of Final Search Terms</i> .....	23
Table 2. <i>Summary of Studies Identified for Review</i> .....	29
Table 3. <i>Demographic Information of Young People Taking Part</i> .....	63
Table 4. <i>Storylines and sub-stories</i> .....	88
Table 5. <i>Inclusion and Exclusion Criteria</i> .....	156
Table 6. <i>Search Terms for Literature Review</i> . .....	157

### Figures

Figure 1. <i>The process of study selection</i> .....	25
Figure 2. <i>Wonderwoman. Artwork by 'Nadia'</i> .....	87
Figure 3. <i>Flowchart for Literature Review Process</i> .....	158

## **Chapter One: Introduction and Systematic Literature Review**

### **1.1 Chapter Overview**

This chapter begins with an overview on current understandings and conceptual frameworks of participation. The wider historical and socio-political context which mental health service participation sits within will be discussed. Young people and their societal position will also be considered and how this might relate to participation in mental health service design. A brief overview of youth participation in practice will be presented. Existing literature exploring experiences of youth participation in mental health service design and delivery will be reviewed, followed by a discussion on what research is lacking in this field and the clinical relevance of this research.

### **1.2 What drew me to the area of research**

I hold the view that it has become increasingly important to illuminate how the 'expert psychologist' position can perpetuate unhelpful, and arguably harmful, power dynamics. This relates to the argument that the person who is positioned as the 'client' in relation to the professional 'expert' is reduced to occupying a disempowered position within the dominant professional discourse (Foucault, 1977, 1980). I see being in both a position of 'researcher' and 'clinician' a privileged opportunity to investigate and explore with people the origins of their difficulties and consider possibilities for change, but also recognise the responsibility this brings, that privilege becomes supremacy when we neglect our responsibility for the other. As a white researcher and clinician working in London with clients from numerous ethnic minority backgrounds, I am aware that I am representing a dominant culture with a colonial past and working within one of the least diverse health care professions in the NHS. I am also aware of the power differential which pervades interactions as a result. As a trainee clinical psychologist in the process of developing and shaping my

own professional journey, I feel strongly about seeking opportunities to work in partnership with people accessing services, yet recognise the importance of continuing to be aware of what it means to 'involve' people.

I have continued to try and find ways to learn how power influences what is accepted as knowledge in mental health services and how marginalised or alternative knowings can be silenced or appropriated. This has led me to become increasingly interested in participatory approaches. Within this project, I am grateful to have the opportunity to work with Leann Stollenwerk, research co-supervisor. Leann has the dual experience of accessing child and adolescent mental health services and participating in the design and delivery of such services. It is felt if the traditional division between 'us' (professionals) and 'them' (those who access services) is to be challenged, both clinicians and researchers need opportunities to learn in a variety of ways from the experiences of those accessing mental health services, both bringing valuable and different assets to the field.

### **1.3 Epistemological Position**

My epistemological position is rooted in the continued questioning of the nature of knowledge, who is the 'knower' and whose knowledge counts. I hold the view that what we regard as 'truths' are constructed within our particular time, place and historical context (Burr, 1995), in that all information about the world is filtered by our own constructs, allowing us to develop a personal representation of the outside world. I hold the view that language and the way we use language does not describe the world in a neutral way, instead has implications for the speaker and the subject (Burr, 2015). Constructing 'professionals' and 'service-users' in dichotomous ways has consequences bound up in power relations, which can give different rights and claims to 'truth' (Campbell, 2009). I see the value in local knowledge constructed between people who actively engage in its development, holding the

position that knowledge is seen as relational. This relates to privileging knowledge developed alongside communities and prioritising work with community groups using value-led and participatory work (Burton, Boyle, Harris, & Kagan, 2007). Therefore, this research project is not undertaken in order to discover an answer or an attempt to investigate something 'out there,' but to better understand the stories of young people's experiences of participation in the design and delivery of NHS mental health services.

#### **1.4 A Reflexive Introduction to the Research**

Throughout the research project, I attempt to make it clear that the research is written from the position of a reflexive researcher in the strategic use of first and third person pronouns. This is a way of reminding the reader of my presence and influence on the research process. It can be said that having an honest exploration of personal values and interests, and understanding their effect on the area of research can work towards balancing the "tension between involvement and detachment" (Berger 2015, p221). Finlay (2002) explains qualitative research should not be about detached scrutiny. Instead, there is need to recognise that knowledge is actively constructed and that the world and our experience of the world cannot be separated. Reflexivity is important as a way of attending to my own ideas, experiences, preconceptions and my relationship to youth participation. For example, it is important to question the ways in which my values around participatory practices could cause me to interpret the data in an overly positive light and what I might be more drawn to within people's stories. It is therefore important to show careful consideration and be explicit in any assumptions brought into the analysis, highlighting the contextual factors that shape (and are shaped by) interpretation.

## 1.5 Participation

### 1.5.1 Defining Participation

The process by which citizens take part in and influence their own mental healthcare and wider service provision, has been described using a number of terms. These include participation, co-production, involvement and consultation, which are used interchangeably in academic literature and clinical settings. Further terms include service co-design and co-planning, co-commissioning and co-delivery, through to co-assessment, co-monitoring and co-evaluation (Bovaird & Loeffler, 2013).

The language and key concepts of participation are often contested, and the terminology and ideas criticised as being vague or poorly defined (Beresford, 2005). Various authors have offered definitions of participation in mental health care that can be said to demonstrate a degree of confusion and overlap. Tambuyzer, Pieters and Van Audenhove (2011) identify participation as the “involvement in decision-making and active participation in a range of activities (e.g. planning, evaluation, care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals” (Tambuyzer et al., 2011, p. 142). Cutler and Taylor (2003) refer to ‘participation’ and ‘involvement,’ defining the terms as taking part in decision-making. They recognised the varying degrees of ‘taking part,’ from giving opinions on areas that are predetermined, to generating the agenda and making decisions. Lansdown (2001) distinguishes between aspects of participation, namely ‘consultative processes’ (young people having no control, activities are initiated, led and managed by adults) and ‘participatory processes’ (collaboration with adults and ultimate sharing of power).

With the lack of consensus over terminology, participation will be the term used in this research. This is to respect the language used by the young people taking part and

involved in the research. It was felt not helpful to take away from the discourses used by those taking part but to remain respectful to the context the research sits within.

### **1.5.2 Overview of Conceptual Frameworks of Participation**

A number of models have been proposed over the years, with Arnstein (1969) and Hart (1992) both influential in their contributions to understanding participation. Arnstein's ladder of participation (1969) describes eight levels from 'manipulation of citizens' as a form of 'tokenism,' to 'citizen control,' which represents full and meaningful participation. Arnstein (1969) recognised the ladder is based on a conceptualisation that "participation is a categorical term for power" (Arnstein 1969, p. 216), with the ladder being a guide to seeing who has power when important decisions are being made. Similarly to Arnstein, Hart (1992) utilises a ladder of participation as a way to highlight the varying degrees which organisations can engage young people moving from being passive to having full control. Hart (1992) argues that the ultimate goal is complete and ongoing collaboration with 'adults of power' as opposed to child mobilisation and control. Both Arnstein (1969) and Hart's (1992) eight-level ladder are considered valuable for considering participation beyond the binary notion of participation versus non-participation. It can be said however, the linearity of a ladder principle suggests the relationship between the levels is static and hierarchical, which may not always be the case 'on the ground' in services (McAuley & Brattman, 2002). Therefore, the model has been described as over simplified with the potential to overlook context (Sloper & Lightfoot, 2003).

Treseder (1997) offers an alternative model, aiming to illustrate that there is neither a progressive hierarchy nor a particular sequence in which participation occurs. The degrees of collaboration are presented as the spokes of a wheel, with no form of participation identified superior to another. Treseder (1997) agreed with others that the nature of participation is

complex and contextual (Abrioux, 1998). The model provides an understanding of different degrees of involvement, such as *consulted and informed*; and *child-initiated and directed*, each degree having the potential to be most appropriate within a certain context. Treseder (1997) also argues there should be no limit to the involvement of young people, but highlighted the importance of those involved to be empowered adequately to be able to fully participate.

Whilst the models of participation recognise power differences between young people and service providers, it can be said there is less recognition of the political context, attitudes of professionals and level of resources needed (Beresford, 2019).

### **1.5.3 Political and Ideological Context of Participation in Mental Health Services**

Participation is not politically neutral. It is important to situate participation within its ideological and political relations to consider potential competing interests of those involved, particularly between key stakeholders, government, its research institutions, family carers, and those accessing and working within services.

Beresford (2002) identifies two main strands of participation, namely consumerist and democratic participation. Although there can be a level of overlap in what they try to achieve, they can be seen to be based on different ideological approaches. The consumerist approach, arguably dominating current health and social care policy in an increasing capitalist society, utilises a market model, referring to services as 'products' and those accessing services as 'consumers' entitled to quality and choice. This approach can be said to be most closely identified with the political right as its interests relate to maximising profitability and effectiveness. Participation, as a consumerist approach, can be viewed as aligning with 'product improvement,' with the use of market testing and consumer feedback, and final decision-making remaining with governing bodies (Beresford, 2002). This overlaps with

ideas of outcome-focused working and 'evidence-based practice,' as seen in the national initiative, *Improving Access to Psychological Therapies* (McHugh & Barlow, 2010).

Therefore, participation aims at improving the quality of services by making them responsive to the needs and preferences of those who use them.

The democratic approach is said to be embedded in a broader historical, political-social human rights framework. Beresford (2002) describes the approach as challenging power inequality with an aim to increase the say people have in systems affecting them. Direct involvement in decision-making within the services is key, with this taking place in the planning, management and review of services. The approach seeks to transfer power and control. This is in line with the survivor movement, in the way that it is "liberatory" and committed to "personal and political empowerment" (Beresford, 2002, p. 97), through individual and collective action.

The profession of clinical psychology is primarily concerned with the 'treatment' of individuals in psychological distress (Hall, Pilgrim, & Turpin, 2015). Smail (1987) argued psychology exerts its power from its core philosophy, locating distress within the individual. The idea of young people having power to change systems may not therefore be in the interests of certain service providers, clinicians and researchers who have an interest in maintaining existing hierarchies as well as the powerful user/professional, clinician/patient and citizen/provider dichotomies as opposed to sharing and transferring power (Renedo & Marston, 2011; Repper & Perkins, 2003). Building on this, authors have highlighted the potential for the use of a 'service user shield' as a way for professionals to strategically use or misuse the voice of those accessing services in order to reinforce their own agendas (Harrison, Barnes, & Mort, 1997). Furthermore, research has indicated healthcare professionals expressing concerns about the legitimacy of the type of knowledge that those

accessing services and members of the public possess and their ability to contribute to healthcare decision-making (Daykin, Evans, Petsoulas, & Sayers, 2007; Martin, 2008).

## **1.6 Young People and Participation in Mental Health Services**

### **1.6.1 The Conceptualisation of Young People**

Young people, defined by the World Health Organization (1989) as individuals aged 10-24 years old, in the UK today find themselves in the midst of political uncertainty and growing societal division. That said, young people have historically been denied the right to make decisions about matters that directly affect their lives (Kellett, 2009). Young people tend to be conceptualised in western societies as a powerless social class, being viewed as vulnerable, dependent or partially competent (Badham, 2004). It appears this conceptualisation aligns with Piaget's model of rational development which is often considered when gaining an understanding of a young person's abilities (Lowden, 2002). Indeed, research has suggested the scepticism of adults about children and young people's capacity to participate in matters affecting them (Kirby & Bryson, 2002; Matthews, 2001). It is argued that the idea of young people being less rational is particularly seen within child and adolescent mental health, with the 'double-bind' of being considered incompetent due to their status as young people in addition to their status as psychiatric patients (Lefrançois, 2008).

Wyness (2013) argues that the involvement of young people in decision-making directly threatens to destabilise the adult paternalist stance of services, as it requires a shift of power and can be seen as conflicting with the interests of adults. Lansdown (1995) describes a self-confirming cycle where young people are constructed as vulnerable whilst adults are given power to act on their behalf. An example of this being that the needs of young people with mental health problems tend to be assessed and defined for them by adult health professionals. They are in turn more vulnerable to adults when they are restricted of

opportunities to gain experience of independence (Lansdown, 1995). This appears in line with previous research suggesting three perceived barriers to involving young people in mental health service delivery. These include young people's developmental level, disempowerment in society and within services, and finally, the attitudes held by professionals (Wiles, 1993).

The conceptualisation of young people as vulnerable is a stark contrast to the ways in which they have been seen as a driving force in recent political campaigns in the UK, from school climate strikes, Extinction Rebellion occupations and multiple Brexit demonstrations. Voting turn-out rates among 18-24 year olds in national elections have also steadily increased, although still lower in relation to older age groups (Dempsey, 2017). James & Prout (1997) talk of young people being social actors in their own right, with others describing young people as the most reliable source of information about their lives and opinions (Kellett, 2009). This connects with the idea of building on young people's intrinsic strengths whilst actively involving them in addressing issues that they themselves identify.

### **1.6.2 Young People and Mental Health**

The prevalence of mental health difficulties experienced by children and young people has been shown to be steadily rising (Fonagy et al., 2014), with research indicating one in three experiencing significant distress (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). With 65% of those who experience distress not accessing support from services (Department of Health, 2015), there has been a growing recognition of the importance of young people being actively involved in shaping services to meet their needs (Thornicroft & Tansella, 2005).

### **1.6.3 Youth Participation in Mental Health Services**

Participation in mental health services, policy and research continues to gain momentum and has significant growing interest both nationally and internationally (Beresford, 2019). Stakeholders have continued to shift from seeing young people as passive recipients of care to working in partnership and viewing them as resources for mobilising change and developing services. The participation of young people in the design of services which affect them is a central feature of the modernisation agenda for NHS England policy and practice. NHS England's Five Year Forward View for Mental Health has participation central to its implementation (NHS England, 2016). The Children's National Service Framework identifies a range of markers of good practice. These include the involvement of young people accessing services in decision-making, with their views taken into account in commissioning strategies, and a senior lead in each organisation with the role to ensure that their needs are at the forefront of local planning and delivery (Department of Health, 2004). Policies and 'transformation plans' such as Children and Young People-Improving Access to Psychological Therapies (CYP-IAPT) focus on participation and feedback-led practice, which can be argued as being in line with consumerist ideological approach (Beresford, 2002). However, there is often disinvestment in services, despite the top-down drive for youth participation and an attempt to embed this in service policy (Murphy & Fonagy, 2012). There also remains a lack of what is viewed as genuine participation from young people within services (Murphy & Fonagy, 2012). Hart (1992) speaks of the risk of top-down participation activity stifling bottom-up participative democracy. Furthermore, some argue participation functions as a means of regulation rather than liberation (Beresford, 2002).

### **1.6.4 Youth Participation in Practice**

Youth participation within mental health services encapsulates a range of different ideas, from active participation at the micro-level of individual decision-making (Gondek et al., 2017), such as active participation in developing service information leaflets (Russell, Hey, & Linnell, 2003), to more macro-level involvement in service development (Dunn, 2017), evaluation, policy development, training (Latif, Carter, Rychwalska-Brown, Wharrad, & Manning, 2017) and research (Faithfull, Brophy, Pennell, & Simmons, 2018; Howe, Batchelor, & Bochynska, 2011).

In terms of micro-level participation, specifically participation in joint decision-making around one's own care, Gondek et al.'s (2017) systematic review identified facilitators and barriers to participation. Barriers included professionals' perceived lack of expertise, a lack of information sharing with young people, and a lack of resources. Professionals also tended to underestimate the willingness or capacity of young people to participate in decision-making about their care (Gondek et al., 2017). Being flexible in the way in which they worked and trusting young people to be involved were reported by professionals as facilitating participation (Gondek et al., 2017).

Relevant to youth participation in training within mental health services, Latif, Carter, Rychwalska-Brown (2017) researched the application of a co-produced digital education programme for nurses supporting children and young people injured through self-harm. Reported challenges included recruitment of young people to participate in the co-produced project due to the sensitive nature of the issues, and ethical safeguards. Dunn (2017) outlined a co-produced Child and Adolescent Mental Health Service (CAMHS) transition preparation programme to improve outcomes and experience for young people leaving CAMHS. Young people shared their experiences of transitioning services to inform the design of the programme. There were opportunities for young people to be involved as co-researchers

which involved co-designing a conference poster, involvement in disseminating findings both within trusts and externally, co-planning and co-hosting clinician workshops, co-authoring a journal article and reviewing research literature. Dunn and Mellor (2017) provided further reflections on the project and detailed an additional two participatory projects co-produced with young people. These involved participatory film-making projects, one of which was a film developed as part of training for foster carers, service providers, decision-makers, commissioners and funders. The film provided an insight to a child's experience of being removed from their family and placed into local authority care. The second film was developed for young people experiencing depression and mental health practitioners, with young people disseminating the findings from a large multi-centre clinical trial for depression in adolescence. Reflections on the participatory process included emphasis on the importance of harnessing young people's ability to utilise their strengths and expertise and work in a flexible and democratic group environment to think creatively. Dunn and Mellor (2017) provided reflections that the approach of participation allowed different ways of working and highlighted the importance of carefully navigating relationships which would previously been confined to 'researcher' and 'researched.'

### **1.6.5 The Impact of Youth Participation**

Literature on the impact of participation in mental health service delivery has focussed mainly on adults accessing services (Crawford et al., 2002; Omeni, Barnes, Macdonald, Crawford, & Rose, 2014). There is limited existing research on young people's experiences of mental health service participation within the National Health Service in the UK (Viksveen et al., 2017), with current research largely focussing on service outcomes of discrete participatory projects. Research tends to be adult led, arguably reflecting adult-centred interpretations and agendas (Coates & Howe, 2014, 2016; Dexter, Larkin, & Newnes,

2011; Howe et al., 2011; Mayer & McKenzie, 2017; Ramey & Rose-Krasnor, 2015; Taggart, Franks, Osborne, & Collins, 2013).

Research has indicated that young people want routine and meaningful participation with a realistic possibility of change (Plaistow et al., 2014). It has been argued that meaningful participation in the decision-making of mental health service delivery can add to a young person's sense of connectedness and belonging, feelings of being valued, and thereby impact on mental health and well-being (Oliver, Collin, Burns, & Nicholas, 2006). It has been proposed that participation can offer young people a way to assert their identity in the public sphere; to state who they are, what their knowledge and experience is, and what their concerns are (Plaistow et al., 2014). Checkoway (2011) argues participation works towards strengthening personal and social development and provides expertise for young people and services. Further research suggests young people can become more knowledgeable and confident about using healthcare through participation in service delivery (Curtis & Singh, 1996), with the view that young people have the opportunities of developing more evenly balanced partnerships with clinicians (Repper & Perkins, 2003). In terms of participation specific to mental health research, it is argued in practice this can improve relevance, recruitment, research materials, methodologies and the interpretation of results (Shaw, Brady, & Davey, 2011). It is argued young people can learn transferable skills, gain self-confidence, knowledge, self-esteem and a sense of empowerment (Day, 2008; Shaw et al., 2011).

## **1.7 Summary**

Participation is a multi-layered concept that can involve young people's active involvement at different levels within mental health services (Tambuyzer et al., 2011). The importance of youth participation in mental health services is a central feature of the

modernisation agenda for NHS England policy and practice, certainly becoming part of contemporary political talk. However, there remains a paucity of literature regarding young people's experiences of participation.

Literature on the impact of participation in mental health service delivery tends to look towards that of adults (Crawford et al., 2002; Omeni et al., 2014). Furthermore, research undertaken in the area of youth participation in mental health service design typically focuses on discrete participatory activities and outcomes of a participatory model or project in terms of overall service improvement, often without recognising the range of potential impacts and experiences of participation on a range of stakeholders, including young people (Crawford et al., 2002). Therefore, a literature search on the experiences of young people and participation in the design and delivery of mental health services was necessary to understand the area in more detail.

### **1.8 Systematic Literature Review**

The search strategy employed in order to systematically review the relevant literature is detailed below. Thereafter, each study is presented in order to provide the reader with an understanding of the available literature on the experiences of young people participating in the design and delivery of mental health services. Finally, thought is given to how the proposed research would be of benefit, and the research questions are posed.

### **1.8.1 The Aims and Scope of the Systematic Literature Review**

The review seeks to systematically identify and synthesise the literature in order to explore the following question:

*What do we currently know about the experiences of young people and participation in the design and delivery of mental health services?*

It is acknowledged that participation encompasses an array of areas. Tambuyzer, Pieters, and Van Audenhove's (2011) model can provide a conceptualisation of participation at different levels. The systematic review focussed specifically on participation at the meta-level (training and research), macro-level (policy making) and meso-level (service planning). Stand-alone micro-level participation (e.g. involvement in decision-making around one's own care), was excluded due to the limitations in the scope of the review. This was in part due to the available timescales of conducting research within the context of clinical training, but more importantly to maintain a specific focus on youth participation in mental health service design and delivery.

Studies included any research design (qualitative or quantitative) used to answer the research question of the systematic review with both methodologies providing a useful insight into this research area. With research in this area tending to focus on the process of involving service users rather than the experiences of participation (Crawford et al., 2002), the scope of the literature review was widened to include the experience of youth service participation from the perspective of young people and adults. Including the perspectives of adults is also important for capturing multiple perspectives and constructions of the experience of youth participation. This is also revealing in terms of the ways in which young people may be perceived, with research and measures completed by other professionals

'about' the young person, with an argument of this potentially devaluing the young people's voice. The systematic review will highlight participatory practices within the research itself, such as co-authorship or co-design of particular measures used within selected papers, addressing the question: who is doing the research and how does this influence the dominance of particular voices?

### **1.8.2 Review Strategy**

Initial search terms were generated based on previous reviews, although not specific to young people (Patel, Bakken, & Ruland, 2008; Petersen, Hounsgaard, & Nielsen, 2008; Simpson, 2002; Crawford, 2002) and scoping searches. A protocol for a systematic review on user involvement in adolescents' mental healthcare (Viksveen et al., 2017) was also taken into consideration when developing search terms. No systematic review to date has focused specifically on young people's participation in mental health service design and delivery.

Search terms mapped onto three areas: young people; service participation; and mental health. To allow for variations in keyword terms, for example, service-user involvement, user participation etc., truncated terms were used. The following keywords were generated: young people terms and participation terms in addition to mental health terms (Table 1). These were combined together using AND; the following search strategy was then used: (young people terms) AND (participation terms) AND (mental health terms).

The databases of PsycINFO, Scopus, CINAHL and Cochrane Controlled Trials Register were systematically searched between November 2018 and February 2019 for relevant articles published. The search was limited to papers in written or translated English, peer-reviewed journals. These databases were supplemented by hand-searches and additional electronic sources (e.g. Google Scholar). The process known as snowballing (Sayers, 2007) was applied, whereby searches are made through references and citations of obtained texts.

There was also scoping of the 'grey literature' that in this case included unpublished manuscripts, blogs, and articles.

**Table 1.** *Summary of Final Search Terms*

<i>Participation Terms</i>	<i>Young People Terms</i>	<i>Mental Health</i>
Inclu*	"Young people"	"Mental health"
Involv*	"Young person"	CAMHS
Participat*	"Young adult"	"Child & Adolescent Mental
"Service-use*"	Teenage*	Health Services"
"Peer-lead"	Child*	Psychiatr*
"Peer-led"	Youth	"CYP-IAPT"
"Co-product*"	Adolescen*	
"Co-design"		
"Co-deliver"		
"Experts by experience"		

The inclusion criteria for the systematic literature search were that papers were:

1. Peer-reviewed
2. Written or translated English
3. Concerning experiences of participation of young people in the design and/ or delivery of mental health services at the meta, macro or meso-level
4. Studies making reference to the experience of young people aged between 10-24 years old in accordance with World Health Organization (1989) definition. Where the upper age exceeds this, this will be made clear
5. Young people's participation may have been reported by young people, researchers, parents/ guardians, health professionals or other stakeholder groups

Studies were excluded if they primarily focused on:

1. Learning disabilities

2. Involvement at an individual level only, concerning decisions about a young peoples' own mental healthcare
3. Young people's satisfaction surveys that were researched by the provider (which do not require partnership with young people)
4. General health services not specifically aimed at mental health
5. Forensic services
6. Services which are not health related, such as housing or vocational rehabilitation
7. Commentaries, opinion pieces, or editorials
8. Experiences of participation as part of discussion

An initial search of all databases yielded 3003 papers with an additional 37 papers through a citation search on Google Scholar and reference screening process. After removing duplicates and applying the inclusion criteria, the total number of papers was reduced to 130 papers. The titles and abstracts of each of these papers were read to assess their potential suitability according to the inclusion criteria. This resulted in 28 articles selected for full text review and quality evaluation. A total of 11 papers were found to wholly meet the inclusion criteria. Table 2 provides an outline of these and their relevant findings. For detailed information on the search strategy, see Appendix A.

The full breakdown of this process of identifying studies is described in Figure 1.

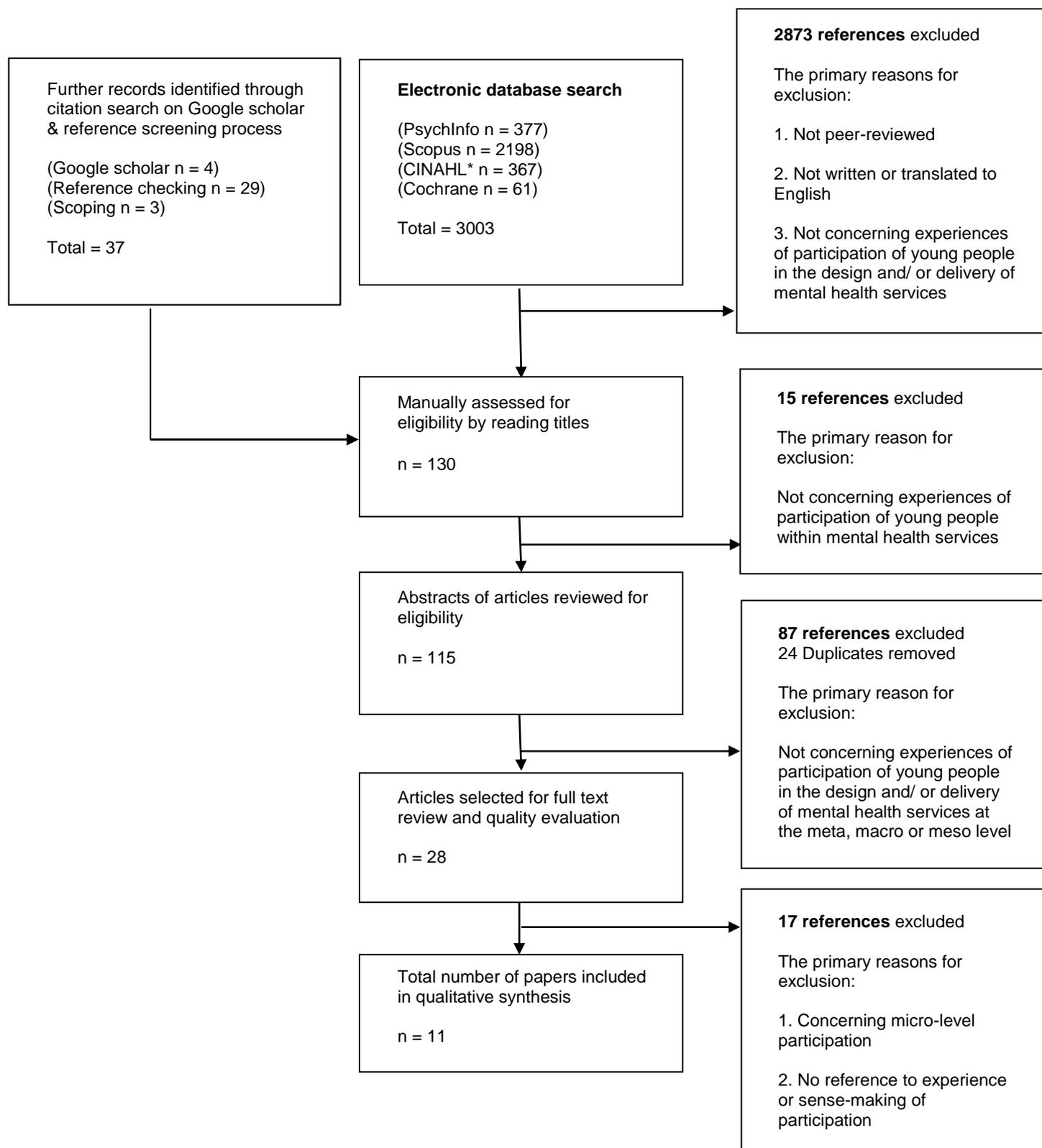


Figure 1. *The process of study selection*

\*CINAHL search consisted of an Subject search as opposed to Keyword as there is no Keyword function

## 1.9 Literature Review

Eleven studies were reviewed in detail in order to provide a synthesis of the body of work on what is currently known about the experiences of youth participation in the design and delivery of mental health services. Studies were conducted in Australia (Coates & Howe, 2014, 2016; Howe et al., 2011), UK (Dexter et al., 2011; Mawn, Welsh, Kirkpatrick, Webster, & Stain, 2015; Mayer & McKenzie, 2017; Price & Feely, 2017; Taggart et al., 2013), Canada (Ramey & Rose-Krasnor, 2015) and US (Gyamfi, Keens-Douglas, & Medin, 2007). Two studies related to the same youth participation model in Australia called Youth Alliance (Coates & Howe, 2014, 2016).

With the majority of findings qualitative in their design, in order to maintain the integrity of the individual projects, avoiding 'thinning out' the richness of human experiences in the original studies, themes were drawn from the literature reviewed. This process involved carefully reading and rereading each study, coding the data whilst looking for similarities and differences between the codes in order to group into a hierarchical tree structure. From this, analytical themes were generated.

The papers included in this review discussed experiences of youth participation from multiple perspectives. These include the perspectives of young people; researchers; clinicians, managers, and staff teams. The review will be organised by exploring those perspectives in turn.

Nine of the reviewed studies explored the experience from the perspective of young people (Coates & Howe, 2014, 2016; Gyamfi et al., 2007; Howe et al., 2011; Mawn et al., 2015; Mayer & McKenzie, 2017; Price & Feely, 2017; Ramey & Rose-Krasnor, 2015; Taggart et al., 2013). Therefore, this is the main focus of the review. Each paper will be presented, drawing upon key findings and methodological limitations. A synthesis of the

overall findings of the experiences of young people participating in service design and delivery can be found in the discussion section of the review.

All studies identified for review used qualitative methodology or a mixed methodology with a significant qualitative component. Elliott, Fischer, and Rennie, (1999) quality assessment framework was systematically applied to each paper to assess their quality. Critiques of each paper have been described more fully in the body of the text, but a summary of their quality against the framework can be found in Appendix B.

## **1.9.1 Participation through the Lens of Young People**

### ***1.9.1.1 Empowerment***

Within studies specifically looking at the first-hand experience of young people and participation, there was the rhetoric of agency, with the use of language such as 'empowerment,' 'strength,' 'opportunities' and 'confidence.' Studies suggested a degree of going beyond what the person previously thought they were capable of (Coates & Howe, 2014, 2016; Gyamfi et al., 2007; Mayer & McKenzie, 2017; Ramey & Rose-Krasnor, 2015; Taggart et al., 2013).

Mayer and McKenzie (2017) studied the psychological impact of co-production for five young people working in a youth mental health charity in a large and diverse area in the UK. Young people spoke of the experience enabling agency and bringing about a sense "*that there's no limits*" (Mayer & McKenzie, 2017, p.1184). It appeared that, rather than occupying a passive position, young people described having a strong sense of personal accountability and responsibility, "*it's all off my own back...*" (Mayer & McKenzie, 2017, p.1183). Price and Feely's (2017) findings suggested participation brought "*an opportunity to build on your skills and learn new ones and to grow in self-confidence*" (p.58). However, this sense of intrapersonal positive change was not experienced by all, with one young person

using a powerful metaphor of feeling like a “*lab rat*” to describe his sense of powerlessness (Mayer & McKenzie, 2017, p.1184). This was reported to be related to the young person feeling decisions were made without him and information being withheld by others (Mayer & McKenzie, 2017).

Taggart et al. (2013) explored the experiences of young people participating in Participatory Action Research (PAR) regarding stigma in mental health. Findings suggested the young people taking part viewed themselves as having a sense of agency and belief in their own abilities in relation to participation. Young people also reported increased social skills which translated to social situations outside the participatory projects (Taggart et al., 2013). Young people reported a noticeable change in their ability to ‘speak out’ and voice dissatisfaction in other contexts, also describing an increase in confidence in the ability to raise their concerns around mental health service delivery (Taggart et al., 2013). Gyamfi et al. (2007) also reported that the social element of meeting as a group provided a hub from which young people could develop their strengths and abilities.

**Table 2.** *Summary of Studies Identified for Review*

<b>Author(s)</b>	<b>Study aims</b>	<b>Sample</b>	<b>Country</b>	<b>Data collection and analysis</b>	<b>Relevant Findings</b>
<b>Mayer, C., &amp; McKenzie, K. (2017)</b>	Explored the psychological impact of co-production for experts by experience working in youth mental health services	Five males aged 21-28	UK	Individual semi-structured face-to-face interviews. IPA analysis with emerging themes identified and clustered.	Themes included: The co-production approach: enabling and feeling valued. "I'm a professional:" emerging professional identity. Identities in transition: shift in the way YP viewed themselves and how they were seen by others.
<b>Mawn, L., Welsh, P., Kirkpatrick, L., Webster, L. A., &amp; Stain, H. J. (2016)</b>	Explored the perceptions of young people about involvement in mental health research	Young people (n= 8; age 14-24; females n=7, males n=1)	UK	Individual semi-structured face-to-face interviews. analysed using Thematic Analysis	Themes included: Research and what it means: preconceptions of research. The research roundabout: exploring the research process. Giving back: learning new skills and gaining experience. Getting young people through the door: generating ideas to increase access. Barriers: anxiety preventing involvement; lack of support; potential impact on MH; technology and face-to-face communication: being flexible to facilitate meetings.
<b>Coates, D., &amp; Howe, D. (2016)</b>	Evaluation of a youth participation model	Young people (n=12, aged 15-23; females n=7, males n=5) Management (n=3)	Australia	Three focus groups analysed using Thematic Analysis	Management spoke of being highly committed; acknowledging the risk of a lack of diversity. Clinical staff perspective: Issues around confidentiality, YP not being 'well,' the risk of overhearing or misinterpreting information. Youth Consultants perspectives: vouchers and their 'tokenistic' value, reflections on moving forward and training, role clarity, views on group vs. individual work.
<b>Gyamfi, P., Keens-Douglas, A., &amp; Medin, E. (2007)</b>	Youth/ youth coordinators perspectives on youth involvement	Young people (n = 22; age range 14-22, female n =13, male n = 9) Youth coordinators (n = 11; age range 26-39; female n=6, male n=5)	US	Focus groups across two phases. Phase I: One exploratory focus group. Phase II: Five explanatory focus groups. Analysed using Thematic Analysis.	Youth groups identified as a key mechanism for youth involvement; youth coordinators playing an active role in the development of YP; YP having limited access to information; little evidence of participation in meta, macro or meso-level involvement. Highlighted the lack of support mechanisms promoting youth involvement.

<b>Dexter, G., Larkin, M., &amp; Newnes, C. (2012)</b>	Clinical Psychologists' views and experiences of user involvement	Clinical Psychologists within a child psychology specialty (n = 8); those with management responsibilities (n=2). Age range of children unknown	UK	Qualitative methods using individual face-to-face interviews. Accounts analysed drawing on Foucauldian Discourse Analysis	Children positioned as developing beings and in need of protection, viewed as powerless. Their position played out as an ethical dilemma. Children as service users positioned as consultants. Service user involvement positioned as radical or common, as a challenge and requiring diligence. Positioned as a two way process and powerful. User involvement requiring particular progress and can be hindered rather than encouraged by the wider organisation.
<b>Faithfull, S., Brophy, L., Pennell, K., &amp; Simmons, M. B. (2018)</b>	Barriers and enablers to meaningful youth participation in mental health research	Researchers who held academic positions. Not identifying as YP with lived exp. Age and gender not included to protect anonymity	Australia	Qualitative methods using individual face-to-face interviews. Data analysed using Thematic Analysis.	Results presented as individual and organisational factors which act as barriers or enablers to participation, and making youth participation genuine.  Individual factors: barriers around level of understanding of participation, how research is perceived within research community, concerns around impact on YP and the need for training. Organisation factors: barriers around lack of resources, outside scope of role, having an established group of YP, 'aging out.' Making youth participation genuine: balancing ideas vs. Feasibility.
<b>Ramey, H. L., &amp; Rose-Krasnor, L. (2015)</b>	Evaluating The New Mentality Program utilising a youth-adult partnership model	Qualitative arm: Young people (n=19); Adult allies (n=5); Partner agency executive directors (n= 7); Program staff and steering committee members (n=9)  Quantitative arm: young people (n=24, mean age = 19.48, SD=2.52)	Canada	Mixed method design  Qualitative arm: Semi-structured interviews, focus groups and program documents analysed using Grounded Theory analysis.  Quantitative arm: online survey	Qualitative results themes included: Relationships with adult and youth: building partnerships and providing support. Youth engagement and youth MH services: cultural gap between the two. Programme structure: Individual learning and knowledge sharing.  Quantitative survey results: Positive significant correlations were found among all four measures: Youth participation in services Positive features Psychological engagement Perceptions of growth

<b>Coates, D., &amp; Howe, D. (2014)</b>	Identifying the key reasons young people joined a participation model, Youth Alliance (YA) and what they hope to achieve in their capacity of YA consultants	Young people (n= 12, 7 females, 5 males) aged 15-23	Australia	Two hour focus group and analysed and themes identified	Key reasons for being involved in youth participation: Make a difference for others; build social skills; meet likeminded friends; build skills and work experience; challenge societal conceptualisation of mental health and improve access to mental health support.
<b>Howe, D., Batchelor, S., &amp;Bochynska, K. (2011)</b>	Evaluation of youth participation model	Young people (n=14) aged 15-25	Australia	Mixed methods approach:  Questionnaires to determine confidence and understanding of role. Group interview exploring experience of Youth Alliance Consultants. Scrapbook and video project providing professional and personal insights into experience of Youth Alliance Consultants.	Recruitment process for YP to join was reported as acceptable. Impact on service: consultations delivered across services; campaigns; putting forward views at executive level. Impact on young people: wanting to make a difference; gain work experience; increased MH knowledge; gaining skills including teamwork, communication, presentation and consultancy skills, skills in public speaking and time management. Challenges included: availability of funding; young people having autonomy; YP working alongside getting support for MH needs; reliability and availability of young people.
<b>Taggart, D.,Franks, W.,Osborne, O.,&amp; Collins, S. (2013)</b>	Experiences of young mental health service users participating in PAR about stigma in mental health	Young people (n=8; 5 females, 3 males) aged 17-22	UK	Individual semi-structured face-to-face interviews. analysed using Grounded Theory analysis	Themes included: Intra-personal change: young people felt a sense of achievement and pride, making a difference. YP noticed increased confidence to speak out against poor quality services and independence. Interpersonal change: Going beyond what YP thought they were capable of; sense of belonging; change in willingness to engage in groups. Social change: having an impact on challenging stigma. Increased awareness of MH: in own family context; in terms of own difficulties. Negative change: emotive nature of the project was distressing for some. Group change: group empowerment and shift in power balance.

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<b>Price, A.&amp; Feely, M. (2017)</b>	Impact on resilience of young people of participating in a youth mental health organisation	Young people (n=10) aged 16-25	Republic of Ireland	Individual semi-structured face-to-face interviews. analysed using Thematic analysis	Themes relating to resilience included: Supportive staff: showing encouragement and respect. New skills: development of communication, organisational and facilitation skills. Life satisfaction: enjoying the experience and making friends. Making a difference: seeing the benefit both nationally and in their communities.
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### Abbreviations

YP = Young people; IPA= Interpretative phenomenological analysis; MH = Mental health; PAR: Participatory Action Research; SD = Standard deviation

Ramey & Rose-Krasnor (2015) also reported the personal benefits of young people participating in mental health service design and delivery, such as respect, value, leadership, confidence, and, at times, a positive impact on wellbeing. Price and Feely (2017) explored the experiences of young people on a Youth Advisory Panel within a mental health service in Ireland. Findings suggested that the young people taking part gained from their experience of participation, a sense of life satisfaction, purpose and doing something they perceived as meaningful (Price & Feely, 2017). Coates and Howe (2016) went further in terms of reporting the importance of managing expectations for young people participating in the design and delivery of mental health services. In their qualitative study with young people and managers involved in a mental health service in Australia, young people reported the importance of having an awareness of the organisational constraints. This seemed to allow them to balance the sense of empowerment around driving their own projects forward with the potential of facing constant disappointment when initiating projects which may not have been feasible due to service limitations (Coates & Howe, 2016).

In contrast to the discourse across the literature around participation and empowerment, Taggart et al. (2013) presented findings suggesting a negative experience reported by a young person. It was argued that the experience of talking about mental health problems was at times emotive and caused distress. Mawn et al.'s (2015) study was undertaken in order to understand the perceptions of young people involved in mental health research. Findings also indicated some less positive experiences of young people taking part, with reports of young people experiencing anxiety due to the assumption that a high degree of intelligence would be necessary for involvement and this anxiety having the potential to act as a barrier to participation (Mawn et al., 2015).

### ***1.9.1.2 Shifting relationships and being seen differently through the eyes of others***

In their mixed methods study evaluating a youth-adult partnership model in Canada, Ramey and Rose-Krasnor (2015) explored the experience of young people and stakeholders during the initial stages of youth participation in a community mental health project. Young people described the benefits of working in equal partnership with adults on projects, wanting to be treated as leaders rather than “as objects or recipients” of services (Ramey and Rose-Krasnor, 2015, p. 33).

Similarly, Mayer & McKenzie (2017) reported that the interviewed young people described feeling valued whilst working ‘alongside’ colleagues and learning from one another. Young people described having trusted relationships with mutual respect where the young person viewed themselves in equal partnership with professionals (Mayer & McKenzie, 2017). However, Howe et al.'s (2011) findings suggested a relational struggle between ‘allowing’ young people to be autonomous and the process having to be a learning experience, with the need to produce ‘good’ outcomes.

There were accounts of the development of trusting relationships and being seen by others as an asset, *“I’m a asset, like, I have some value, yeah, that boosts the ego a lot”* (Mayer & McKenzie, 2017, p.1184). It is important to note, the experience of feeling valued appeared to be influenced by the way in which young people were paid for their involvement. In Coates and Howe's (2016) study evaluating a youth participation model, both management (with a dual clinical role) and young consultants attended focus groups to explore possible barriers to implementation of the project. Young people described the sense of being taken more seriously by others if they were paid a salary instead of vouchers, viewing vouchers as a tokenistic gesture (Coates & Howe, 2014). Price and Feely's (2017) findings suggest there was confusion about the young people's role, with some people seeing them as ‘service users’ and others as professionals.

### ***1.9.1.3 Identity***

There was a theme within the reviewed studies around an apparent emerging shift in identity. Mayer and McKenzie (2017) described young people as embodying the new identity of a 'professional' which contrasted with other language they used to refer to themselves, including 'disadvantaged' and 'excluded.' Young people described wanting to retain a distinction in identity around being an expert by experience, rather than a more generic term of 'colleague' (Mayer & McKenzie, 2017). Mayer & McKenzie (2017) suggest the apparent emerging identity of being a 'professional' could be seen as an opportunity to rebalance the young people's relationship with the system. This seemed to contrast with the research findings undertaken by Mawn, Welsh, Kirkpatrick, and Webster (2015) whereby young people did not necessarily wish to be associated with mental health research due to a fear that others would see them differently.

It should be noted, particularly referring to Mayer and McKenzie's (2017) study, that the experiences relating to emerging identities and a changing view of oneself may have also been associated not only with what it meant to be a young person in British society and potentially occupying a disempowered position as a result, what it meant to experience mental health difficulties and their involvement in co-production. Young people taking part (all but one) had previously served prison sentences, which arguably adds another layer of interpretation around the way in which the young people taking part may have viewed themselves and be viewed by others in their community and wider society.

Across the reviewed studies, findings suggested the importance of helping others through participation (Coates & Howe, 2014; Gyamfi et al., 2007; Mawn et al., 2015; Mayer & McKenzie, 2017; Price & Feely, 2017; Taggart et al., 2013). The experience of 'giving back' by helping and teaching others was described as a positive experience by young people (Mayer & McKenzie, 2017). This was also indicated by young people involved in mental

health research (Mawn et al., 2015). Similarly, Ramey and Rose-Krasnor (2015) reported that the interviewed young people described being passionate about the cause of contributing to mental health awareness and being part of the “*solution to problems*” (p.33). Young people also described enjoying opportunities to mentor other young people (Ramey & Rose-Krasnor, 2015). Similarly, Coates and Howe's (2014) findings suggest young people's reasons for involvement in mental health service participation included the desire to help overcome barriers around access to services for others. For all taking part in the study, there appeared to be a strong commitment to helping other young people access support and to make active choices in the care they receive, as opposed to being passive recipients of care. A young person within the study reported the importance of teaching young people “*how to negotiate their relationship with their counsellor*” (Coates & Howe, 2014, p.297). Similarly, in their evaluation of youth participation in the development and promotion of youth mental health services called Youth Alliance in Australia, Howe, Batchelor, and Bochynska (2011) reported that young people described wanting to make a difference or gain field-related work skills, and described being enthusiastic about improving other young people's access to mental health services.

There appeared to be a process of internalising a sense of connectedness, with studies reporting the experience of participation as an opportunity to make like-minded friends, build social skills and networks, in a safe way (Coates & Howe, 2014). Similarly, Taggart et al.'s (2013) research findings reported the young people taking part expanding their social worlds through participation in mental health research. Taggart et al. (2013) reported young people experiencing a shift from previously having anxieties around being in unfamiliar groups, to going on to forming new relationships. Gyamfi, Keens-Douglas and Medin (2007) interviewed both young people aged 14-22 years old and youth coordinators aged 26-39 years old, to understand their perspectives of participating in service delivery in mental health

services in the US. Consistent with the findings of Taggart et al. (2013), young people described the value of connecting as a group to confide in others who might face similar problems.

#### ***1.9.1.4 Barriers to Participation***

Young people described barriers around participating in services, such as opportunities to be involved coinciding with school, suggesting a lack of buy-in from services (Gyamfi et al., 2007). Similarly, Howe et al. (2011) reported that balancing work with studies or other commitments was the most frequently reported challenge for young people involved. Gyamfi et al. (2007) also highlighted the limitations of involvement, with no effect on shaping change on a larger scale of service delivery. Gyamfi et al.'s (2007) findings also suggested a resistance from the service to involve young people, reporting times when youth coordinators perceived staff as actively trying to prevent them from informing youth about their rights and involvement options. Other studies found other barriers to participation, including time, travel, lack of training and staffing issues (Price & Feely, 2017). Howe et al. (2011) suggested availability of funding impacted upon participation activities. Findings also suggested young people were released from the team as a result of being seen as less reliable or available. Young people taking part in the study felt this was unfair and inconsistent with the desire to have a representative participatory team when aspects such as social disadvantage and mental health difficulties leading to being less available were not taken into consideration.

#### ***1.9.1.5 Summary***

In summary, research addressing young people's experiences of service participation reported inter and intrapersonal values around areas such as connectedness, feeling

empowered, valued and having a sense of agency. Findings suggested a sense of belonging and a shift in relationships with professionals through service participation. Across studies, there appeared an emerging shift in identity through participation, with young people viewing themselves as professionals and helping others. However, it seemed youth participation was not without challenges, such as a perceived resistance of youth participation from services and a lack of flexibility to allow for young people to balance other demands.

### **1.9.2 Participation through the Lens of Researchers**

Faithfull, Brophy, Pennell, & Simmons (2018) drew upon the perspective of mental health researchers employed at a youth mental health research institute in Australia. The main study aim was to explore barriers and enablers to meaningful youth participation in mental health research. Researchers considered youth participation as an essential aspect of research, such as increasing recruitment rates. Researchers spoke of their views around valuing youth involvement in research, arguing that participation improved the overall quality of the research. However, some researchers believed young people had little knowledge of research and that they would not be interested in participating. Researchers also described the challenges of youth participation in mental health research, with it being an additional aspect of their work, requiring time and additional costs. Researchers interviewed in the study spoke of participatory research being less accepted by peers, potentially having less methodological 'rigour,' but with the potential of having translational impact and broader significance. Researchers taking part also described feeling anxious about losing control of the research process with concerns around involvement not being compatible with what makes for 'good' research.

### 1.9.3 Participation through the Lens of Clinicians and Managers

Dexter, Larkin and Newnes (2012) carried out a qualitative study of child clinical psychologists' understanding of service participation. Findings indicated that the clinical psychologists taking part positioned young people as developing beings, powerless and in need of protection. This appeared to reflect the prevailing western constructions of young people as passive and vulnerable. Findings suggested an implicit drawing upon developmental discourse as a way of legitimising the child's lack of agency in decision-making, making it difficult to justify young people participating more actively in the design and delivery of mental health services (Dexter et al., 2011). With young people positioned as 'patients' and therefore vulnerable and in need of protection, it was felt that this may act as a barrier for participation (Dexter et al., 2011). However, clinical psychologists also spoke of young people having influence in mental health service delivery, with the example of having the power of veto over the professional's choice of candidate in the recruitment process (Dexter et al., 2011).

The concept of participation was positioned as powerful, and as a result could feel threatening to the status quo: "*it can be potentially challenging, opening yourself up as a service, to say well what is it you don't like about our service?*" (Yvonne) (Dexter et al., 2011, p.258). This was also consistent with the findings of Faithfull et al. (2018) who reported that researchers taking part in the study described feeling anxious about losing autonomy of the research process. Coates and Howe's (2016) study contrastingly reported that staff expressed enthusiasm and support for youth participation.

Youth participation was seen as taking a lot of effort and energy, with it being difficult to achieve, with pressures of long waiting lists (Dexter et al. 2011). Furthermore, Gyamfi et al.(2007) found that those coordinating youth involvement found other professionals were actively trying to prevent them from informing young people about their

rights and involvement options. Ramey and Rose-Krasnor (2015) reported that having youth allies on board, specifically people leading on participation projects and working closely with young people was key, having someone who *“believes in youth engagement, fights the fight inside that agency to keep it out there, and relates to youth”* (p.31). Ramey and Rose-Krasnor (2015) reported the account of a clinician ‘turning off’ their aspects of their professional identity which maintains the patient/professional dichotomy: *“Something that’s going to be challenging is turning off the social worker or psychiatrist in you. It’s about accepting them as who they are. Believing that young people are just as competent as we are is a big deal”* (Adult ally in adult-youth partnership model, Ramey & Rose-Krasnor 2015, p.33).

In Coates and Howe’s (2016) study evaluating a youth participation model, management overseeing the participation project were found to demonstrate a strong commitment to implementing a sustainable model. They spoke of the challenge of engaging young people with diverse needs and those from diverse backgrounds, and the risk of an over representation of highly performing young people described as ‘more easily engaged’ than those having additional needs. They described a tiered and flexible approach helpful as a way to allow young people at different points in their life to participate (Coates & Howe, 2016). Coates and Howe (2016) reported that other concerns raised by staff included that of confidentiality and youth participation, specifically around the potential for young people to access private information about their peers. They also spoke of a co-produced model potentially becoming a barrier for young people accessing services due to a fear of being recognised by their peers. Another reservation was reported to be around the mental health of young people with lived experience, the risk of distress, secondary traumatic stress and vicarious trauma. Findings reported a debate around whether young people currently accessing the service for support should be allowed to participate, and if not, how long they should be a ‘past client.’ There were concerns around participation compromising young

peoples' care plans. Another concern reported by staff in Coates and Howe's (2016) study was the concern of young people misinterpreting or getting upset by "black humour used by clinicians as a coping strategy" (p.294).

### **1.10 Quality Evaluation of the Literature**

Apart from two studies which used mixed method designs, the remaining nine studies identified for review use qualitative methodology. In assessing the quality of the eleven papers included for systematic review, Elliott, Fischer, and Rennie's (1999) criteria for evaluating the quality and credibility of qualitative and quantitative research were used (for quality evaluation extract, see Appendix C). Age and gender were not specified in all studies in order to protect anonymity (Faithfull et al., 2018), having implications around the quality criteria of the paper, but seemed appropriate in order to maintain respect of those taking part who may wish to remain anonymous. Overall, all studies highlighted the benefits of participation as a way of introducing the area of research and tended to have this as their primary focus. This brings with it assumptions around the position of the researcher in their stance of valuing participation. Studies tended not to take a critical perspective of participation or deconstruct the concept (Price & Feely, 2017), writing solely about the apparent benefits of participation as a way of introducing the reader to the research (Coates & Howe, 2014; 2016). In contrast, Dexter et al.(2011) took a noticeably different stance, exploring the context within which service participation sits, particularly around power discourses and the positioning of the child. All papers reviewed were explicit in addressing the scientific context and purpose of their research. Appropriate methods were utilised by most researchers to address their aims, with two studies not detailing the approach taken to analyse the data (Coates & Howe, 2014; Howe et al., 2011). Most papers explicitly stated their approach towards respecting those taking part through ethical considerations. However,

two studies did not address ethical standards (Gyamfi et al., 2007; Howe et al., 2011). All papers included in the review produced appropriate discussions that reflected the research context and findings, with one exception. Coates & Howe (2014) integrated the research data and the understandings derived from them in terms of their contribution to theory, with the concluding section omitting an acknowledgment of limitations. All papers were presented using variations of conventional formats for scientific publication.

### **1.11 Limitations of Research and Critical Reflections**

The research presented provides multiple perspectives which contribute to the understanding of youth participation in mental health services. Mayer and McKenzie (2017) point out the issue of self-selecting samples in this area of research. The young people taking part in the research were already involved in youth service participation and arguably advocates for this way of working. It is argued the population of young people participating in mental health service delivery may not represent the population demographic (Howe et al., 2011). Those struggling to attend participatory activities regularly, often being young people facing social disadvantage and emotional needs, were found to be perceived as less reliable and 'released' from the team (Howe et al., 2011), therefore less likely to take part in the research presented. It should also be noted that the research included what is known as insider researchers (Simons, 2006), whereby the researcher was also involved in the participatory project itself (e.g. Price & Feely, 2017). Some studies made use of 'guided conversations' when interviewing, in order to be flexible enough for the accommodation of new ideas introduced by interviewees. However, in the presence of insider researchers, it could be argued that young people may not have been able to freely express their opinions without pressure. Although studies state that care was taken to ensure discussions were guided by

issues raised by the young people (Coates & Howe, 2016), it is unclear how this was achieved, or indeed the recognition of the co-constructed narrative.

Studies tend to combine the process of a project and the exploration of young people's experience of participation in the project (Howe et al., 2011), rather than the sole focus of exploring the experience of young people as a standalone study. This meant that there arguably was less clarity of the young people's meaning making around their experience of participation.

There appears to be a consensus in the view that user/professional, clinician/patient, researcher/researched dichotomy should be challenged (Mayer & McKenzie, 2017); however this dichotomy is maintained in the way in which the research is itself undertaken. The powerful dichotomies between 'service users' and professionals remain strong throughout the literature, with an argument around whether there should be a primary focus of refining the user/professional, researcher/participant, clinician/patient and citizen/provider dichotomy. This includes the way in which people are written about and research presented. With no studies utilising participatory action research, this arguably seemed counter-intuitive to what the studies were hoping to achieve, particularly around challenging such dichotomous ways of working. It would be useful to understand if participatory research was considered and if not, the reason why this was not thought beneficial.

There is an argument that there is a responsibility of research systems in promoting social change, through a critical perspective around the use of language and the ways in which research practices support or stifle survivor movements. Overall, it is understood the research was carried out by adult researchers. Although most researchers probably have young people's best interests at the centre of their work, their practices may unintentionally reinforce generalised attitudes towards those experiencing psychological distress, potentially

perpetuating the 'incompetent' stereotype and stifling the recognition of young people's voices.

### **1.12 Conclusion**

This systematic literature review explored what is currently known about the experiences of young people and participation in the design and delivery of mental health services. This is the first systematic review around what is currently known about the experiences of young people participating in mental health service design and delivery. As evidenced within the systematic literature review, several areas for further research were identified. Most importantly, the review highlights the notable paucity of research into youth participation at the macro and meso-levels in mental health services. It is therefore difficult to determine whether the experiences of participation in the systematic literature represent a wider phenomenon or are simply reflections of the services, young people or research aims of these studies. Further research would need to be carried out to determine whether the findings of these papers share similarities or differences.

It is important to note that the research undertaken in this area typically focuses on discrete participatory activities rather than wider service delivery. Research also tends to focus upon outcomes of a participatory model or project in terms of overall service improvement, often without recognising the range of potential impacts of participation on a range of stakeholders, including young people (Crawford et al., 2002).

## **1.13 Rationale and Aims for the Study**

### **1.13.1 Rationale for the Study**

#### *1.13.1.1 Addressing the scarcity of research on the experiences of young people and participation*

The profession of clinical psychology produces a large proportion of the published literature on service user involvement and participation, of which Repper & Perkins (2003) provide a detailed discussion. However, there is very little from the perspective of young people, and no known research with the combined involvement in the research itself. This leads to the strong rationale for research understanding the experience of young people and participation in mental health service design and delivery.

Although research has been carried out around the personal impact on youth participation in mental health service design and delivery, the nature of the impact is not well researched (Crawford et al., 2002) and there is little consideration of how involvement impacts on the 'self.' Although recognised as highly valued, young people participating in service delivery plays a far less prominent role in the academic literature and has a relatively scarce evidence base around how young people accessing mental health services story their experiences and meaning of active service participation. To meet this research need, I considered narrative inquiry to be an appropriate route to contribute towards these noted omissions within the literature.

#### *1.13.1.2 Addressing the lack of research involving young people in the research process*

The powerful and oppressive dichotomies between 'service users' and professionals remain strong throughout the literature reviewed. This brings about questions around power, especially in the potentially exploitative relationship between the researcher and the researched. It is understood that no studies within the reviewed literature utilised

participatory action research. This is argued as being counter-intuitive to what the studies were hoping to achieve, particularly around challenging such dichotomous ways of working. In participatory research, there is arguably a more equitable collaboration in the research process. Participatory research is seen as a way of achieving a more 'relevant', morally aware, and non-hierarchical research practice (Pain, 2004). The forms and extent of this collaboration vary from individuals being involved in some, or every aspect of the research process, including establishing research priorities and setting research questions, collecting and interpreting data. Within the reviewed literature, Faithfull et al. (2017) reported that the interviewed researchers felt it would be beneficial to read research and hear from others who have engaged in the process of participatory research. Therefore, addressing the limitations within the literature reviewed in this field, this research aims to use a participatory research design.

### **1.13.2 Aims of the Study**

The aims of the current study are to explore *what* and *how* young people account for their participation, through the research questions:

How do young people story the experiences and meaning of participation in the design and delivery of mental health services?

What aspects of the self are expressed in these narratives and for what purpose?

In answering these questions, I have paid particular attention to the research design and analytical procedures as a way to give an overall research narrative that provides insight into how young people story their experience of service participation. The following chapter details the methods in which this has been made possible.

## **Chapter Two: Method**

### **2.1 Overview**

The chapter aims to describe the methodological rationale used for this project. The reasons for applying a qualitative approach using narrative analysis will be given. Following this, I explain the ways in which I have continued to hold a reflexive position to explore my personal views, preconceptions and other influences on the research process. Thereafter, I describe the research design, with insight into how the stories of young people taking part were elicited and the process of data analysis. Particular consideration will be given to the use of participatory practices, ethical conduct, and the quality controls employed in the research.

### **2.2 Qualitative Research**

Historically, there has been a dominance of positivist approaches within mental health research (Gill, 2012; Rogers & Pilgrim, 2014; Slade, 2012), often privileging one form of knowledge (objective truth) over another (subjective, interpretive). The researcher tends to hold an objective position within quantitative approaches (Burr, 2015). It could be argued that this has perpetuated societal divides between the 'expert' professional, who have access to this form of knowledge, and the subordinate 'patient' or 'participant' (Delvaux & Schoenaers, 2012). Bruner (2004) argues that qualitative approaches explore the way in which individuals make sense of their experiences in the context of their social lives. Henwood (1996) states qualitative methods "address the problem of inappropriately fixing meanings where these are variable and renegotiable," and that they "can act as a vehicle for bringing the relationship between researcher and researched into view" (Henwood 1996, p27-28).

This research aims to hear the narratives of young people participating in mental health services design and delivery. It also seeks to capture the diversity of these experiences.

This aligns with qualitative approaches which hold the notion that there is no objective or universal truth that we can identify. Although it can be said that both qualitative and quantitative approaches can bring valuable contributions to our understanding of phenomena, researching youth participation in mental health service design and delivery using qualitative methods may provide valuable information that may be lost if quantitative methods are employed alone.

Taking this into consideration, a qualitative method has been used. In light of there being a number of qualitative methodologies, it was important to consider the research questions and underlying epistemological position of the study in order to select the most appropriate qualitative methodology.

### **2.2.1 Epistemological Position**

It is important to draw upon my epistemological position rooted in my underlying values when discussing methodological considerations. The view is taken that research is an interactive process shaped by many factors (including my personal history, gender, and social class) and by the individuals who take part (Denzin & Lincoln, 2005). I am not neutral about politics and the social contexts of which this thesis is a part; these issues are one reason for researching this area.

‘Experiential knowledge,’ which can be described as knowledge gained through lived experience of a phenomenon rather than through study, can provide a valuable knowledge-base which can also challenge power relationships where stories are subjugated, appropriated and silenced (Beresford, 2005).

I have the view that language and our use of it does not describe the world in a neutral way but instead is a social act with material consequences for the position of the speaker and the subject. The use of language around ‘researcher,’ ‘professional,’ ‘service user’ and

'participant' indicates a dichotomous relationship bound up in power relations, with different rights and claims to constitute 'truth' (Campbell, 2009). I have considered the use of language relating to those taking part in the research. Rather than the use of 'participants' and 'service user,' it was felt 'young people' would best describe those taking part. However, I am aware that, in order to avoid confusion and misinterpretation, there may be times when it is necessary to use such terms. It is useful to draw upon the idea of Wittgenstein (1963), that meaning comes from use and through this research I am entering a 'language game' whereby I use but also critique dominant terminology. Contested terminology will be placed within inverted commas as a way to highlight this.

### **2.2.2 A Case for Narrative Inquiry**

Narrative inquiry was decided upon to approach this research for many reasons which will be elaborated upon below.

Narrative inquiry looks to study experience (Clandinin, 2013) and is inspired by the idea that people, individually and socially, lead storied lives (Connelly & Clandinin, 1990). Storytelling is considered the way in which people make sense of their experiences and create meaning, organising experiences in relation to others (Bruner, 2004). Telling stories about past events or experiences enables people to claim identities and construct their lives (Riessman, 1993). Through stories told and retold, people create a narrative identity (Ricoeur, 1988). Moreover, identities can be seen as fluid; they are constructed and reconstructed through the narratives that are told (Bruner, 2004). Identity narratives change over time as they adapt to new information, experiences and circumstances (Bruner, 2004).

Narrative inquiry also acknowledges the importance of the wider context such as the social, historical, medical, institutional, political, and cultural narratives within which peoples' experiences are shaped, expressed, and enacted (Clandinin & Rosiek, 2007). Stories

are bound by power issues and social practices which construct, prevent or marginalise available identities (Emerson & Frosh, 2004). This research is concerned with exploring the experiences of young people participating in mental health design and delivery. Narrative inquiry can allow the exploration of experience whilst acknowledging the multiple contexts young people find themselves in; the social, political, societal, cultural, and institutional narratives which shape the way in which they view themselves in relation to others. It enables the researcher to consider the ways young people draw on, or challenge, particular dominant discourses and cultural narratives. This is important to this research as it allows the consideration of how young people make use of dominant discourses around age, 'mental illness' and accessing mental health services in how they construct their own identities.

You're The Only One  
with your story,  
the nuance, the jokes,  
the grit and fairytale of it  
all. Who's more qualified  
than you to tell it?

Yrsa Daley-Ward

I believe stories hold power. Langellier (2001) illustrates this by stating that "embedded in the lives of the ordinary, the marginalised, and the muted, personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities, and illuminate new understandings by telling...their stories" (p. 700). This suggests narrative inquiry would be an insightful method for studying experience and identity. With the strong political agenda around participation in services, yet a lack of understanding around how this is experienced by young people, narrative inquiry offers a way to explore this. Williams, Labonte and Brien (2003) state "storytelling has re-emerged as a method with which people might begin to challenge dominant social discourses (and hence social structures) through their assertion of non-dominant cultural constructions, personal identities

and world views in the public sphere” (p. 34). These counter-narratives within research can work to challenge the master narratives, or dominant ‘truths’ in a given context by presenting alternative stories and views of reality (Bamberg & Andrews, 2004).

### **2.2.3 A Discursive Narrative Approach to Analysis**

Narratives can take many forms such as spoken word, text and images. They can be sourced historically or created in current contexts (Andrews, Squire, & Tamboukou, 2013). A discursive approach to narrative analysis can be particularly useful in exploring identities in talk as it considers identity in the context of broader social meanings, with the person actively taking up or contesting these in particular interactions.

Experience-centred narrative inquiry suggests a single event can bring about different narratives, which can vary over time and circumstances depending on the context in which they are produced and who they are told to (Andrews et al., 2013). In line with experience-centred narrative inquiry, narrative in the context of this research is considered as sequential and conveying a transformation or change. It can reflect human experience and assist people to make sense of both themselves and the world around them. Therefore, this approach aids the exploration of how young people make sense of their own experiences and identity as they move through their journey of participation in the design and delivery of services.

Even though life stories and narratives, as well as ‘service-user’ participation, are objects of an extensive body of research, and although personal experiences are understood as a key component in participation (Beresford & Croft, 2001), there is very little research investigating narratives within mental health service participation. When narrative approaches are adopted, the narratives of individuals tend not be central to the research (Eriksson, 2018). For example, Lloyd & Carson (2012) presented a service-user involvement model in which individuals’ narratives created a ‘critical conversation’ between those

accessing services and practitioners. This involved practitioners critically reflecting upon their practice. However, the narratives of individuals did not form the focus of the research, instead the focus was around the activity of involvement or the specific opinions that the narratives expressed.

#### **2.2.4 The Choice of a Narrative Approach**

It is important to further expand upon the rationale for applying a narrative approach as opposed to other qualitative methods.

Discourse analysis and Foucauldian discourse analysis are methods frequently used in social constructionist research, with both based on the broad premise that knowledge is created by, and taken from, social interaction. Discourse analysis focuses on the way in which meaning, and therefore knowledge of the world, is contingent upon cultural, societal and historical context (Smith, 2008; Willig, 2001). Foucauldian discourse analysis, which draws upon the work of philosopher Michel Foucault (1969; cited in Parker, 1994), considers the relationship between discourse and power, viewing individuals as products of discourses and explores the ways in which discourse constructs subjects, objects and institutions of social practice. However, it can be said that they experience limitations in accounting for 'self' in research (Burr, 2015; Emerson & Frosh, 2004). Furthermore, it can be said that narrative analysis can be used in a way which synthesises these two approaches (Burkitt, 1999).

Other methods which are interested in the content of narratives include Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009), Grounded Theory (Charmaz, 2014), and Thematic Analysis (Braun & Clarke, 2006). Firstly, I was particularly interested in experiences of participation over time, with particular memorable moments in time and their constructed meaning for young people, which seemed pertinent to narrative

approaches. Narrative inquiry allows the exploration of the content of narrative i.e. *what* people say, but is also concerned with *how* narratives are constructed, and *why* certain experiences and events are told and for *what* purpose (Riessman, 2008). It is of interest to draw upon surrounding contexts when researching youth participation as this can assist in exploring the ways the young people might draw on dominant discourses as they construct their identities. Finally, I also felt strongly aligned with the way in which narrative analysis maintains a case-centred focus on individual narratives, each analysed as a whole, rather than a movement towards observing generalisations across narratives (Riessman, 2008).

## **2.3 Design**

### **2.3.1 Participatory Research Design**

Central to this research is the consideration of the positioning of young people participating in mental health services and research. Traditionally, research 'participants' take a passive role, undertaking tasks which have been pre-set by the researcher (Ergler, 2017). Along with the intersecting societal position of young people as vulnerable and in need of protection (Dexter et al., 2011), young people can be excluded from research or included in ways which can be problematic (Yee & Andrews, 2006).

Participatory-action research challenges traditional assumptions of how to conduct research as traditional roles and relationships are disrupted or re-examined by the professional and 'service-user/survivor' researchers (Whyte, Greenwood, & Lazes, 1989). The research itself is a social practice, a practice changing practice. The approach enables the active inclusion of members of communities that the research sits within, contributing to the life of the research project. Participatory methodologies provide a vehicle for members of the community to contribute to the research design, coordination, analysis and implementation.

In order to provide an insight in to the supervisory relationship and way of working alongside Leann, research co-supervisor, young person and expert by experience, we have both shared reflections on the process, which can be seen below.

*Laura:*

*I began to consider ways in which I could move beyond the traditional involvement of young people as “participants” or “data contributors” within the scope of a doctoral research project. With the research being a project I am expected to lead on as partial fulfilment for doctoral qualification, I began considering possible ways of working with young people, with expertise in service participation, in the research process. I was introduced to Leann Stollenwerk, a young person with lived experience and expertise in service involvement, by my external supervisor Dr James Randall, Clinical Psychologist. They had originally met with plans to co-produce a transitions hub within a Child and Adolescent Mental Health Service (CAMHS) for young people transitioning to adult services. Due to a number of reasons, this project did not take place. Dr Randall was aware of my interest in participatory practices and Leann’s previous experience of shaping services, including advising on interview panels within adult mental health services, writing resources which were made available to those accessing services, and involvement in business development meetings within mental health services. He suggested we meet to consider ways we could work together and to see if Leann would be interested in building on her research experience.*

*Leann and I met at the initial stages of the research to think about ways she might want to be involved. We considered the idea of taking on a supervisory role and what this might entail. We were aware this is not a road well-trodden and that we were entering a new relationship as research colleagues and a new way of working. This could bring both obstacles we would need to navigate and opportunities of learning. There was also the*

*acknowledgement that although there is often an expectation that participatory research produces 'better' or more relevant research, we began to think about how this might not always be the case. Not having a pre-existing relationship with Leann meant we had some ground to cover when we first met, with time getting to know one another and why we were both interested in participatory approaches. It was important to bridge the personal and professional. We shared our ideas around the limiting terms of 'service-user' and 'expert by experience' and how they might function to further perpetuate mental health stigma and potentially further the divide between those who work in mental health services and those who are referred to them.*

*I was aware that involvement in the research would be a commitment and that Leann was soon to be relocating to university to embark on an undergraduate degree. Therefore, I wanted to create a space for an honest dialogue around hopes and expectations. It was important to understand what Leann would like to gain from co-supervising the research. I found reading Holland, Renold, Ross, and Hillman's (2010) article on a critical exploration of young people's engagement in participative qualitative research useful. I took from it that I wished to let Leann know I did not hope to position myself as an adult 'expert' attempting to teach Leann how to research, but instead tried to be collaborative and open to whatever aspect of research she wished to engage in. There were different areas of the research Leann felt her skills tuned into. These included advising on the stages of research and consulting on all written information given to young people taking part, advising on interview schedules, reading anonymised transcripts and commenting on analysed narrative accounts. I also explained that there may be times I might give too much information or not enough and we needed as much guidance from each other about ways to adjust this where necessary. This related to being aware of the risk of 'partial participation' where Leann may not feel able to contribute due to not having enough information available.*

*We also agreed that speaking on the phone, or texting throughout the research process was a good way of staying in contact. As part of the expectations of supervising on doctoral research, it was agreed to meet face-to-face as a full supervisory team at different points in the research process.*

*Leann:*

*Building a working relationship with Laura and collaborating with her has been a great experience for me. There have been difficulties regarding moving for university, but Laura and I have overcome these together and remained in contact throughout the project via different platforms. Laura has been patient and considerate of my personal struggles and supported me with remaining involved and feeling heard.*

*My role as a co-supervisor has been both challenging and rewarding. Drawing on my experiences as both a 'service-user' and my role in service participation, I've supported Laura with investigating the nature of young people's involvement in service development and the outcome on individual progress. I've taken part in shaping and evaluating research with Laura, contributing with my own reflections and interpretations.*

*Whilst connecting with young people and reflecting on my own experiences, I've discovered there can often be obvious power structures between 'service users' and their healthcare providers. This can be hindering and sometimes even painful for a young person as it can create a barrier between themselves and the support services necessary for their care and recovery. Working as a co-supervisor of Laura's research, I've found that I've been able to act as an advocate for young people and help bridge the gap between 'service-user' and 'provider.'*

*It has been inspiring for me, to see her work progress and to be able to take part in research vital to understanding and shaping services offering support for young people. Giving young people the opportunity to voice their opinion and reflect on their experiences of*

*involvement has given me time to reflect on my own and consider the impact of service-user participation. I am confident that if services are consistent with the inclusion of young people and their voices continue to be heard and make an impact, services can only improve.*

### **2.3.1.1 Involvement of Young People across Stages and Levels of the Research**

Holland, Renold, Ross and Hillman (2010) believe that close attention should be paid to how young people's engagement in participative qualitative research is facilitated, at what stage, with a clear outline of how much participation was achieved. An outline of how this was achieved within this research will now be detailed. It is important to note all young people involved in the research, either taking part in storytelling or consulting on the research were remunerated for their involvement.

#### *2.3.1.1.1 Advisory Groups*

Advisory groups took place in youth councils within an NHS site as a way to consider the relevance of the research and quality of the design. It was agreed in the advisory groups that it is important that young people as research 'participants' get to see the outputs of what their interviews contribute towards so it was agreed to share this directly with those taking part. Young people in the advisory group and the interviewees for the research requested a summary of findings to be sent once the research had come to an end, which was agreed (Appendix U). Young people shared their views on appropriate means and methods for wider dissemination, for example the potential for sharing via social media such as Twitter which has the potential to reach young people and engage in a dialogue. It can be said that this dialogical process resists the potential to colonise the knowledge generated through the evaluation and use it independent of the platforms young people have access to.

### *2.3.1.1.2 Consultation*

All young people involved in People Participation Networks within two NHS Trusts were invited via the People Participation Leads of the respective Trusts to advise on the current research. This led to a meeting with a young person to consider the current literature on youth participation in the design and delivery of mental health services. This involved reading an article reviewed as part of the current literature review and using the journal article as a central talking point. This was a helpful process as the young person made useful contributions by sharing aspects of the qualitative findings which related to his own experience and his views on the recommendations relating to future research. The discussion allowed for new perspectives, such as recognising that there should not be an assumption that all young people want to participate in mental health service design and delivery, the inevitability of additional responsibilities and active roles in the service which might conflict with competing demands around school etc. and also 'wanting to be a kid.'

### **2.3.2 Sampling Strategy**

Given the richness of accounts provided in the interview process and the importance of exploring the data in sufficient depth within the time and resource limitations of this research, it was anticipated that 6-8 young people taking part would be appropriate (Wells, 2011).

Purposive sampling was adopted for this project. The following inclusion criteria guided recruitment:

1. Involved in the design and delivery of mental health services
2. Previously or currently accessing People Participation Networks across two NHS sites in the South East of England.
3. Young people aged between 16-19years old

#### 4. Fluent in English<sup>3</sup>

It is argued that the inclusion criteria of young people previously or currently accessing participation networks allows for a more diverse group of young people taking part. This can provide an opportunity for young people to share stories of participation which may have come to an end and potentially share the reasons for this. This aims to address the limitations within the reviewed literature relating to a possible selection bias towards young people who may be more likely to advocate for participation in the design and delivery of services, and those who face less obstacles attending participatory forums. Young people who may have faced challenges around attending participatory activities regularly were less likely to take part in the research presented. Including young people whose participation work has come to an end may offer new insights and a space for young people to share their experiences.

Although not an inclusion criterion, young people taking part were likely to have a diagnosis of a psychological disorder, possibly a neurological disorder and/or learning disability. The age range 16-19 years offers an opportunity to consider both an important transition from adolescence to adulthood and from a service perspective, young people are potentially more likely to have had a range of experiences of service participation to draw upon. It is argued narrative identity emerges in the late-adolescent and early-adult years, partly as a function of societal expectations regarding identity (McAdams, 1985). A potential broadening of social networks at this age may lead to young people being found in a wide range of conversational contexts, encouraging young people to “figure out” who they are (McAdams & McLean, 2013). Furthermore, the transition from CAMHS to adult service during this time may also shape stories told. It was also known that this was the typical age

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<sup>3</sup> The approach of narrative inquiry looks at the use of language in co-constructing accounts of events, identity, and meaning. As an interviewer speaking only English fluently meant that the subtleties and nuances of how language is used and presented could be missed. Therefore, it was not possible or ethical to commit to interviews in other languages.

range of young people involved in People Participation Networks across the two respective Trusts.

## **2.4 Ethical Considerations**

### **2.4.1 Process of Ethical Approval**

Ethical approval was obtained from a NHS Research and Ethics Committee and the Research and Development department of the host Trusts (IRAS no: 244042, REC reference: 18/SS/0107) (Appendices D-I). The research was subsequently granted approval from the University of Hertfordshire (protocol number: LMS/PGT/NHS/02918). With interviews taking place across sites, including young people's homes, local Trust lone working policies were adhered to throughout.

### **2.4.2 Confidentiality and Consent**

Written informed consent from young people taking part was obtained. This also included consent for the young person's GP to be informed they were taking part in the research (see Appendix J). They were informed of limits to confidentiality and also of their right to withdraw at any time with no implications for their clinical care. See a copy of the information sheet and consent form in Appendices K-L.

During data collection, interviews were recorded using an encrypted audio recording device. To ensure the safety and confidentiality of the data, on the same day that the recording was made, the recording was stored electronically as a password protected file and the recording deleted. At the time of electronic storage, data was anonymised using a unique pseudonym allocated to each young person. The electronic audio recordings were then transcribed. The transcription files were password protected using a high strength password and anonymised.

### **2.4.3 Potential Distress**

It was recognised that interviews exploring personal stories may be associated with distressing feelings. Therefore, provision was made for support to be available should this happen. Young people taking part were provided with information detailing information for seeking support and information around access to services (see debrief sheet in Appendix M).

### **2.4.4 Remuneration**

There was payment for young people's participation as a way to respect the time spent participating in the research. NHS Ethics requirements stipulated vouchers to be used for those participating in interviews.

## **2.5 Procedure**

### **2.5.1 Recruitment**

The People Participation Leads in both respective Trusts were provided with an invitation letter and email (Appendix N) with an attached Information Sheet (Appendix K) to disseminate to young people part of the two Trust's People Participation Networks. The Information Sheet detailed the aims of the research, what participation would involve, and their rights to withdraw at any time (see Appendix L). Those interested in taking part were advised to contact the People Participation Lead or myself directly.

The role of the People Participation Lead within each Trust includes engaging with young people to gather feedback on services; involvement in the development and training of young people e.g. interview training; organising stakeholder events in which young people play a key role; organising regular meetings which young people attend in order to advise on service design and delivery.

Those interested in taking part were contacted by phone or email depending on preference, in order to introduce myself, respond to any queries, revisit the research aims, and

allow space for questions. It was ensured that young people were equipped with all of the information they would need in order to make an informed decision about whether to participate.

### **2.5.2 Young People Taking Part**

The study recruited six young people to take part in the research. A time and date was arranged for the interview to take place with each young person by phone or email. Arrangements were made for travel expenses and payment for taking part. Upon meeting, time was spent revisiting information about the research and answering any questions. All young people gave their informed consent to take part (Appendix L).

Demographic information was gathered at the initial stage of the interview to provide a context of those taking part (Elliott et al., 1999) which is detailed below. Those taking part were advised they did not have to answer these questions, and that approximations would be acceptable if they were unsure.

**Table 3.** *Demographic Information of Young People Taking Part*

Pseudonym	Age	Gender	Ethnicity	Length and reason for accessing CAMHS	Examples of participatory involvement	Participation length
Ana	19	F	British Indian	4 years Psychiatry review appointments; Psychological therapy	Interview panels; training events for nursing staff; involved in video making event for Trust; attended Green Paper Conference; review written resources for those accessing the service e.g. leaflets; involved in developing service newsletter	3 years
Drew	17	F	White British	9 years intermittently Medication management; Psychotherapy	Involvement in arts event; involvement in theatre event; delivering training; interview panels; involvement in safeguarding conferences for staff.	4 years
Rowena	19	F	British Pakistani	1.5 years Psychological therapy	Role of Youth Champion; speaker at parent support group; involved in video making event for Trust; involved in developing suicide prevention strategy; involvement in film showcase event on mental health awareness.	4 years
Jordan	17	M	White British	3.5 years Psychological therapy; Access to Gender Identity Service	Delivering training; interview panels; involved in video making event for Trust; involvement in staff events.	1 year
Beth	19	F	White British	15 years Psychiatry review appointments; Psychological therapy	Interview panels; on Green Paper Conference MH Discussion Board; on Health and Wellbeing Board.	18 months
Nadia	18	F	White European	2 years Psychiatry review appointments; Psychological therapy	Interview panels; review written resources for those accessing the service e.g. leaflets; involved in website development for service; involved in video making event for Trust.	4 years

### 2.5.3 The Interview Process: Collecting Stories

The research made use of narrative informed one-to-one interviews. Each interview lasted between 60 and 90 minutes. An interview guide (Appendix O) was designed with the research aims in mind and through supervisory input. The interviews were 'unstructured' as a

way of allowing young people to tell their own story (Wengraf, 2001). This meant there were a list of themes and prompts during the interview which could be added to, used in any order and were explicitly positioned as partial/incomplete. The general guiding themes of the interview related to anticipated stories of emerging identity construction through participation in mental health service design and delivery. The interview schedule was followed in a flexible way in order for narrators to tell stories that were important to them. The aim was to enable the young person to lead the interview, whilst recognising the construction and co-construction of stories through the asking and answering of questions (Mishler, 1991).

The interview began with the following open ended question designed to elicit narratives (Wengraf, 2001):

*'I would like you to tell me your story of how you got involved in different ways within mental health services. I would like to hear about all of the experiences that have been important to you, and how your understanding of yourself has developed over time.'*

## **2.6 Analysing Young People's Stories**

### **2.6.1 Interview Transcription**

All interviews were transcribed verbatim, including pauses, expressive utterances, where emphasis of speech was used, non-audible speech, laughter, overlapping conversation, interruptions, and the use of 'voice' or parodies of others (Wells, 2011). An extract of a transcript can be found in Appendix P.<sup>4</sup>

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<sup>4</sup> 'Drew' provided written consent for their transcript to be included (Appendix P)

### **2.6.2 Framework for Guiding Analysis**

It is understood there is no formal guidance on the analysis of narratives (Riessman, 1993). Instead, there are a range of approaches that can be drawn upon. Riessman (2008) refers to three broad approaches to narrative analysis. Firstly, thematic narrative analysis which refers to the exploring of content and *what* is said. Secondly, structural narrative analysis focuses on how a story is told, exploring the use of language, and how this is presented and organised. Lastly, performative narrative analysis, which combines aspects of both thematic and structural analysis. This looks to examine how narratives are interactively created and co-constructed within the research context.

As part of exploring the narratives of young people's experiences of participation in the design and delivery of mental health services, the three approaches were drawn upon in order to depict *what* the young people retold, *how* the retelling was presented, and with what *context* in mind. The multiple layers of analysis spoke to the exploration of stories of identity of young people within various contexts, including social and political contexts. This also allowed for other questions to be explored such as *who* is being spoken to, *when* and for *what* purpose (Riessman, 2008). It can be useful to consider how 'present' particular audiences are during the storytelling, referred to as 'ghostly audience' (Minister, 1991). This may be relevant for storytelling around mental illness and the way in which this might be told, with audiences such as a psychiatrist, a parent, a friend, peers within a participation network, or society held in mind at the time.

### **2.6.3 Analytic Process**

After the transcribing process was complete, each individual transcript was read several times whilst listening to recordings as a way to become immersed in the narratives. Reflective notes were made noticing content, identity performance and context (Wells, 2011).

Emerging stories and key messages were commented upon, noticing researcher position (Murray, 2014). Any apparent plots or the forming of narratives by linking events over time were noted (Riessman, 2008). I paid particular attention to preferred identities around what kind of stories were told (Riessman, 2008) and the way in which narrators employed or challenged societal discourses (Wells, 2011). Following this, the following questions were asked (Riessman, 2008; Wells, 2011):

*Reading for Content:*

- What kind of stories are being told?

*Reading for Performative aspects:*

- How does this person prefer me to see them? What kind of person do they want me to see them as?
- How is the person constructing their identity through this storytelling?
- Are there gaps and inconsistencies that might indicate preferred, alternative or counter narratives?
- Who is the story constructed for, and for what purpose?
- How does the narrator strategically make preferred 'identity' stories/ claims?
- What other identities are performed or suggested, and how?
- How did I respond to the person? How did this influence the unfolding of the story and its interpretation (Mishler, 1991)?
- Is there a way it could be interpreted differently? If so, how?
- What counter-narratives (Bamberg & Andrews, 2004) may be drawn upon?

*Reading for Context:*

- What cultural discourses does the story draw on, take for granted or challenge?
- Is there a master narrative the person is drawing on?
- How is this story situated in social, cultural, or institutional discourses (Daly, 2007)?
- Who might the 'ghostly audiences' be, such as a psychiatrist, a parent, a friend, peers within a participation network (Minister, 1991)?

NVivo qualitative data analysis software (QSR International) was used to support the data analysis. The software was chosen because it supports the analysis of large data sets. See Appendix R for an extract of data analysis process.

*Reading for Contrasts and Comparisons across stories*

After completing each individual analysis, a summary was written for each young person taking part. The final stage involved examining all accounts collectively, looking across accounts for comparisons between each young person's emerging stories. Looking across each young person's accounts for similarities and differences allowed emerging plots and subplots to be established. Once the plots had been determined, the transcripts were re-read with these plots in mind to assess whether these plots were reflected in the narratives.

**2.6.4 Gaining Alternative Perspectives**

The process of analysing each individual's narrative involves 're-telling,' and as a researcher, my findings would be a reflection of my own understanding. It is viewed that what is regarded as 'true' is only so in that particular time and place (Burr, 2015; Riessman, 2008). This highlights an important tension in the topic of research and participation, which is also present within the context of narrative research, but potentially extends further when

considering participatory practices and non-hierarchical relationships. In the context narrators tell their stories, they do so from a structurally subordinate position. As a researcher, I am now in a place where I am going to make an interpretation in a position of power within the research hierarchy. This might lead to unintentionally getting things wrong (Squire, 2013). Perhaps there would be a preference of those taking part for their stories not to be mediated by me, an adult professional researcher clinician who stands outside the experience of being a person who has been diagnosed with a 'mental illness.' This highlights the importance of giving perspective to their experience without violating that person's story. With this in mind, I looked to measures to ensure I did not make unjustifiable leaps within the analysis.

It is not uncommon with qualitative approaches to return to those taking part once analysis is complete as a way of exploring the way the researcher had presented their accounts (Lyons & Coyle, 2016). Member checking is used in qualitative research as a way to meet again with those taking part as a way to check that analysis resonates with them and is 'accurate.' However, this is more common within other forms of analysis, such as Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). In the context of narrative analysis, the act of member-checking would create a further layer of analysis, with re-representations requiring further analysis which is beyond the scope of this thesis. Without this, it was important to look to other means of considering alternative perspectives to narratives. Attending narrative workshops facilitated by a researcher with expertise in narrative inquiry alongside another trainee clinical psychologist created a space for discussion on narrative approaches. We were also able to collaborate on analysing anonymised transcript extracts. In addition to this, supervisors for the research independently analysed interviews and met following this to discuss and reflect on the similarities and differences in our analyses.

### **2.6.5 Representing the Narratives**

It is important to explore the ways in which I worked towards presenting a transparent account of the narrative accounts of young people taking part. As a way of 're-presenting' the accounts, a short summary of each narrative account is given. This offers background information and my interpretation of each individual account, including the main storylines and the tone, structure, and performance of their narrative. In order to make my interpretation explicit, these are written in the first person (Saukko, 2000). Direct quotes are interspersed within the text as a way of situating the young person within their narrative. Subsequently, collective narratives are presented with a consideration of the main storylines observed and the commonalities of experience across the young people involved in the research.

### **2.7 Credibility, Rigour and Pragmatic Use**

The standards employed in qualitative research to ensure quality and strength are based upon ideas of credibility, rigour and pragmatic usefulness of the research (Riessman, 2008; Yardley, 2014). Quality criteria for carrying out qualitative research have been proposed by many (e.g. Elliott et al., 1999; Henwood & Pidgeon, 1992; Tracy, 2010 etc.). These guidelines are intended to provide considerations for the conduct and publishability of all forms of qualitative research. The guidelines proposed by Elliott and colleagues (1999) have been applied to the research, with steps taken throughout the research process to ensure such criteria were met (see Appendix S for full details of quality evaluation). These include sensitivity to context, commitment and rigour, coherence and transparency, owning one's perspective, and pragmatic usefulness.

To allow for transparency throughout the research, I have attempted to make my position known. The ideas which shape this research and reflections on the process are shared. It was important for the findings to remain close to young people's narrative

accounts, with the use of extracts to highlight the links between transcripts and interpretations made. A section of Drew's interview<sup>5</sup> (Appendix P) along with details of the analytic process (Appendix R) has also been provided as a way to show methodological transparency.

I hold the view that knowledge should be created between people in dialogue, with the positioning of psychologists as working alongside communities to find shared solutions to problems. Participatory approaches have been employed within the research as a way of ensuring credibility but also in an attempt to continue to question the traditional roles adopted in mental health research. It is hoped this can further contribute to participatory research practices within the field of psychology.

It is argued that the sharing of narratives creates a context for social action and change (Andrews et al., 2013). Language and power are important areas to consider. It can be said the way in which language is used can determine who holds power (Foucault, 1980). The nature of the doctoral thesis requires academic language to be used. With the ethos of the research being participatory and accessible, I aim to co-write journal article(s) summarising the findings in accessible language with young people interested in the role of co-authors on the completion of the overall project.

### **2.7.1 Reflexivity**

Reflexivity is important in ascertaining whether the narrative research is valid and credible. A reflexive stance was taken to consider my own influence on the interviews and analysis, but also to attend to my own thoughts, feelings, opinions and values in relation to the area of research. Throughout the research, from inception to write-up, I kept a reflective journal (See Appendix T for extract). This included reflective notes made following interviews with young people taking part. This allowed me to attend to my own emotional

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<sup>5</sup> 'Drew' provided written consent for their transcript to be included.

responses, notice ways in which I influenced the co-construction of narratives, what particular parts of the interview I was struck by, what identities did I participate in during the interview (such as researcher, female, clinician, student, trainee, jovial, sensitive) and how this contributed to the co-construction of the story told. The reflective notes throughout the research contributed to all aspects of the research, particularly the analysis of the transcripts and discussion of results.

The supervisory team for the research provided a space for the sharing of critical reflections at each stage of undertaking the research. The research supervisors held a wealth of expertise in narrative research and service participation which allowed for a rich learning experience. It also provided an opportunity to reflect upon the ethical stance of participatory working, but also the tensions this brings from wider institutions when conducting research. The collective and supportive nature of the supervisory team was invaluable in this process.

## Chapter Three: Findings

### 3.1 Overview

This chapter provides an overview of the analysis and interpretation of the accounts of young people with experience of participation in mental health service design and delivery.

This reflects the stated research questions:

How do young people story the experiences and meaning of participation in the design and delivery of mental health services?

What aspects of the self are expressed in these narratives and for what purpose?

All individual accounts are initially presented as a way to introduce the reader to the main storyline and performance of their narrative. Each story brings to light a key thread for each young person, drawing upon the young person's own words (in italics), along with my observations of context.

This in turn answers the questions of *what* is talked about, *how* the young people taking part story their experiences, and *why* i.e. for what purpose (aspects of the research aims). This has been written in the first person as a way to show that this is a construction from my own perspective. Thereafter, I present my interpretation of collective storylines across all of the accounts.

Pseudonyms have been given to all accounts in order to maintain anonymity. All personally identifiable information has been omitted or anonymised.

## 3.2 Introducing the Individual Accounts

### 3.2.1 Drew's Story

Drew began by speaking of her passion for TV and film, particularly the way in which they can function as a catalyst for social change within communities. She also spoke of the multiple cultural contexts that film can capture, saying *"it's a way of reaching a lot of people."* She spoke of the importance that *"we tell people's stories in the right way,"* which seemed also to resonate with the interview itself, with Drew seemingly speaking to me as her audience. She appeared to bring a strong ethical discourse, describing the importance for herself and others to be treated the way they deserve, *"some people think they're better than everyone else and in my experience, like nobody is."* She also showed her thirst for debates and challenging misconceptions of sexuality and mental health, holding a satirical conversation with herself as a way of calling on others to deconstruct their own misconceptions of mental health problems:

*"well why do you think that... because I go to CAMHS or because I am on medication...and that means I'm mentally unstable?" "Okay...so why do you think that?" "Oh...because the media representation of people with mental illnesses is really inaccurate?" "Okay, yeah you're right it is...maybe we should do something about that."*

Throughout her narrative, Drew appeared to position herself as having knowledge and expertise, and as someone who can educate others. She referred to a time she told her peers *"we need to have a proper debate now because you guys are not up-to-date with feminism knowledge."* Drew appeared to convey a grittiness and hardiness as a narrator, which was enthralling. She told her story of participation in an immersed way, moving at a fast pace

through her experiences. Drew spoke energetically, telling detailed stories containing the description of events, but also characterisation with active “voicing” (Wooffitt, 1992).

Drew described her initial involvement in service participation as down to “convenience,” as it was during a time she was not attending school due to illness. She was invited to be on an interview panel and spoke of the expertise she realised she could bring *“I’ve had a lot of different therapists and psychologists and psychiatrists in my life, erm...so I kind of I think I can know roughly what makes a good one and what makes a bad one.”*

Drew storied feeling appreciated and the unexpected gains around confidence from participating in services, *“it made me feel really confident in something I wasn’t really expecting,”* particularly at a time when she described experiencing *“low self-esteem.”* Drew used a transformation discourse around how she previously defined herself and her identity. She used past tense to explain how she identified solely as someone with mental health difficulties, *“I couldn’t really understand my own identity and who I was...erm, because I had mental health issues for such a long time...that’s kind of all I identified myself as.”* She seemed to work towards re-authoring her own self narrative with the help of her friends, to a more rich multifaceted self. She described the experience over time of how she began to see herself as a funny, confident person, who can openly express her opinions, saying *“that’s something I’ve never been able to do before.”* She also spoke of coming to the realisation of being someone with the power to influence, *“it was like, actually I can change people’s minds.”*

Drew spoke of *“using participation as almost like a safety blanket,”* *“relying on it too much”* and it becoming *“destructive.”* It seemed that being part of the Participation Network from its inception led to a sense of belonging and ownership. She was able to lead on initiatives which seemed to have a positive impact. However, when other young people became involved in areas of service design, this seemed to lead to Drew feeling vulnerable to

being replaced *“Oh they just don't want me to do it anymore...they found someone new and they just don't wanna do it with me.”* *“I panicked thinking that that was going to get taken away and it seemed at the time I felt like that was the only thing I was good.”* She talks of a psychiatrist telling her their concerns that her involvement was not *“healthy,”* and Drew questioning this. She spoke about her involvement coming to an end for a period of time and how this was a real loss for her, particularly the loss of friends who understood her and opportunities to overcome social isolation. She then spoke of the People Participation Lead within the service staying in contact with her and at a later date, suggesting that she return if she felt comfortable to do so. She narrated an account of feeling *“nervous”* to return but also excited to be involved again in a range of projects.

### **3.2.2 Ana's Story**

Ana's story began with sharing her interests and how she liked to spend her time, which was the starting point of all narrative accounts and initiated by me. She presented a narrative around creativity, animal rights activism and politics, sharing that she enjoyed night photography, poetry and mental health blogging. Ana was careful in pointing out what she chose to share and not share to a wider audience. When referring to enjoying writing, she said, *“I like writing articles and things but I also like to write poetry but I don't generally share that...that's for me,”* implying a mutually exclusive public and private self, with aspects of her self she wished to protect and preserve away from others. It also seemed to speak to the research itself, perhaps communicating to me that there were pre-defined terms of what would be talked about. Ana was playful and evocative in her reference to the pivotal role she played in actively shaping the research, placing herself in a position of power to influence, *“this might just be great for your references...especially if I say something sarcastic [LAUGHTER] you know, that is generally what I do.”*

As Ana and I started the interview process, I noticed her looking to me for guidance. There were times when she let me know that she was unsure what else to say and indicated that she did not have any further points to make. Rather than sitting with silence and allowing space for contemplation, I noticed I was more active in the conversation. This meant the interview was shaped by the performative expectation of turn-taking which inevitably shaped the emerging story in a reciprocal way.

Ana told her story of participating in the design and delivery of services, speaking of a time where it seemed that the smoke screen cleared, whereby knowledge of service delivery not previously available to her became available, *"It is really interesting to see the other side. I'm like...so that is what she was trying to do."* It seemed that participatory practices allowed more transparency in the way in which services operated. She spoke of a shift in the patient-professional dichotomy which she had experienced previously, for example speaking at an event and working alongside a nurse who she had met with previously during a difficult time in her life, *"the person who was like, doing the talk with me was my old erm home treatment team nurse and yeh, it was interesting, it was really good."* Ana's experience of participation allowed her to story a narrative of being capable of doing something she did not believe she could previously *"so I am not very good at public speaking at all and I was like, it was only a room full of twenty people, so I went along and I tried anyway and I did it."* She explained how this helped her see herself in a new way *"maybe I don't suck as much as I thought."* This appeared to propel her to want to continue in this role *"I loved it, like I...I felt so good after it...I was really happy and I wanted to do something else."*

The theme of a private and public self continued through Ana's account as she storied her experience of participation, particularly the way in which participation allowed her to show a side of herself less known to others. She seemed to align with a self-disclosure narrative around sharing personal information about her mental health through service

participation and this requiring being brave. She spoke of a video around mental health awareness which she featured in, saying *"I managed to say everything that I would like to say but I am never brave enough to say,"* and goes on to say *"I would never say anything that sort of raw."* Her narrative account of this experience seemed to transport her into new identity constructs. There appeared to be a sparkling moment of self-expression and a point of entry into an alternative story for herself around showing vulnerability and relational risk-taking, *"I mean I sort of did learn that maybe it is sort of not that bad being more open about things."*

Ana ended on a position of uncertainty around transitioning from CAMHS as she moves into adulthood. She seemed unsure whether this meant she could no longer be involved in CAMHS service participation, potentially cutting short possible collaborations which she was hoping to be involved in, saying *"yeh it's just really uncertain,"* *"I mean I would love to do that but I don't know."*

### **3.2.3 Rowena's Story**

Rowena started by sharing her keen interest in musical theatre and her strong values around education and family. She explained that she was a carer for her grandmother, with her positive narrative centring on optimism. This seemed to suggest she wanted to show to her audience how being a carer was enriching, perhaps preferring not to draw upon times when this might be difficult. This seemed to relate to the social and cultural constructions around femininity and female societal roles. Similarly, Rowena appeared to position herself as a strong advocate for participation, storying her experience of participation as positive and optimistically framed, saying *"it's funny 'cause I think I just tend to like focus on the good that has sort of come out of it."*

Rowena told her story of being at her final therapy session within CAMHS when it was suggested she become involved in youth participation. Her story of participation centred on a self-disclosure discourse. By being involved in service design and development, this by virtue meant that she would be known to others as accessing CAMHS and experiencing psychological difficulties. Her anonymity would be removed, with this seemingly bringing both a sense of fear of how she may be viewed by others, *“what would they think of me, would they change, would people still want to be friends with me, would they wanna be friends with someone that is broken,”* and shame, *“part of it was the shame I might put on my family.”* This appeared to speak to the internalised and actual societal stigma around experiencing mental health problems and the potential of negative harmful outcomes such as social rejection.

*“I want everything to be anonymous and I never want my name to be associated with CAMHS and I never want people to know that I have been through, like I have had anxiety and been through self-harm...I don't want anyone to know I have had this, I was so adamant that I never want anyone to know.”*

Rowena then spoke of her surprise around the positive outcome she received after sharing her mental health difficulties with others. Through private experiences becoming public, Rowena appeared to story a narrative of acceptance, saying *“it's amazing how much support and how much positivity I received when I did openly speak about it.”* Rowena spoke of the wider societal stigma around mental health difficulties and within Indian culture, saying *“in my culture it's not really, sort of, mental health isn't really picked up on in Indian culture.”* Her story suggested a ‘breaking of the norm’ for someone in her family, culture and

community of speaking openly about the mental health difficulties. She appeared to speak to a narrative of working to “*break the barriers*” by sharing openly her experience.

Rowena's apparent values around family and supporting others seemed to be juxtaposed against the way in which she presented her own psychological difficulties within an individualised conceptualisation. It seemed the way in which Rowena at times construed her difficulties owed a lot to influential psychological theories, particularly cognitive behavioural and biomedical theories. She spoke of her experiences of psychological distress as not dealing well with “*change*,” saying “*change really triggers me*,” as opposed to drawing upon her circumstances of multiple familial trauma, death and illness in the family. Psychological language seemed to provide a resource for meaning-making around Rowena's difficulties.

*“Subsequently my anxiety peaked and I was diagnosed with generalised anxiety disorder and erm and I didn't really know, sort of, what was going on and why I was feeling, so sort of, nervous tense on edge.”*

Rowena's narrative seems to speak to westernised recovery scripts, a possible example of this being, “*I am more much more rational and I think CBT definitely helped with that.*” Her account also appeared to suggest a quest narrative (Frank, 1995) around gaining some understanding and meaning-making from the difficulties experienced.

*“I can deal with my anxiety now but it doesn't mean to say...it doesn't erm...it doesn't mean it has completely gone away. There can be times where I can be so anxious and feel so ill...I am not just an ill person, I can rationalise it and I think that is a massive difference now.”*

Rowena narrated the surprise participation brought when she realised her own capabilities, saying “*wow, I can actually do stuff [LAUGH] like I am not completely hopeless.*” She spoke of participation opening doors and providing a platform for other opportunities of career development which she described as a vehicle in building her “*confidence*” and “*self-esteem,*” saying “*it has rebuilt my confidence.*” Her motivation to pursue a career in psychology seemed to allow for her professional and survivor/service-user identities to merge.

### **3.2.4 Jordan's Story**

Jordan began his story sharing a bright array of creative interests including music, drama, theatre and dance, before describing his studies at sixth form. He later spoke of his involvement in participating in the design and delivery of mental health services and how this created a space for him to be creative in film and writing poetry about mental health. Jordan then started his story of participating in service design and how his initial involvement came to an abrupt end when the therapist he was meeting with “*told the Participation Lead that it was best if I stopped for my tre... to help my treatment if I stopped getting involved, erm but I wasn't told about that at the time.*” He described this leading him to feel annoyed and disappointed, going on to say “*I felt a bit rubbish I think for a while.*”

When it was later suggested for him to be involved again in service participation by a different therapist he was meeting with, he described feeling cautious as a result of having felt let down before. He described feeling nervous around new people at the Participation Network meetings again, but persevered and “*pushed through that difficult bit.*” He spoke of this becoming “*one of the best...most relaxing places to be.*” His story appeared to build from his involvement in co-producing service resources such as letters, posters and leaflets, to then sitting on interview panels for those applying to work within CAMHS. He described

this experience by saying, *“you get a say in who works here ‘cause they are going to work with young people, so it’s just fair really and that’s really cool because it’s like you are having a real impact in how it’s being run right down to who works here.”* He used a narrative around making a difference and being recognised as making a valuable contribution to mental health services, saying *“we are often told we are the best part of the day or the most helpful which is really nice to hear ‘cause you know, we are making a direct difference.”*

Jordan described the way in which participation in service design and delivery provided a space to speak about his own mental health difficulties and experiences of gender identity to a wider audience. He spoke about how this in turn helped him reframe the problems he encountered in his life as a way to help others and change systems. This appeared to speak to the importance he placed on raising awareness and helping others. Jordan featured in a film about his journey with his gender identity which he described as at times being a difficult process:

*“I was thinking ‘oh yeah I can talk about it because that will really help people’...that was tough but actually I can look back at it and yeh, so it is nice to yeh, realise and being able to be given that space to talk and think, yeh, to think about those kind of things because it is easier to push those things aside and get on with your day.”*

This suggested a need for stepping into a less comfortable position and demonstrating emotional risks in his relationships. He spoke of his experience allowing him moments of reflection to notice a transformation in himself, saying:

*“[Making a film] about my journey with my gender identity which was really nice and a bit difficult at times to talk about but it felt good afterwards like again it makes you realise how far you've come, I think it's quite easy on day-to-day basis to forget that and how every day you are just like living as yourself but you don't realise like 'wow' actually a lot has happened.”*

He appeared to use an authenticity discourse when storying his experience of sharing his own personal struggles through service participation, saying *“I've been able to stand on stage and perform and things but as myself, it is more difficult, like I wouldn't have stood up on my own as myself and not a character, but now I am doing that.”* He went on to speak of the confidence his experiences of participation had brought him and how this transferred to other areas of his life, *“I don't even really get nervous about it which is really cool to say and in my daily life, I think that has helped me to be more confident on a daily basis.”*

### **3.2.5 Beth's Story**

As Beth began her account of service participation, very early on it seemed important for her to share her story of accessing CAMHS, with less time spent on storying her personal interests around computer gaming and film, which were shared after my prompts. It seemed Beth's story of the reasons for accessing the service was an account that 'needed to be told,' that there would be a key part missing if the story that precedes participation stories was not said.

Beth, was initially referred to CAMHS at the age of three and felt it important to say *“I have had quite a long stay,”* positioning herself as different from others typically accessing CAMHS who may *“dip in and out.”* She spoke of not being informed that there was the option to participate in service development until she was seventeen, referring to it

being on a *“need to know basis.”* It was suggested by the psychiatrist she was meeting with during the time she was accessing CAMHS and had developed a close relationship with. She described it as a *“welcome distraction”* at a time she was moving to adult services.

She then began her account of service participation as having a function to feedback to services about her experience of accessing CAMHS and not feeling believed by clinicians, saying *“maybe if they had believed me in the beginning things wouldn't have got as bad as they did.”* Her experience of accessing CAMHS during her early years seemed to have created a sense of unsafe uncertainty around making sense of her difficulties. She talked of her experience seeking a diagnosis of schizophrenia in order to have ‘answers’ and some certainty around what she was experiencing whilst the service appeared to resist this, *“I kind of needed to know that what I was going through wasn't like, in my head and made up...I needed to know that it was something.”* She talked of her experience of not feeling heard or believed around her mental health difficulties *“they kind of thought in the beginning that I wasn't really hallucinating. They thought that it was like an attention-based thing.”* She described participation as a way to reclaim confidence, saying *“it just kind of helped me get some confidence.”* It seemed to provide a way of initiating a dialogue with services to voice that the way in which she was treated was detrimental to her wellbeing, she said *“participation has just been really good so I can go back and say...you know, ‘I know you were trying your best, but maybe kind of look at it from my point of view as well’...”* *“...Through participation a big part of it is also speaking about what went wrong so that the services can improve.”*

Beth appeared to present with a discourse around wanting to be heard. She appeared to acknowledge and challenge the service and wider societal conceptualisation of the way in which children and young people tend to be positioned, and the powerlessness that this brings, *“I was quite young so I could understand...maybe they, you know, they had to take a*

*more kind of view from my whole family 'cause you know, I don't know...I feel like they should just listen to children."* She also reflected on her experience of hallucinations at a young age which seemed to have brought about a perceived scepticism and a sense of not being listened to. Participation seemed to provide Beth with a way of working alongside services to mobilise change and to feel heard. For example, she talked through her experiences of being on interview panels for prospective CAMHS staff and the powerful role she had in the decision-making of appointing staff; *"they don't get the job because they haven't erm treated me as an equal."*

Beth went on to share a particular moment of change in how she viewed herself, when she was speaking at a health and wellbeing board attended by MP Councillors and clinicians, including psychiatry and service managers, saying:

*"it kind of clicked in my head that I must have progressed a long way to be able to actually stand in front of all these people and talk about it, because I was always very anxious I would have panic attacks four, five times a day and I still struggle with those kind of things, but it kind of clicked in my head when I was standing there and telling everyone, like wow, though like my confidence must have improved along the way."*

### **3.2.6 Nadia's Story**

I met with Nadia in her home and immediately my eye was drawn to the artwork covering her door and around her room. I was quite openly taken aback by her attention to detail and use of vivid colours, and shared with her that I thought it was really beautiful. Nadia showed me a wonder woman drawing which she pointed out as her favourite piece

(this can be seen below). Nadia was an engaging narrator of her story, for the most part presenting a coherent, although not always chronological, account of her experiences.

Nadia's story of service participation was rooted in a narrative of acceptance, purpose and connectedness. She initially described her route to participating in the design and delivery of mental health services, sharing that she had asked the clinician within the service she was accessing if there were groups available which offered peer support. She then began to describe the way in which the people participation lead appeared to carefully consider suitability of young people taking part. She described the nature of the group as a "*sensitive ecosystem that really can't like, yeh, that shouldn't be disrupted and it could be disrupted.*" This appeared to speak to the importance she placed on creating a sense of safety in social settings. Being in a nurturing and "*safe environment,*" and around others who were open about their experiences of mental health seemed to allow Nadia to be open about parts of herself previously hidden,

*"I did see that it really changed, like...it really helped me with my anxiety it really helped me be more confident and also made me more confident to talk about like my issues, because I have been surrounded by people who have similar experiences," "it did like make me realise that it is ok to talk about it and I am a lot more comfortable talking about it with other people not just from the group, and like I don't hide it, which I did hide for like years, like I wasn't even able to open up."*

She storied the way in which her experience allowed her to build relationships and get to know people at a time when she had recently moved to the UK and was learning to speak English. She described initially feeling very "*shy*" and "*nervous,*" but still enjoyed the sense of connectedness with others. Through participating in service developments, Nadia

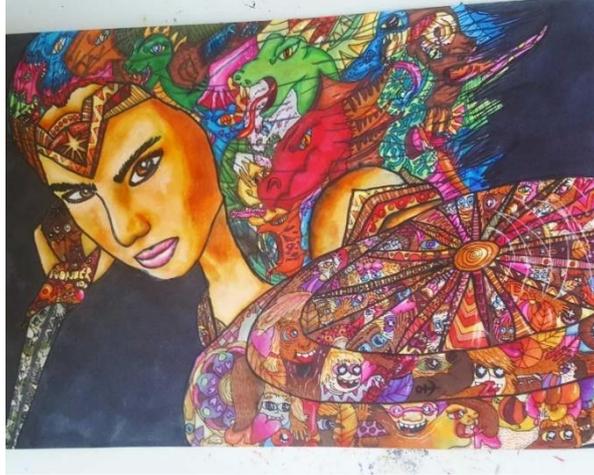
described meeting a group of friends with a shared understanding, *“I’d say we are all like good friends now, just great, and it’s good to have, like...the sort of group, because we all understand each other.”*

Nadia shared her experience of featuring in a film on mental health awareness and seeing the impact it had on others when watching the film. She spoke of being congratulated afterwards on her achievement, saying *“it was really nice because, like...while we were watching it and watching like other people watching it, we can like see the impact it has on them, and some people did get emotional.”* She described sharing *“personal”* aspects of herself in the film, a side of herself she would tend not to share, specifically saying that she suffers from *“anxiety and depression.”* She spoke of feeling nervous showing this side of herself to others. Not having a personal connection with her audience seemed to help her show vulnerability, but it also seemed strange to Nadia to share something so personal without the typical reciprocal nature of sharing in relationships, *“I was pretty nervous at first but...but...it does help in a way that the people we are showing it to don’t know me.”* Not seeing them again allowed her to show a different side to herself.

*“it would be a bit awkward seeing someone again that I had never met that just saw the video and like, the only thing they know about me pretty much is that I struggle with depression and anxiety and that like other interests that I said in the video; it’s like I don’t know anything about them but they know really personal things about me.”*

She spoke of the positive things that came out of her experience participating in service development, returning to a narrative of “quest” and personal development (Frank, 1995). Nadia presented a progressive narrative of ongoing identity reconstruction, focussing

on confidence and being more open to those around her, *“I am definitely a lot more confident and I do like get people pointing that out, like saying that I speak a lot more, that I am happier and that I do like socialise a lot more.”*



**Figure 2.** *Wonderwoman. Artwork by 'Nadia'*

### 3.3 Storylines

The narratives of each young person were considered collectively, noticing similarities and differences across the stories told, particularly making reference to stories of identity. This process involved examining the storylines which the narrators chose to tell, whilst considering the way these narratives communicated a preferred sense of self. The analysis of the narratives and interpretations of identity construction were considered in relation to wider social, political and broader contexts in which they were co-constructed. The possible ways in which narratives may align with, or contest discourses and wider community narratives were drawn upon. It is argued that such discourses and contexts provide a framework for, and also limit to, identity construction.

Four main storylines were observed across accounts. These were stories of 1. Moving into social spaces and holding out a helping hand; 2. Having to become the 'right fit' for

participation; 3. Repositioning from patient to person; 4. Strengthening alternative identity stories through relationships. These narratives included sub-stories within each (Table 4).

**Table 4.** *Storylines and sub-stories*

<b>Story</b>	<b>Sub-story</b>
<b>Moving into social spaces and holding out a helping hand</b>	Self as social “They kind of get me” Self as helping others
<b>Having to become the ‘right fit’ for participation</b>	Youth participation offered to those “well enough” Youth participation taken away: perpetuating power differentials Self as heard
<b>Repositioning from patient to person</b>	“we are both just people” Stepping in and out of an illness narrative Flipping the power imbalance
<b>Strengthening alternative identity stories through relationships</b>	Calling deeper on courage and stepping into new realms “Wow, I can actually do stuff” Empowerment and building confidence A message to you

### **3.3.1 Moving into social spaces and holding out a helping hand**

The process of being involved in service participation appeared to bring opportunities for young people to form a collective in shaping services. Young people spoke of this reducing social exclusion and contributing to their overall wellbeing, bringing about a valued social identity.

The peer support element of service participation appeared to give the young people taking part a positive experience of receiving help from other young people and also taking the role of helping young people in times of difficulty. This suggested an important relational aspect of participation in the design and delivery of services, in which there was an investment in building trusted relationships between young people. Young people spoke of their relationships with others involved in service participation, who they perceived as people

who genuinely cared, were non-judgemental and available in times of need, as core to their experience of participating in service design and delivery.

### 3.3.1.1 Self as Social

Participation was storied by all the young people taking part as a vehicle for making connections. There were stories of youth participation allowing young people to foster friendships and mutual trust with others involved in service development and outside this context. Rowena stated, *"I see them in a different way...I see them as friends."* All the young people taking part used the collective pronoun "we" when referring to others involved in service participation. Drew spoke of her experience being part of a film making project, saying *"it was a really empowering process for all of us because it meant that we got to...you know...put our ideas in and actually talk about things."*

Nadia spoke of the social aspect of meeting other young people through service participation allowing her to reveal new parts of herself, *"it did help me a lot to come out of like my shell."* It appeared that this transferred to other social situations, such as school, with Nadia saying, *"I barely spoke at school at all and I am like...comfortable with that now."* Similarly, Drew stated, *"there's just parts of myself that it's like flourished so much more...so like my ability to like talk to people and say things in a jokey way and actually feel like I'm actually a fun person."*

Jordan described how joining a network of young people actively participating in mental health service developments created social connections with young people who could help brighten tough days.

Jordan: *"I always feel better afterwards 'cause I'm in a setting that is relaxing and with people that I know make me laugh and we have a great time so it's really nice in*

*that way, it has helped me a lot. I have seen that change. It's been like a tough year but this is quite a regular good thing that has been happening."*

There were times the young people taking part spoke of being able to sit with their peers' distress in the participation network without fear, judgment, or sympathy. Rather than try to fix, change, or rescue, sitting and bearing witness to the person's suffering was enough. Drew shared, *"if you're struggling with it, then we're gonna be there for you."*

Nadia: *"If I make plans with someone from the group, like...if one of us says, 'actually like, I am really struggling today, I am not sure if I can come,' it is totally fine and like...they, it's like...ok like 'is there any way I can help you' or like...like, just be there for that person, that person is there for me but there is no judgement."*

It seemed experiential knowledge, insights and skills developed through coping with life challenges helped relate to other young people and provide support, rather than the perceived and actual societal stigma associated with 'mental illness' setting the young people apart from each other. This appeared to give the young people solidarity in times of need and a space to share when they were able to overcome personal challenges. Drew spoke of rooting for one another by lifting each other up and recognising when they had achieved something they had previously found hard to do, *"You know, stuff that they're going through...that you can then highlight it and say, 'I've just noticed that you've done that. That's great."*

Interestingly, Beth storied a different perspective, describing a "catty" or "unwelcome" environment between herself and other young people participating in service development. There seemed to be competition fostered between young people when speaking

to wider audiences and sharing their stories of accessing CAMHS. This appeared to set a scene of young people pitching against one another, with a question around which marginalised voice would be heard. Beth seemed to employ a rivalry discourse, suggesting a competitive nature between young people around who is heard.

Beth: *"It seems like, jealousy between, like you know, each other and there's kind of like, a kind of catty environment and people are trying to contradict what you say and like, well no, I experienced it like this and you are like, okay, I appreciate that but I am talking about my experience."*

### **3.3.1.2 "They kind of get me"**

Across accounts, it appeared that the exchange of emotional support, informed by experiential knowledge, was invaluable. Trusting relationships seemed to allow for mutual aid. Ana said *"it was nice to like talk to other people who err erm who went through similar things,"* going on to say *"I had made a lot of like friends who did sort of understand."* Similarly, Drew said *"they kind of get me"* suggesting a sense of feeling understood, going on to say *"it just feels ...makes you feel you're part of something."*

It seemed the shared experience of mental health problems for young people engaging in service participation acted as a key bonding point in the development of supportive relationships. This commonality seemed to engender trust and a feeling of acceptance. Drew spoke of being open about her feelings and not feeling judged, misunderstood or perceived as vulnerable or in need of help.

Drew: *"I'll make a joke about like 'Oh it's fine, it's just the voices in my head'"*  
*"...everyone will think that's really funny because they know, you know, I'm only*

*joking...it's not something that's still going on but at the same time we can laugh about it and make light about it. But if I said it to anyone else they'd be like 'Do I need to talk to your counsellor? Do we need to let someone know?'"*

Rowena spoke of the peer support nature of her involvement in the participation network and this being a safe space to bring important life issues presenting at the time. She talked of young people uniting and being there for one another in times of need, *"you know, everyone will at one point, will come to a meeting and they won't look ok but you will go home and get messages from everyone like, 'are you ok? We are here for you.'"*

It appeared that young people who have also 'been there' are viewed as being better prepared to give support to each other by virtue of the expertise and understanding what these experiences convey, with their similar experiences giving them knowledge that is more accurate and a deeper appreciation of what a person is going through. Rowena shared, *"it does help to just offload with people, you know, who aren't gonna judge you...sort of have similar experiences...they're gonna get it."* This appears to speak to the contesting of westernised concepts around individualised mental health problems and receiving help, along with the privileging of independence over interdependence. Rather than being fixed in the role of being helped, the young people taking part described moving between the roles of 'helped' and 'helper' as opposed to being thought of as a 'problem' in need of 'being fixed.'

Drew: *"You can come in and say, 'actually I've had a really bad day today and I thought of killing myself three times,' and everyone goes, 'Okay, do you need to talk about what's going on?' And I don't really want to talk about it, 'okay, that's fine. Let's do something that will make you feel better,' you know?"*

Mutual encouragement seemed to help the young people to realise they were not alone in their struggle or abnormal in their experience. Drew speaks of being able to “*cheer each other on*” and offer mutual support, saying, “*I was like ‘You know what? Good job, like I’m gonna buy you a coffee after this.’ And he is like, ‘did you notice?’ and I’m like ‘yes I did. Well done. I’m so proud of you.’*”

### 3.3.1.3 Self as Helping Others

Across narratives there seemed to be shared stories of wanting to help other young people experiencing mental health difficulties by improving services. These seemed to speak to ‘quest’ narratives (Frank, 1995) where the young people met suffering head on with a view to conquering adversity by supporting others with a similar struggle.

Rowena: “*the response you get from people it sort of reinforces wanting to do it because you feel like...I feel like I am making a difference and taking a really negative like difficult time and making into more of a positive one.*”

This seemed to speak to the idea there is something to be taken from suffering that can be achieved by helping others and offering hope. Rowena said, “*I love when people come up and talk to me afterwards and tell me thank you, like you have given me hope and like it is really nice.*” Ana seemed to go further in storytelling her position on the importance of being ‘well’ in order to help others, “*If I am ill, I can’t really help other people.*”

By being granted authority by virtue of their experiences of psychological distress and service access, it seemed the young people taking part wished to seek progressive developments in services and change societal perceptions of mental health. Three young people storied their interest in helping others and working in mental health settings,

suggesting a merging of professional and survivor identities. It seemed that by helping others, this was a way to 'give back.'

Beth: *"I have been with CAMHS for a very long time and mental health has been a big part of my life. I kind of decided quite early on that I would go back into the services to help other people."*

### **3.3.2 Having to become the 'right fit' for participation**

There were differences across accounts around how service participation became known and their experiences of others deciding when or if it should be taken away.

#### **3.3.2.1 Youth participation offered to those "well enough"**

Nadia spoke of the importance of having the "right" people join youth service participation. She made use of educational discourses, explaining that people had been previously "excluded" from youth participation, although it became unclear whether this was because they no longer wanted to be involved or if others made the decision for them. Beth also spoke of the importance of being "well enough" in order to participate in the service delivery.

Beth: *"We need to make sure we are getting people who are far enough along in their recovery to be able to cope with it but essentially they still need to be a service user 'cause they need to have things that they can reflect on and help us with."*

It seems that Beth then suggested a perceived deeper more implicit power imbalance and control that seeps within the service around who can share their views and opinions to

services, and what the consequence of this might be, saying *“people don't really want to come forward and speak about that because then they are worried about, 'well if I speak out about that, then I will get discharged and I won't be able to get more treatment and I don't really want to speak about that because I am scared.’”* This suggested a perceived culture of fear amongst young people accessing CAMHS. She appeared to employ a discourse around protecting one's own interests, with the idea that openly sharing negative experiences of accessing CAMHS may result in access being pulled.

There appeared a lack of clarity around the decision-making process behind why youth participation was suggested to young people accessing CAMHS. Rowena said, *“I dunno, maybe she saw something in me I didn't see in myself.”* Drew spoke of the time it was suggested she get involved, being told *“Oh well, [Drew] you're really good at speaking to people,”* suggesting this was a quality suited to service participation. Ana spoke of perceiving herself to be suited for youth participation due to her having strong views and voicing her dissatisfaction with services, sharing:

Ana: *“I didn't enjoy certain parts of my service, I dunno...I was pretty difficult and I wasn't afraid to tell her that I didn't like the way she was doing things and so she was like, 'you would be great, you would definitely be able to tell people what you know.' So erm...I dunno, I think it all started from the fact I was just really negative about everything.”*

Interestingly, she spoke of a nurse with different views on her being a 'good fit' for participation and how the nurse's views changed, *“she joked to me, erm, she would have tried anything to dissuade me from coming on a talk with her because I was so negative about services [LAUGH] back then but now she is so glad that I did go.”*

Young people taking part spoke of participation being on a “*need to know basis*” and finding it difficult to find out it about it. Nadia said, “[I] *had to ask like if there’s anything specifically...it wasn’t just like offered to us like as an option.*” These stories suggest a selectivity process not explicit in the ‘service-user’ arena which may privilege some over others in being ‘offered’ involvement in service participation.

*Beth: “I’d been with CAMHS for quite a long time but I was never really told about the participation kind of side of things. I found out quite late which seems to happen to a lot of people. It is not really erm known about [LAUGH] you kind of...it’s on a need to know basis which I understand. You have to make sure the people are well enough to participate and things but I...I feel like it’s a little bit too hidden.”*

This appeared to speak to agency and power almost as attributes that young people can ‘have’ and that are enabled, promoted or ‘given’ by the service or professional as opposed to the foregrounding of young people’s conceptual autonomy and locating young people as active social agents. It also seemed to align with discourses around young people with mental health difficulties being vulnerable, in need of protection and unable to make decisions for themselves.

### **3.3.2.2 Youth participation taken away: perpetuating power differentials**

Other young people taking part described experiences of their involvement being rescinded, seemingly without either their knowledge or agreement.

Jordan: *"I stopped involvement because my therapist at the time told the Participation Lead that it was best if I stopped for my tre... to help my treatment if I stopped getting involved erm but I wasn't told about that all the time."*

Jordan's response seemed to place him in a position of powerlessness and accepting the decision made, saying *"fair enough if it is not gonna help with my progress."*

Drew spoke of *"using participation as almost like a safety blanket"* and it becoming *"destructive."* She spoke of a psychiatrist telling her their concerns that her involvement was not *"healthy"* and that she was *"relying on it too much."* Drew seemed to contest and reframe service constructs of dependency to valuing and holding onto relational gains and valuing the sense of belonging that participation opened up for her. She spoke of what she lost when she no longer was able to engage in service participation, *"friends who also understood what I was going through because they were going through similar things."*

### **3.3.2.3 Self as Heard**

The self as heard and having an impact seemed to be a narrative shared across stories. It seemed participation acted as a way of sharing stories of the young people's own care and the service they received in a space they felt heard.

Beth spoke of noticing her position of standing up and contesting a position of being silenced and marginalised when speaking with her local MP about mental health provision *"with the local MP and he was kind of saying erm you know...well there's nothing we can do...the situation is what it is and I was like... 'well then find something you can do,' [LAUGH] when I was kind of saying all that, I was like... ok I have definitely progressed."*

This seems to raise an interesting tension between having a say vs. being heard. There

appeared to be a surprise when the young person's voice was heard, with Ana saying *"it felt like they were actually listening."* There also seemed to be ghost audiences of services which the young people were speaking to as a way of emphasising their right to be heard and valued.

*Nadia: What I say matters and my opinion mattered because the feedback we gave was like, actually taken into consideration. They did act on it and they did change some things so that felt good."*

Drew spoke of perceiving members of staff as disregarding of her due to her age in the context of youth participation and expressing her views, referring to staff saying *"Oh well...you're a young person you know...you can't speak for all young people."* She described actively challenging this, *"So I'm like 'Yeah I know I can't, you know ...there's loads of us out there but I'm just here to give like a general idea of what I think and what I think could be helpful."*

The apparent sense of feeling heard also related to a sense of being valued and having purpose. Beth seemed to tell a story indicating an immediacy of a transformation of feeling heard and valued.

*Beth: "As soon as I went on interview panels it was like, actually I'm someone who has an opinion that people value and want to hear, and I'm seen as an equal with these professionals in this environment."*

Although there appeared to be shared stories of feeling heard across the narratives, there were also stories which appeared to question whose opinion stands and whether

differing opinions can sit alongside each other in youth participation. This seemed to speak to issues around the validity of different knowledge standpoints and the ownership of knowledge and its interpretation, and the dominant hierarchies of what knowledge is considered credible.

Young people within the research spoke about noticing when they were being heard by professionals around service decisions such as recruitment, service infrastructure, resources for people accessing services and when speaking about their experience of accessing CAMHS in conferences and training sessions. Beth spoke about her experience of 'having to tell the right story' to be heard, and this separating her from the other young people. This suggests having to be innovative in finding ways to be heard but this sometimes coming at a cost. Beth spoke of being part of board meetings and the perceived expectation to provide clear recommendations and a 'buy in' rather than share experiences of accessing services with apparently no clear aim. She appeared to be mindful of the message to give and how she might be heard. She spoke of appearing "*heartless*" to other young people when she tried to shape the messages they were trying to convey. It seemed by trying to conform to service expectations around participation, she felt distanced from other young people.

*Beth: "Other people on the Board, they kind of look at me as like, 'ok, no she gets what we want to know,' then to other people I seem heartless, because they are trying to tell their story."*

### **3.3.3 Repositioning from Patient to Person**

Roles are fundamental determinants of self-concept and components of someone's identity. Across all narrative accounts, young people indicated a transformation from being a 'patient' in professionally-led services (i.e. 'top-down' services') to being positioned as a

person who is equal to professionals. There appeared to be a challenging of the assumptions underpinning the labelling and 'othering' processes arguably at work in the mental health system and the communities they sit within.

### 3.3.3.1 "We are both just people"

Drew seemed to position herself against dominant discourses about people with mental health problems a number of times in her account, confronting perceived and actual societal stigma, *"people seem to think we're called patients."* *"Well I'm not a patient I'm just a person...like, I don't need to be referred as a patient."*

Beth: *"I think for the first time for them I was kind of just another person. Like, I wasn't their patient. I wasn't someone who was vulnerable and ill who needed help. I was just someone who was there to give a training session."*

Stories of Beth and Drew embodying the patient identity in the past seemed to bring with it assumptions around their future and career opportunities. This seemed to reflect wider societal discourses of discrimination of those experiencing mental health difficulties in the workplace.

Drew: *"I really wanted to work with children...I was like...;Oh I'm never going to be able to do that because they'll look on my records and see 'oh she has a history of mental illness, we can't let her around children' and actually that's not true."*

Participation appeared to allow a shift in seeing the self as equal to others, with equal opportunities in work, particularly working with children or in mental health settings. This

discourse appeared to enable a resistance of a 'mental patient' subjectivity, for example, providing Beth with an opportunity to use her knowledge and gain experience in a profession she hoped to move into. This shift in identity from patient to person seemed to allow for new possibilities and an embracing of new role expectations. The young people appeared to make references to the self as having purpose, being valued by others and feeling heard. Nadia spoke of the sense of purpose service participation offered, saying "*that did make me feel like, like I had an impact on something which was like, I am not just sitting there and being useless in a way...like...I am doing something.*" She spoke of her experience of participation as a way for others to learn more about her, "*It's more like they are getting to know a different part of me so like they get to know me a bit better.*"

### 3.3.3.2 Stepping in and out of an illness narrative

There appeared to be a moving within and stepping out of an illness identity for the young people taking part, suggesting fluidity to their positioning. Beth talked of her early life experiences which suggested a self as abnormal or different, with an individual defect, saying "*I wanna know what's wrong with me.*" This seemed to speak to societal discourses around 'madness' and distress, arguably the tendency of society to distance mental health service users, separate and discriminate. Similarly, Rowena described her fear of others perceiving her as "*broken*" if she were to disclose her mental health difficulties through participation.

Ana appeared to make reference to being perceived as vulnerable and in need of protection, "*I do think a lot of people do sort of when someone has mental illness are like... 'right, that's it, we must be careful around you.'*" She then appeared to challenge such disabling and limiting discourses, storying her school teacher telling her "*'to come back, you know, when you are not ill,' and I was like, 'it is never going to go away, is it? So, you are just telling me to never come back.'*" She appeared to contest a recovery discourse, with its

often narrow definition, arguably used as a means of masking greater coercion. Similarly, Rowena appeared to contest a recovery discourse when speaking of her experiences of mental health difficulties, *“it doesn't mean it has completely gone away, there can be times where I can be so anxious and feel so ill, I am not just an ill person.”*

Drew at times appeared to sit within an individualised 'mental illness' narrative, saying *“although I have a lot, I don't have all the mental health illness, you know. I'm sure I take a good portion, but not ...not all of them.”* Beth spoke of the seemingly all-encompassing nature of the mental health difficulties she was experiencing, seeming to eclipse her sense of self.

Beth: *“being with CAMHS for so long I kind of...kind of just lived by that label of, I have mental illness, I get treatment for mental illness, I am with CAMHS, I get seen by these people.”*

There appeared to be a stepping out of an illness identity, moving away from a problem-saturated discourse, from being passive and vulnerable, to an active agent in her own wellbeing.

Beth: *“I was able to kind of say to people ‘actually I think you should be doing this and that I don't think this is right’ and by kind of giving myself that voice, I kind of was able to step away from all that a little bit.”*

### **3.3.3.3 Flipping the Power Imbalance**

Ana appeared to playfully capture a visual image of the hierarchical mental health structures and the dichotomy between those who make key service decisions and those who

access services. This is in the context of speaking about her experience of accessing CAMHS at a mental health event, *"it was like to all of the...I dunno...people in the big seats I guess...I dunno...whoever they are [LAUGHTER] whatever they do."* This suggested both a disregard and a detached position with those perceived as holding positions of power making decisions about service delivery. Ana also appeared to speak to the patient/professional dichotomy and crossing the 'invisible line' when she was told she was not able to work voluntarily in the service for work experience, saying *"she [therapist] was like, well obviously because of confidentiality, I can't have work experience in CAMHS."*

Ana appeared to speak of her own shifting position, having a sense of power in being heard by those who previously seemed so out of reach to listen *"it felt like they were actually listening"* and *"things actually happened."*

Jordan talked of service participation allowing him to see himself as powerful.

Jordan: *"it gives you the confidence because you know that you're like yeh powerful and knowing that you can make a change..." "...and it's not just the people that haven't been through it running the system."*

Beth stories viewing herself in a subordinate position in relation to clinicians when sitting on an interview panel, saying, *"I don't have that kind of power and status,"* but then noticing a shift in the way she saw herself. She talked of her views around being treated equally alongside mental health professionals as someone with expertise and knowledge.

Beth: *"I deserve equal respect to the people who work for kind of CAMHS because there has always, kind of, been to me, like a power dynamic, like they are above me, they're like a prestigious professional or they are an academic..." "...actually I have*

*a kind of a better understanding of what these people will be going through than someone who hasn't had those, kind of, experiences."*

Drew appeared to playfully use sarcasm to challenge professionals who seemed to position her through the lens of a label and in a subordinate position in an interview:

*Drew: "I said, 'actually I don't think that's true,' and they go, 'well, in my professional opinion,' and I go, 'Well, in my crazy person opinion, in my mental health sufferer opinion, I can tell you that actually I don't think that's quite true.'"*

### **3.3.4 Strengthening alternative stories through relationships**

Dominant stories can be detrimental as they privilege certain interests and can potentially leave power relationships intact. It is argued that such discourses and contexts provide a framework for, and also limit to, identity construction. On the other hand, alternative stories can do the opposite.

#### **3.3.4.1 Calling deeper on courage and stepping into new realms**

Stories of embracing vulnerability and being courageous appeared to be shared across all young people's narrative accounts. This seemed to transform the ways in which the young people viewed themselves, bringing new possibilities and frameworks of meaning. All young people taking part spoke of times in which they stepped into something new, such as speaking to large groups of people at events or conferences. Ana spoke of speaking at an event attended by 150 people around her experience of accessing CAMHS and what she found helpful, *"I had no idea what it was, I was just like 'yeh you know what I will try it.'"*

Across stories there were narratives of self-disclosure, or the sharing of personal information with others. This seemed to provide opportunities to express thoughts and feelings, develop a sense of self, and build intimacy within personal relationships. Rowena spoke of her experience of sharing less visible sides of herself to others, *“being so open to a group of people is really scary.”* Drew seemed to align with a social and self-disclosure discourse around participation, saying that her involvement provided *“a space to be able to talk to people and be honest about who you are and also, you can be honest about the bad stuff as well.”* She went on to share how this in turn illuminated different parts of herself less known:

Drew: *“I feel like as well there's just parts of myself that it's like flourished so much more...so like my ability to like talk to people and say things in a jokey way and actually feel like I'm actually a fun person.”*

All young people storied revealing different parts of themselves to others. Ana spoke of surprising herself in sharing more personal aspects of herself around her mental health in the public sphere, *“I don't mind sort of spreading awareness, it is just I don't like to sort of talk about sort of intimate details of about my mental health,”* *“it was another sort of thing that like, I never thought I would do but I did.”* She spoke of how this allowed her to access another means of managing, *“it definitely helped me be more open with sort of mental health and that in turn helped me deal with it a better.”* It seemed to transcend to being open to others and reaching out for help instead of spending *“so long suffering”* which she described previously finding *“terrifying,”* *“it made me more open to it, so I do ask for help more than I have in the past.”*

Jordan talked of his experience speaking at mental health events about feeling nervous and also the feeling after, *“you are so proud of yourself talking about your experiences.”* He spoke of others telling him the difference he was making having an impact on how he saw himself, *“you don't really get that boost until you like hear it off people.”*

Drew described times when she surprised herself by noticing her own strengths when participating in service delivery, saying *“I was like, ‘wait did you just give yourself a compliment?’”* When other people also acknowledged changes, this seemed to further shed light on her shift in perceiving herself in a more positive light, *“especially with other people, they really notice a change in me.”*

#### **3.3.4.2 “Wow, I can actually do stuff:” Empowerment and building confidence**

Across the young people's narrative accounts there appeared to be stories about how the young people were creating their identities in a relational form by drawing on who they were in relation to how others saw them. It seemed there were opportunities within service participation to see others witness seeing them differently.

Ana: *“It was nice for my mom to see that like I had come so far ‘cause I know that like, even I know there have been bad times and stuff, it's like she still knows I have come a long way and she actually has physical proof [film] of that which I think is nice.”*

All young people taking part appeared to story feeling confident and this at times coming as a surprise. Beth spoke of a time speaking in front of a large group of people, saying *“like, wow though, like my confidence must have improved along the way.”* Confidence sometimes seemed to be conceptualised as fixed or something that is gradually

building or being rebuilt, with Rowena saying, *“doing the participation work, it has sort of like, it has rebuilt my confidence quite a bit.”*

Drew spoke of her first experience speaking at a conference, saying *“...I was a total mess, where I was so so nervous,”* to then having experiences of speaking at events holding 200-300 people, saying *“that gave me a lot of self-confidence.”* Jordan, as with others taking part, appeared to convey how his sense of confidence through activities of participation such as delivering training and delivering conferences transferred to other areas of his life, *“I don't even really get nervous about it which is really cool to say and in my daily life, I think that has helped me to be more confident on a daily basis.”*

Beth talked about the value of participation in gaining a sense of agency and control, rather than being seen as a passive recipient of care *“being able to talk about your experiences really kind of puts you in control of that and you get to say, ‘well this is my story and this is what I have gone through,’ rather than just being just another person who went through CAMHS.”* It seemed like there was a shedding or a breaking away of an illness saturated identity for her, *“you definitely feel listened to and then that starts to kind of help you recover because you're like, ‘oh actually, I went and did that, I can do that.’”*

Rowena seemed to tell a story of surprising herself after giving a talk, saying, *“I sat in the car I was like... ‘wow, I can actually do stuff,’ [LAUGH] like I am not completely hopeless.”* Rowena appeared to make use of a ‘quest’ narrative (Frank, 1995) around confidence, saying *“I think I still have a fair way to go with confidence and self-esteem I think it is something I will always erm...battle with...”*

Through her experience of participation, Nadia was told by others she was brave. She appeared to give a narrative around participation enabling her to notice her confidence build over time. She talked of noticing when she was able to do something she had not thought she

could do, like present at conferences or speak to large groups of people *"I did become a lot more confident over time so after speaking on conferences...I did see that I was able to do it."*

### **3.3.4.3 A Message to You**

Some young people spoke of the way in which being involved in service developments and informing services provided a means to give a message to others. It seemed to be a way of 'setting the record straight' when their views of what would have helped them most in times of difficulty did not match the response of others. There were a number of times where it felt like the audience for the story might be those who hurt the young person in the past through insensitive comments or lack of understanding, whose perceived disabling attitudes acted as barriers for the young people.

Ana: *"Some [teachers] who were like really horrible about everything and I think maybe it might make them think even if they weren't nice to me, they might be nicer to someone else who has sort of issues like mental health..."* *"maybe she won't say so many insensitive things to people who are struggling."*

Participation seemed to create a context for the young people to confront those who may have made mistakes in the past, leading to an apology. This seemed to lead to becoming emboldened.

Drew: *"a lot of the teachers are really taking in what I had to say which was amazing and it felt so empowering for me...erm but yeah, for her to come up to me and say 'I'm ...you know, I'm really sorry and I'm sorry if I was ever super detrimental to your mental health.'"*

Ana spoke of participation allowing her to share with others a side of her she was not able to show previously, *“it was just nice to show her like she did manage to help me, erm because I would never have done anything like that when I knew her.”* Re-engaging in the service in a different way allowed re-connections with clinicians in different circumstances, with Ana saying, *“I think like it helped that I had known her [nurse] before and she had known me in one of the worst periods so we just sort of discussed how everything had changed.”* Within the young people's stories, there appeared to be a confirmation of having moved on from a difficult time and people being surprised and validating of the perceived change.

Participation seemed to provide a means to say thank you to those supporting the young people in the past. There appeared to be opportunities for clinicians the young people had worked alongside in the past to see them in a different context through the lens of participation, with Rowena saying, *“I am glad that we can show that their work is paying off.”* Young people spoke of wanting clinicians to see them accessing services in a different position to that of a 'patient,' saying *“I think all practitioners that watch their people go from where they were in therapy to receiving an award, like a [Trust] award, is like a huge thing and they definitely, yeh definitely view them as a warrior”* (Rowena).

Finally, as a final message to others, invited by me as part of the interview schedule, all young people taking part offered a message to other young people accessing mental health services about involvement in service participation. This can be found in Appendix V.

### **3.4 Summary**

Throughout the interviews, there were narratives of identity construction and shifting relationships with others reflecting wider hierarchies of power between adult-young person relationships and patient/profession dichotomies. This reflects an interesting aspect of how

young people story the experiences and meaning of service participation in the design and delivery of NHS mental health services. It also provided insights into what aspects of the self were seen to be expressed in these narratives, including a social identity, the self as heard, empowered and having confidence.

The next chapter will discuss the findings with particular reference to the research aims and wider literature, followed by the clinical relevance of the research and suggestions for future directions.

## **Chapter Four: Discussion**

### **4.1 Overview**

This research set out to understand how six young people story the experiences and meaning of participation in the design and delivery of NHS mental health services. It sought to understand what aspects of the self were expressed in these narratives. Narrative analysis was used to explore the content, performance, context and discursive elements of the accounts individually and collectively. Consideration was given to the social and political contexts that arguably shaped these accounts.

This chapter will summarise the research findings and consider them in relation to the research aims and relevant literature. Theories including Social Capital Theory (e.g. Coleman, 1988; Putnam, 2000) and Empowerment theories (e.g. Rappaport, 1987) will be drawn upon, under the meta-framework of Community Psychology, which both can be said to sit within. Clinical relevance and implications for young people, practitioners and services are considered, along with methodological reflections of strengths and limitations. The chapter concludes by setting out recommendations for future research directions.

### **4.2 Discussion**

From the accounts of the young people taking part, four broad stories were observed. These were stories of 1. Moving into social spaces and holding out a helping hand; 2. Having to become the 'right fit' for participation; 3. Repositioning from patient to person; 4. Strengthening alternative identity stories through relationships. Within these stories there seemed to be important narratives with implications for changes in identity, and how discourses around 'participation' and 'mental illness' are co-constructed. Identity and positioning are therefore key aspects of this research.

Identity can be conceptualised as socially constructed, narrated through language and the ways people tell stories about themselves in relation to others (Freeman, 1993). It can be said to be something people actively perform and negotiate, to construct and adapt to suit changing circumstances.

Narrative models of identity hold that we are reshaped over time by the experiences we have (McAdams & McLean, 2013). Identity is viewed as reflecting self-understanding, with stories told to the self and those around us. These are then applied to knowledge of the self, others and the world to make meaning (Singer, 2004). This construction and sharing of stories of the self is said to be central to navigating significant life events, such as the experience of psychological distress. The 'self' can be seen as a "story-teller" and a "constructor of narratives about a life" (Bruner, 1990, p. 111). It can be described as multi-storied, in that we have stories that we choose to tell or not tell within different contexts we find ourselves in and in relation to the person the story is told to. Therefore it is recognised how people may define, resist or adapt their identities through the stories they tell. This suggests a purposeful and chosen identity presentation with the consideration of prevailing expectations and wider power differentials. Within this research, a narrative model of identity allowed an exploration of how narratives can emerge from various influences based in specific societal, institutional and social contexts (Bruner, 1990).

This chapter will summarise the research findings and consider them in relation to the research aims and relevant literature. Important and interrelated arguments about identity as a construct are developed in this research. Firstly, there were apparent individual changes whereby the young people taking part shared a transformation discourse of viewing themselves differently through service participation. Transformation narratives around identifying with a social identity, an identity transformation from a 'patient' to person, characterised by the shaping of resistance and oppositional master narratives will be

discussed. The distancing from a subjugated 'mentally ill' identity and the generated possibilities for transgressive and resistance discursive positions will be built upon. However, it can be said that changes in the self are not just psychological processes, but rather differentially invoke and involve particular parts of the community (Bruner, 1990). It can be said that through the individual identity formation process, narratives of a given social order which serve the interests of those in power (Foucault, 1980), are either reproduced or contested.

The research suggests that the young people taking part continually formed an identity by integrating their life experiences into an internalised, evolving story of the self that provided the young person with a sense of belonging and social identity. The development of social relationships seemed to provide the means to acquire a social identity and receive social and emotional support. It can be said that when interdependent, mutually supportive relationships form, a sense of community develops. Forming a sense of community in turn can promote empowerment (McMillan, Florin, Stevenson, Kerman, & Mitchell, 1995).

It can also be said that positioning young people with experiential knowledge and experience of participating actively in the design of mental health services as having a certain set of values, identities and behaviours, they are 'othered' by powerful groups of people. It can be argued that they are seen as a separate entity, and as a result remain within a subordinate, marginalised position within services. Carr (2019) provides an insightful and important personal reflection on commodification of individuals with lived experience within the context of research.

With this research indicating a focus on interdependence rather than independence in constructions of selfhood, the relatedness and camaraderie among the young people is a key social value. As such, it can be argued that identity becomes a relational matter whereby the individual's social location in a community supercedes a focus on individual uniqueness in

identity. Therefore, theories including Social Capital Theory (e.g. Coleman, 1988; Putnam, 2000) and Empowerment theories (e.g. Rappaport, 1987) will be drawn upon, under the meta-framework of Community Psychology, which both can be said to sit within. Clinical relevance and implications for young people, practitioners and services are considered, along with methodological reflections of strengths and limitations. The chapter concludes by setting out recommendations for future research directions.

#### **4.2.1 Moving into social spaces and holding out a helping hand**

Stories of camaraderie appeared central to the stories told by young people. Participating in the design and delivery of services seemed to bring opportunities to form a collective, shaping a valued social identity. Stories were told of positive experiences of helping and receiving help from other young people in times of difficulty. Across accounts, it appeared that the exchange of emotional support, informed by experiential knowledge, was invaluable. These trusting relationships seemed to allow for mutual aid.

The findings appeared consistent with existing research demonstrating the emotional and relational benefits of sharing experiences with others who have faced similar hardship (Helgeson & Gottlieb, 2000). Research suggests this can offer opportunities for receiving validation from others, provides spaces for normalising experiences, can reduce social and emotional isolation, and facilitate a sense of belonging (Helgeson & Gottlieb, 2000). In relation to research specific to youth participation in mental health service design, this seemed consistent with previous findings around participation bringing a sense of belonging, creating friendships and building social skills (Coates & Howe, 2014; Price & Feely, 2017; Taggart et al., 2013). Social relationships are widely regarded as determinants of physical and mental health (Berkman, Glass, Brissette, & Seeman, 2000). Social connectedness among

people in times of hardship has been linked to fewer psychological difficulties, improved quality of life, and higher self-esteem (Goldberg, Rollins, & Lehman, 2003).

The current research adds further richness to our understanding of this social connectedness within the context of participation. It seemed the lived experiences of psychological distress acted as a key bonding point in the development of supportive relationships between the young people within the research. A key aspect of this appeared to be the opportunity of sharing distressing experiences without judgement. The research suggests that the social aspect of youth participation networks served to normalise and contextualise a person's experiences within the particular challenges shared by the group. For example, young people in the current research spoke of others sharing when they experienced suicidal thoughts and having a particularly difficult day, perhaps without the concerns about the more prescribed statutory or risk-orientated responses they would be likely to receive from practitioners. The sharing of hopes, fears, stories, and meanings with peers going through related challenges, appeared to help the young people taking part realise they were not alone in their struggle or 'abnormal' in their reactions.

In narrating their 'lived experience' as a resource to help others, young people taking part appeared to resist the dominance of 'professional knowledge,' bringing value and credibility to their 'user perspective.' It appeared that young people who have also 'been there' were viewed as being better prepared to provide support to each other by virtue of their expertise, as argued by Helgeson and Gottlieb (2000). This can be said to speak to a way of contesting westernised concepts around individualised mental health problems and receiving help, along with the privileging of independence over interdependence. It can be argued that this aligns with ideas within the psychological sense of community theory (Sarason, 1974), described as "the perception of similarity to others, an acknowledged interdependence with others, a willingness to maintain this interdependence by giving to or doing for others what

one expects from them, the feeling one is part of a larger dependable and stable structure” (Sarason, 1974 p.157). This theory has strong links with Community Psychology principles, such as the view that an individual exists within a larger network and that these individuals are interdependent.

Social support has been shown to be an important buffer to scaffold mental health and wellbeing in times of stress (e.g. Thoits, 1995). The observed stories of camaraderie within participation networks can potentially be accounted for using the concept of social capital, often referred to within Community Psychology writing (e.g.Orford, 2008). Social Capital Theory emphasises the way in which social networks provide positive outcomes for the group as a whole, activated through shared values and a sense of enhanced connectedness, therefore supporting the benefits of forming a collective of young people participating in shaping services (Putnam, 2000). Putnam (2000) makes a distinction between two forms of social capital, these being bridging and bonding social capital. Bridging social capital speaks to the concept of collective social action and is said to take place when members of one group connect with members of other groups to seek access or support or to gain information (Larsen et al., 2004). Bonding social capital refers to people coming together to advance mutually beneficial social action through association, shared experiences and the development of trust (Coffé & Geys, 2007). This is a theoretical framework potentially helpful in understanding the social connectedness between young people taking part in the research.

A narrative analysis perspective allowed for the recognition of the multi-layered and intricate nature of relationships of young people taking part in the research. In addition to our understanding of the stories that particularly facilitate camaraderie, the current study also brought to the fore stories of when relationships could become “*catty*” and environments “*unwelcome*.” These stories suggest having to maintain a competitive edge in order to be

heard and feel listened to when participating in services and sharing personal experiences to stakeholders, and how this could undermine camaraderie. This allowed an awareness of how discourses of rivalry and competitiveness invited between young people by processes of how participation is decided and organised, could potentially at times undermine this key benefit of participation for some young people. It also implied a level of assertiveness on the young people's part to navigate complex social interactions to find ways to be heard.

#### **4.2.2 Having to become the 'right fit' for participation**

It would be assumed that youth participation would appeal to most, with services potentially being sympathetic to the ethos of individualistic self-improvement and young people potentially solving problems without the input of clinical intervention. Services may also be sympathetic to the cooperative, communitarian sense of solidarity, with young people coming together to actively shape services. There were differences across accounts around how the opportunity of service participation became known; at times this seemed to be withheld with others deciding when or if it should be taken away. Barnes et al. (2003) argue that people may take part in participation initiatives because they have volunteered or have been invited, or in some circumstances as a result of pressure or coercion. They also argue that participation may be motivated by experiences of oppression or exclusion, motivation to improve service for others or seeking to develop skills and self-confidence (Barnes et al., 2003). The young people taking part in the current research had different routes into service participation, namely by volunteering (*Nadia*) or being invited by mental health professionals (*Rowena, Ana, Drew, Jordan, Beth*).

There were stories observed of having to become the 'right fit' to participate in the design and delivery of services, suggesting processes involved in the recruitment and selection of young people, and service perceptions of who may or may not benefit. Some

spoke of professionals encouraging them to participate (*Ana and Drew*) as it was felt they held strong, sometimes negative views of the service they received. This seems to provide an interesting contrast to the view that professionals may be keen to maintain the dichotomy between 'service-user' and professional, rather than transfer and share power (Repper & Perkins, 2003). This also suggests a selection process which may be useful to understand. Nairn, Sligo and Freeman (2006) suggest those seen as 'troublemakers' or 'achievers' are often invited for forms of youth engagement, leaving out many young people who may not articulate themselves in this way or are less 'seen.' The 'excluded middle' are often unaware of opportunities to engage or do not feel their efforts would make a difference (Nairn et al., 2006). This seemed to be apparent within the current research, with young people being invited to be involved due to strong and sometimes opposing views of the service.

The current research implied potential barriers and restrictions that seemed to operate on who could get involved and remain involved. Young people shared stories of youth service participation being on a "*need to know*" basis and not routinely shared to all young people accessing services. It appeared that the young people taking part were often unaware that they could be involved, similarly to previous research findings (Gyamfi et al., 2007).

Although those taking part in the research represented a diverse group in terms of gender and ethnicity, it is unknown whether the participation networks involved in the current study represented youth diversity (i.e., race, ethnicity, gender, ability). However, it can be said that with participation arguably being on a 'need to know' basis, this can lead to the issue of inequitable representation of young people participating in service delivery. Indeed, research has reported managers within mental health services expressing concern around the risk of a lack of diversity within youth mental health service participation (Coates & Howe, 2016). Therefore, the research suggests a selective process of recruitment and selection of particular young people, which can create a misrepresentation of the voices of youth within a

community. When higher performing young people are provided with opportunities to be involved within mental health service participation, these networks can reproduce patterns of inequality and misrepresent the voices of one group of youth to account for the youth at large (Matthews, 2001).

Once 'in,' it seemed there was a potential of being 'thrown out.' Jordan shared his experience of it being decided for him by professionals that youth participation was not helpful for his "*treatment.*" Furthermore, Drew spoke of her experience of being viewed as "*depending too much*" on youth participation and this being seen as "*unhealthy.*" This appears to mirror existing research reporting concerns from clinical staff around participation having a detrimental impact on young people's wellbeing (Coates & Howe, 2016). Furthermore, the decision of practitioners to rescind involvement seemed to support research suggesting the positioning of young people by adult professionals, specifically clinical psychologists, as in need of protection and that youth participation in service design and delivery requires diligence (Dexter et al., 2011). Foucault (1977) theorised power in child-adult relations as being both a productive and repressive force which can operate to constrain and empower in different socio-cultural contexts. It can be said that the construction around wellness and normality, and that of illness and abnormality, is one way that the dichotomous us-and-them positioning is created. The discourse around being 'well enough' for youth participation but still being required to be an appropriate level of 'unwell' to be included and of value appeared to suggest a further strategy used to maintain the dominant discourse around young people experiencing distress and being in need of protection. It seems there is a fine line for young people to walk of being the 'right fit' for youth participation, not to seem to be relying on it, and to not become too unwell whilst also accessing support from the service. Similarly to the user led group for mental health survivors and supporters, Recovery in the Bin (2019), the idea is posited of having to be 'mad enough' to be suitable for youth

participation, but not 'too mad' as this may disrupt the status quo. This brings questions around the use of clinical judgement, or clinicians arguably showing a duty of care when they may be concerned about young people they meet with and prioritising needs. Perhaps there may be circumstances when practitioners feel an additional role of participation in service delivery may be unhelpful and should not be offered or should be withdrawn. The current research points to the impact this might have and the importance of how this is managed. It is argued that an open dialogue with the young person would be beneficial, with transparency in thinking this through and a shared agreement of what would be most appropriate for that young person's care.

Young people within the research spoke about noticing when they were being heard by professionals around service decisions such as recruitment, service infrastructure, shaping resources for young people accessing services, and when speaking about their experience of accessing CAMHS in conferences and training sessions. This supported previous reports of the benefits of youth participation including developing and strengthening a sense of pride, self-esteem and identity, feeling empowered, and having their voices heard (Matarese, McGinnis, & Mora, 2005). It can be argued the observed stories of participation speak to theories of empowerment (e.g. Rappaport, 1987; Zimmerman, 1990). Zimmerman's (1990) proposed theory of individual psychological empowerment involves connection between intrapersonal, interactional and behavioural components. The experience of empowerment has an emphasis on strengths instead of weaknesses, and has been indicated to reduce mental health difficulties, or rather improve a person's ability to manage or change their environment accordingly (Chinman & Linney, 1998).

However, within the current research, stories of being heard seemed to be multi-layered, with Beth speaking about her experience of 'having to tell the right story' to be heard, and this separating her from the other young people. This seems to mirror Hodge's

(2005) case study, with findings indicating that individuals participating in service delivery *could* assert different types of knowledge, but these assertions would not be meaningfully incorporated if they were challenging to dominant discourses. The idea of getting commissioners to 'buy in' to the young person's story seemed both a dynamic of a power divide but also suggested the restricting of particular stories as a way to maintain the status quo and existing power relations. Indeed, previous research has suggested that the perspectives of those accessing services were apparently only validated when it supported dominant discourses, supporting an argument that participation only reinforces the power/knowledge of dominant discourses (Stickley, 2006).

Through a narrative approach, staying 'experience near' to understand the experiences of young people participating in the design and delivery of mental health services, arguably allowed for a rich understanding of their views on the selection process of being involved and their workings through around why they may have been invited to get involved. There seemed to be less preparedness around these stories, indicating these may be stories less told, again suggesting a process of 'working out' by the young people taking part, which was helpful in suggesting this may be less transparent within services or shared directly with young people.

#### **4.2.3 Repositioning from Patient to Person**

Roles are fundamental determinants of self-concept and components of someone's identity. Discourses bound by power relations and social practices can construct, prevent or marginalise available identities and positions (Emerson & Frosh, 2004). It seemed the young people taking part shared a transformation discourse of viewing themselves differently through service participation. There appeared to be a distinct line being drawn between 'us' and 'them' that permeated the storytelling, with stories of resisting this and breaking down

'professional boundaries' and the distinct divide between 'patient' and professional. Young people appeared to resist the subjugation and subjectivity produced by dominant discourses, with Drew stating "*I'm not a patient, I'm just a person.*" The young people's storytelling can be understood as resistance stories against being placed in a subordinate position of abnormal or "*crazy.*"

The young people involved in service participation could be said to occupy a dual position of 'service-user' and 'professional,' or sitting somewhere between. This apparent duality can be argued as disrupting practices that dichotomously construct a categorically different 'abnormal'/'mad,' and 'normal'/'sane,' with those accessing services in the former group and professionals placed the latter. Wanting to pursue a career in mental health seemed to enact further distancing from the subjugated 'mentally ill' identity or 'service-user' position. Similarly to Adame (2011), instead there appeared to be an integration of professional and survivor/service-user positions, rather than these being constructed as separate aspects of self.

Within stories told, there appeared to be a number of ways young people resisted the subjugation and subjectivity produced by a 'mental illness' discourse. These included using a dominant discourse to remove themselves as a legitimate object of it, with, for example, Beth positioning herself as previously living by a label, "*I have mental illness, I get treatment for mental illness, I am with CAMHS, I get seen by these people.*" There appeared to be a reclaiming of credibility and a new identity by stepping "*away from all that a little bit.*" Young people taking part arguably used a survivor movement discourse (Adame, 2011) to contest a 'mental illness' discourse and reclaim a subjectivity with greater power, to be alongside professionals, with Beth stating, "*we are both just people.*"

Discourses can be said to produce different positions, rights and possibilities for action. Dominant discourses can be critiqued and resistance to this power can be explored,

examining how identities are claimed, accepted or resisted (Burr, 1995). Young people appeared to realise new possibilities of employment which seemingly were unknown to them before. For example, the moment of realisation of being able to work in mental health if they too experienced psychological difficulties. It appeared there was at play a construction of 'abnormal'/'ill' which is categorically different to 'normal'/'well' (Crowe, 2000). From this, there seemed to be a stepping away from the dichotomous construction of young people and 'the mentally ill,' who are vulnerable, have problems coping and need help, and 'normal' people, who are 'mentally strong' and capable of managing their selves. Therefore, through storytelling there appeared a reclaiming of power and an opening of new possibilities around future ventures. Within the context of empowerment, Zimmerman (1990) suggests that awareness of a person's choices produces the motivation to successfully exert control over the environment.

#### **4.2.4 Strengthening alternative identity stories through relationships**

The development of rich, meaningful and multi-stranded stories can assist people with living out "new identities, new possibilities for relationships, and new futures" (Combs & Freedman, 2004, p. 138). The possible ways in which narratives aligned with, or contested discourses and wider community narratives were considered, with potential alternative identity stories reflected upon.

The young people taking part in the research spoke of the experience of sharing with others aspects of their mental health. Decisions to disclose concealable stigmatised identities were complex because they had the potential to yield unfavourable outcomes such as social rejection and discrimination. Therefore disclosure can be said to have the potential for both benefit *and* harm. There appeared to be stories across the narrative accounts of the young people taking part in showing courage, being brave and stepping into new identity realms.

There seemed to be a stepping into a seemingly exposing position of vulnerability by disclosing their experiences of mental health difficulties and other aspects of 'self' in public platforms, with this seemingly bringing new possibilities and frameworks of meaning.

Vulnerability is difficult to define (Hurst, 2008), and it is argued that a reflexive attitude is needed when referring to someone as 'vulnerable' (Witham, Beddow, & Haigh, 2015). The concept can be said to have various meanings and is said to be "so loaded with political, moral and practical implications that it is potentially damaging to the pursuit of social justice" (Brown, 2011, p. 314). It is important to consider the different ways of understanding vulnerability. Indeed, within the current research, there have been different meanings drawn. For example, when considering conceptualisations of young people in western societies, it is argued that young people can be viewed as lacking competence and 'vulnerable,' therefore implying a position of powerlessness. However, here I talk of young people embracing a position of vulnerability in order to step into new identities. Brown (2011) suggests that the concept can be understood in at least two ways. Firstly, vulnerability can be defined as a paternalistic and oppressive way of conceptualising someone, a mechanism for expanding social control and a means of stigmatising and excluding individuals (Brown, 2011). Secondly, there is the view that vulnerability has a transformative quality and represents a fundamental characteristic of humanity that functions as a basis for freedom and justice (Brown, 2011).

Sharing experiences of mental health difficulties and experiences of accessing CAMHS, appeared to have different uses in the narratives: to provide hope to others, to contest 'us-and-them' dichotomies, to disprove negative assumptions, and to step into new identities. Young people appeared to share narratives of capability, purpose and confidence. Similarly to other studies, there was the rhetoric of agency, with the use of language such as 'empowerment,' 'opportunities' and 'confidence' (Coates & Howe, 2014, 2016; Gyamfi et

al., 2007; Mayer & McKenzie, 2017; Ramey & Rose-Krasnor, 2015; Taggart et al., 2013). All young people suggested a degree of going beyond what the person previously thought they were capable of, building skills and enabling agency, similarly to previous findings (Mayer & McKenzie, 2017; Price & Feely, 2017). Young people taking part also reported increased social skills which transcended to social situations outside the participatory projects. Young people reported a noticeable change in their ability to 'speak out' and voice dissatisfaction in other contexts, also describing an increase in confidence in the ability to raise their concerns around mental health service delivery. These findings are consistent with that of young people taking part in the study by Taggart et al. (2013). The stories also suggest wider therapeutic possibilities in terms of the development of agency and identity. It could be said this active participation in positive activities speaks to an empowerment process, which may lead to the development of positive self-schemata (Markus, 1977) and a positive identity (Chinman & Linney, 1998).

Some young people spoke of the way in which being involved in service developments provided a means to give a message to others as their audience, a way of 'setting the record straight' when their views of what would have helped them most in times of difficulty did not match the response of others. Young people appeared to resist the subjugation and subjectivity produced by dominant discourses of 'mental illness,' aligning with a survivor discourse with its focus on power, voice and human rights (Beresford, 2002). There also appeared a strong interest in seeking service improvements for others in the future, in line with previous research (Barnes et al., 2003). This could be accounted for using theories of empowerment, whereby there appeared to be a gain of a critical understanding of the socio-political environment, from which the young people could dispute the ways in which they had previously been treated by others (Perkins & Zimmerman, 1995). This may sit within the ideas held by Community Psychology which looks to create contexts whereby

people can develop a critical awareness of their social surroundings and take collective action to address community problems (Orford, 2008).

### **4.3 Clinical Relevance and Implications**

The research indicates that there are changes all policy makers, mental health services and those working within them can potentially make. This includes services adopting a stance which allows a reciprocal arrangement with those accessing services, where their strengths are seen as equal and as valuable a resource as those working within services. Critically exploring and 'paying attention' to the ways in which power relations shape, mediate and transform relationships in mental health research and within clinical practice is central to the relevance of this research.

Clinical implications will be presented, firstly considering young people who participate in mental health service delivery; routes into service participation; those who facilitate youth service participation; and finally service and policy implications.

#### **4.3.1 Young people participating in mental health service design and delivery**

Young people participating within mental health service design may want to expand upon opportunities for camaraderie and the forming of a collective with other young people accessing services. This could be facilitated by participation leads in order to create more spaces within services whereby helping and receiving help from other young people can be mobilised.

Forums with key stakeholders to build a critical understanding of the socio-political environment the mental health service sits within should continue to allow opportunities for young people to find ways to improve services and be heard.

There is limited research available to understand the experiences of young people involved in participating in mental health services design (Crawford et al., 2002). Furthermore, research is lacking in understanding the experiences of young people involved in participatory research (Holland et al., 2010). This questions the drivers behind participatory practices. Therefore, it would be important to continue to build upon existing research alongside young people to develop an understanding around what it means to undertake participatory research and be involved in the design and delivery of mental health services. In doing so, it is recommended that issues of power, agency and researcher reflexivity should be central.

Young people involved in participation networks within services are arguably well placed to work with services in identifying issues around equity of access and decision-making relating to times when participation within services may not be viewed as helpful. This provides an opportunity for young people to co-produce guidance for staff on how to invite young people to participate and how to address concerns together about the possible challenges of doing so when accessing services. This could lead to an accessible guide co-produced with young people which could be shared across services.

It should be said, most young people involved in service participation do not want to be viewed as tokenistic commodities, but want to change service cultures and knowledge production to make it broader and more inclusive (Carr, 2019). Therefore, appropriate recognition of the contribution and commitment of young people participating in service design and delivery through remuneration is essential, challenging the concept of dependency and the assumption, often without grounds, of continued involvement being detrimental to the young person. Rather than being 'othered' as separate to the team, young people who wish to, be could be offered roles more embedded within CAMHS teams such as youth leaders, youth mentors, and youth consultants. Employing young people with lived experience as board

members and senior colleagues, as part of a long-term strategic approach to workforce planning is also a clear recommendation. As part of the training to undertake these particular roles within services, it would be important that young people co-produce the training delivery and content alongside services, with appropriate employment opportunities created for young people to achieve this. A clinically relevant example of how this has been implemented within services can be offered by Project Future, a community-based holistic wellbeing and mental health service in partnership with the NHS, Council, and charity MAC-UK (Stubbs et al., 2017). This service offers mental health service providers and commissioners with key principles for developing services with young people embedded across all levels within services.

#### **4.3.2 Routes to Participation within Services**

The current research highlights the ways in which youth participation is often siloed off and seen as a separate entity within services. This can result in it being an unknown enigma to young people, as suggested from the findings. It has been argued that schemes for participation can mirror societal discrimination on the grounds of age, gender, ethnicity, sexuality, disability, class, culture and belief (Matthews, 2001). The route into youth service participation may result in those involved not reflecting wider views and the full diversity of the communities for which they speak, instead potentially reflecting broader inequalities.

There is an apparent decision-making that falls on clinicians who may not have interests in this area or may not be aware of what it is or involves. Furthermore, there may be an additional layer of decision-making before they make it known to young people. It seems in order to make it a fair democratic process for all young people to be aware that participation is available, it should not solely be down to clinicians to decide. This is reinforced by Bessell's (2009) claim that "adult attitudes are the greatest barrier to effective

participation” (p. 299-300). The research suggests that service providers should develop more visible youth participation networks across all areas of the system. This would mean youth participation networks finding possible solutions in ways to tackle the ‘need to know’ basis of youth participation in services. There could be spaces created for young people already involved in participating in mental health service design to speak with other young people accessing the service to talk about their experiences of participation and also to staff who might not have a good understanding of what participation involves. Whilst young people themselves are essential to developing these networks, services can also play an important role in supporting them, for example, by providing resources and promoting awareness of youth participation activities. Services would also benefit from systems to identify groups of young people who regularly get missed when it comes to participation in service design and delivery, therefore having their views not taken into account. This may include the views of young people who have been in contact with the criminal justice system, young people facing homelessness, care leavers, those with learning difficulties, and those with complex health needs.

In summary, holding regular accessible spaces facilitated by participation leads for participation networking to invite young people to, have their input recognised and their time acknowledged with payment would be key.

#### **4.3.3 Practitioners currently involved in the shaping of service participation**

This research points toward the particular value of participation in helping to shape identity in preferred ways. Participation leads play a significant role in coordinating and overseeing participatory practices. They therefore play a key role in actively facilitating and scaffolding activities and processes that could enable such preferred identity development.

The research highlights the importance of continuing to create forums where there can be non-judgemental openness about young people's experiences accessing services and the care they receive and working together to find solutions, which participation leads are well placed to facilitate. Participation leads play an integral role in initiating steering groups or forums with young people which are directly involved in decision making. NHS England has worked with young people and the British Youth Council to develop some guidance on setting up local youth forums (NHS England, 2015). Such forums could extend beyond young people consulting upon service delivery to young people leading or co-producing projects within the service, entering the same 'space' as clinicians as opposed to being on the periphery. This requires training being made available for young people to be equipped with the necessary skills, structures and procedures in place to support young people and organisations in participation. According to a report exploring children's participation in decision-making developed with the National Children's Bureau and the Office of the Children's Commissioner: 'there remains a high demand for further training on evaluating children's participation and training on participation techniques and strategies' (Davey, 2010 p.12). Participation leads can play an important role in identifying training needs through discussions with young people due to their unique position bridging staff and young people.

There is a clear need to address the lack of evaluation of work undertaken, especially on the impact on service development from the involvement of young people, as well as the experience of those involved in the process. Participation leads could be trained to develop and publish Participatory Action Research with young people, which could showcase the possible roles of participation and the experiences of those involved. This could share stories of camaraderie, contesting of an 'illness' narrative and alternative stories of identity more widely in ways which potentially have wider impact, for example via different social media platforms.

The research suggests the need for both transparency and shared communication to allow young people to make informed decisions about their choice to participate in aspects wider service design and delivery. Both young people involved in participation networks and participation leads could work together to find solutions for greater transparency within services for other young people who may want to become involved in participation. Looking toward measuring whether this has been achieved within services could be beneficial for equitable access for all young people accessing services where appropriate.

#### **4.3.4 Service Implications**

The young people taking part in the research appeared to use their expertise and experiential knowledge to claim legitimacy and credibility from a survivor position. They storied the power of forming a collective and sense of belonging in participation networks. All services could therefore ask themselves some key questions around how this is harnessed. These include: How much and in what ways are young people accessing the service able to network with each other? Also, how are they able to share their experiential knowledge based on their experience of accessing services? This includes sharing such knowledge with other young people accessing services.

It should also be highlighted, the young people taking part committed their time and energy to participation in the design and delivery of mental health services, often for little or no monetary reward to shape services, provide peer support, advocate and share their experiences with others. Other studies have recognised the large commitment participation requires (Howe et al., 2011). Services could therefore ask the question, how is this recognised and accounted for?

Narratives of dependency on services and participation being perceived as having a negative impact on the emotional wellbeing of the young person should be made more

explicit and critically explored. Bonavigo, Sandhu, Pascolo-Fabrici, and Priebe (2016) conceptualise dependency on mental health services as being associated with social isolation, being dislocated from the outside world, and an over reliance on services. However, the research suggests that participation in the design and delivery of mental health services can give young people the opportunity to share similar life experiences, which may in turn decrease feelings of social isolation, increase people's social networks, and foster a sense of community. The current research adds to our understanding of social connectedness within the context of participation and the sense of being part of a dependable and stable network, drawing upon the sense of community theory (Sarason, 1974). Young people taking part storied their experience of being interdependent on one another within participation networks. There were stories of coming together to advance mutually beneficial social action through association, shared experiences and the development of trust. Young people within the research spoke about noticing when they were being heard by professionals around service decisions, speaking to theories of empowerment (e.g. Rappaport, 1987; Zimmerman, 1990). Therefore, narratives of empowerment and social connectedness through service participation can offer an alternative narrative to concerns around dependency which may not be justified. More opportunities for dialogues and alliances with mental health professionals who may not know about the purpose and activities of service participation would help bring forward such alternative narratives.

#### **4.3.5 Policy Level Implications**

This research has implications for changes at a national and international government policy level. Though this may appear paradoxical in itself, 'top-down' policy level efforts can arguably work alongside 'bottom-up' development. Rather than thinking in 'either-or' terms, with the more of one the less of the other, it can be argued both are needed to achieve youth

participation in mental health service design and delivery which is integrated within service practices, equitable to access, and meaningful for young people. A significant body of evidence already exists, including policy guidance documents, providing practical step-by-step ways in which services can implement youth participation in services (Carr, 2004). These guidelines are mostly based on empirical studies bringing the views of a range of stakeholders including young people. While this evidence has offered important guidelines and led to the development of critical approaches to youth participation, there is a lack of understanding around how participation in mental health service delivery is experienced by young people.

Given the many benefits of youth participation highlighted by the current study, investment of staff, funding and time to fully support and resource participation seems important. Involving young people with lived experience at policy level in looking toward pragmatic approaches to building the evidence-base for youth participation in service design and delivery is argued as being key to the current research. This will work toward a greater understanding of the impact, implications and barriers of participation within services. This will also develop understanding around how much services are seen through the lens of social capital and the importance of social networks as a resource unto themselves. It is understood that establishing evidence for youth participation within service development can be a challenge, with its focus on relational aspects of process in an era when performance measures focus on outcomes and impact. However, it is argued that participatory research should be recognised as evidence and should continue to contribute to service policy guidelines including NICE guidelines, allowing a growth of 'bottom-up' approaches to policy development. Therefore, roles for young people at policy level with clear training around organisational systems to work with teams on building research around participation in services is recommended.

The research suggests being part of a participation group can bring great benefits to young people. In terms of policy implication, this further supports increased youth spaces to be created within mental health services where shared understanding, a sense of belonging and mutual aid can be fostered.

A lot can also be learnt by looking at the international policy context in this field. For example, in Brazil, lessons can be learnt from their youth engagement policy. Rather than reinforcing structures of oppression within services whereby young people feel the need to fit into a certain mould of what is expected of them in order to participate in service development, they have developed a new approach. They have incorporated ideas from the stages of the stimulus cycle (Melo, 2019) as a way to cultivate young people's interests and exercise their analytical and critical thinking skills. This enables them to create their own projects to further develop services, whilst drawing from their lived experiences.

#### **4.4 Methodological Reflections**

##### **4.4.1 The Use of Interviews**

The decision to use interviews aided the exploration of how young people make sense of their own experiences and identity as they move through their journey of participation in the design and delivery of services. However, central to this research is the consideration of the positioning of young people participating in mental health services and research. It can be said that the young people interviewed within the research took a passive role, participating in an area of research pre-set by the researcher. I considered ways in which those taking part could feel comfortable in sharing their experience whilst holding an awareness of the limitations within which I was approaching the research i.e. my position as researcher and clinician. The use of narrative inquiry allowed for unstructured interviews which were

'respondent led,' arguably allowing for those taking part to express themselves and explain their views more fully than with structured interviews.

It was hoped that applying narrative inquiry could help towards creating a space for a story to unfold. It is argued the approach may also have allowed young people to have an active role in shaping the direction and content of what they brought. Furthermore, the value of narrative inquiry allowed space to acknowledge that I am entering into this interaction and consider how I might shape stories told, by explicitly attending to power and discourse. It can be argued that holding the position of trainee clinical psychologist and researcher undeniably influences the co-construction of stories told. For example, when introducing myself as a trainee clinical psychologist, I explained the research was part of my learning and development, which may have allowed the young people taking part to take the position of 'teacher' and 'participant,' imparting knowledge to enable me to understand better. There could also be the possibility that my position as a trainee clinical psychologist immediately detracted from the level of collaboration achievable, with the young person feeling the need to conform in a way they thought was expected (Yee & Andrews, 2006). As an 'outsider' of accessing services and an adult researcher, it would be neglectful to ignore my position and my role in co-producing the research in text. Therefore, I have used a method of analysis to explicitly incorporate myself as the researcher, whilst telling my stories in more depth in reflexive research notes (See extract of reflexive journal in Appendix T).

Narratives are understood as a vital means by which individuals conceptualise the self and their identity (Battersby, 2006). Therefore, it can be said that the use of narrative inquiry allowed for a rich insight into the ways in which the young people taking part storied the experiences and meaning of participation in the design and delivery of mental health services over time. It also allowed the exploration of what aspects of the self appeared to be expressed in these narratives.

#### 4.4.2 The Use of Narrative Analysis

Research on the experiences of young people participating in the design and delivery of mental health services is lacking, with a limited amount of research investigating narratives within youth participation. The research used a narrative approach which allowed young people's stories to be situated within a larger social context. Narrative analysis enabled social and political critiques of social structures by taking into account marginal experience narratives (Stone-Mediatore, 2016). Master or dominant narratives which were viewed as relating to the young people's stories were considered within the analytic process.

As discussed, attempts were made to incorporate participatory practices when undertaking the research. However, it can be argued that the 'participants' of the research remained in the traditional passive role, undertaking tasks pre-set by the researcher. Due to ethical frameworks, those participating in the research 'data' could not also advise on the research itself. It can be argued that within traditional approaches to research, it is not possible to occupy *both* roles of researcher *and* participant. With the research being partial fulfilment of a doctoral qualification, the requirement was to show the analysis of results was undertaken by me, the author. This meant I was offering my own 'expert' and 'outsider' interpretations of young people's accounts that were collected as 'data.'

In the context narrators tell their stories, they do so from a structurally subordinate position. As a researcher, I am in a place to make interpretations in a position of power within the research hierarchy. Perhaps there would be a preference of those taking part for their stories not to be mediated by me, an adult professional researcher clinician who stands outside the experience of being a person who has accessed mental health services or received a diagnosis of a 'mental illness.' This highlights the importance of giving perspective to their experience without violating that person's story. With this in mind, I looked to measures to ensure I did not make unjustifiable leaps within the analysis.

It is not uncommon with qualitative approaches to return to those taking part once analysis is complete as a way of exploring the way the researcher had presented their accounts. However, as discussed, in the context of narrative analysis, the act of member-checking would create a further layer of analysis, with re-representations requiring further analysis which was beyond the scope of this thesis. As a result, I looked to other means of considering alternative perspectives to narratives. Attending narrative workshops facilitated by clinical psychologist and senior lecturer with expertise in narrative approaches alongside a trainee clinical psychologist created a space for discussion on narrative research. We were also able to collaborate on analysing anonymised transcript extracts. I was also able to make use of reflective sessions with the supervisory team to conduct partial analysis and discuss themes, differences, and understandings of the stories told by young people taking part in the research. Secondly, the aim is to work with the participation networks involved in the study to discuss the research and explore ways to disseminate the findings further, building on these understandings through dialogue with a view to develop new, participatory ways of bringing this project to life.

A key issue is seeking ways within current traditional contexts of undertaking research of gaining equality for experiential knowledge, research approaches and knowledge claims, which was attempted in this research. However, the shortcomings of this research should continue to be challenged, with young people accessing services invited to offer their own analyses of their experience and of the services and systems they encountered, if indeed it is agreed by young people this would be valuable to do. This would work toward ensuring that the stories of young people participating in the design and delivery of mental health services are not just colonised or reduced to a new area for academic activity, taken from the control of their own authors.

The use of NVivo qualitative data analysis software (QSR International) during the analysis process allowed for the organising and storage of large datasets, although initially time consuming as the programme was unfamiliar. It provided an accurate and transparent picture of the data and also helped provide a useful audit of the data analysis process as a whole. See Appendix R for an extract of data analysis process. Therefore, it is argued that the use of computer assisted qualitative data analysis software (CAQDAS) provided rigour to the process of analysis (Richards & Richards, 1991).

#### **4.4.3 The Use of Participatory Methods**

This narrative study aims to contribute to the understanding of youth participation in the design and delivery of mental health services. There is awareness of the risk of being in a position of an 'expert,' not having accessed services and undertaking research on narratives, 'to take them over' (Russo & Beresford, 2015), potentially creating new kinds of inequality. It could be argued that there is both an ethical and political impetus to engage young people accessing mental health services in the research process rather than just as providers of data. The research is novel and unique in its focus and use of participatory means. A participatory approach was used for the research, with input from youth advisory groups, supervisory input and youth consultation on existing literature, by young people accessing mental health services with additional expertise in service participation. This was an enriching experience from my perspective, which allowed for the adding of new perspectives on existing research, co-producing information materials such as: information sheets; invitation emails and letters; debrief information. Involvement in critiquing results is argued to have improved the research rigour, added new considerations for analyses and produced more succinct and 'to the point' resources for young people interested in taking part in the research. Those involved in advising and consulting on the research described the conversations considering the wider

implication of youth participation useful. Co-creating resources which young people interested in taking part would better understand, was described as worthwhile and a learning experience by those involved. The study has been carefully considered around how to recognise and acknowledge the equal value of experiential knowledge in the research area.

Not without its challenges in this being authorised by wider university systems, the research has been co-supervised by a young person with experiential knowledge in accessing services and participation roles within the design and delivery of these services. This has helped gain insight into ways of engaging with young people to take part in the research, allowed an exchange of knowledge on the input on methodological stages and analysis, as well as discussing wider implications of the study.

#### **4.4.4 A Reflexive Approach to the Research**

I have attempted to hold a reflexive stance throughout the research process, allowing time for introspection and considering my own contribution to the unfolding of the research. With the use of a reflexive journal, I have tried to attend to my own ideas, experiences, preconceptions and my relationship to youth participation. For example, I noticed early on that my journey to this area of research was related to my own experiences as a young person. Growing up in inner city Birmingham in an area where unemployment was high with seemingly little opportunity for social mobility, it seemed the narrative of many people in the community I lived was that nothing would change. Conversations I had with people around voting made me aware of the view that the people around me held, that their vote didn't matter and wouldn't make a difference. This sparked my growing interest in the social constraints on people's lives *and* their resistance to these.

I have continued to reflect upon and hold a critical stance of language within the research. As noted, throughout the research I attempted to enter a 'language game'

(Wittgenstein, 1963), using but also contesting dominant terminology such as 'patient' and 'participant.' This has been used in approaches such as narrative therapy as a way to create and shift meanings which facilitate a change. It is questioned to what extent this has worked toward challenging such terminology, with the potential for these constructions to be verified through the use of this language. It could be argued that dominant discourses were better challenged in the interviews with young people through the co-construction of narratives around 'mental health' experiences and possible shifts in positioning.

During the research itself, there were young people taking part I considered more rehearsed or articulate in their story which led them to potentially having a stronger voice in the research than quieter young people. Efforts were made to notice and understand why I might be more drawn to particularly young people's stories, for example if they were succinct and seemed to convey a powerful message to the audience, and the further potential of marginalising young people who may not have been perceived as being as 'impactful.' Ana speaks of her involvement in a film through service participation, saying "*they just sort of picked out the right bits and stuff*" which really seemed to resonate with the research itself for me. It helped me continue to hold an awareness of stories I might be more drawn to and the potential of extracting stories from the context they were situated in. Having a dialogue with supervisors around differences in analyses and where ideas overlap has been a highly valued and important part of the process in attending to what I may have been drawn to as a result of my own multiple lenses I was seeing the research through.

#### **4.5 Future Research Directions**

Youth participation in the design and delivery of mental health services has continued to gain momentum both nationally and internationally over recent years. With research lacking in the experiences of young people accessing services and participating in service

design, this has resulted in a lack of clarity whether this has led to progress or is even advocated by young people. Indeed, the drive for service participation is led by government within key health policies with arguably competing interests between key stakeholders in the venture. Enhanced knowledge of the views of young people, practitioners, and mental health researchers, would contribute to debates on the ethics, relevance, and benefits of youth service participation. This has the potential to contribute to knowledge that has wide-ranging benefits for research, policy, and practice. Most importantly, this has positive implications for the well-being and human rights of young people with experience of mental health difficulties.

The small number of young people taking part in the research means that a number of important voices may have been neglected. It is also important to note that the group of young people taking part in the research were those deemed suitable for participation in the design and delivery of services by those involved in their care within the service. The research did not include young people who may have been told they were not suitable or those who chose not to be involved in service participation. In order to address this, future research should pursue the same research aim and questions with the discussed neglected groups, including young people who may have decided service participation was not for them. It can be argued that the more stories that are heard, the more understanding of the multiple, complex ways that interacting discourses and positions can be negotiated.

Barnes, Newman, Knops, and Sullivan, (2003) suggest the drivers for individuals to engage in participation, proposing a motivation out of collective experiences of oppression or exclusion, seeking service improvements or wanting to develop skills and self-confidence. Young people taking part seemed to differ in their motivation to be involved in service participation, with interests in meeting people, interests in gaining work experience and wanting to help others all being reasons for participation. The reasons for youth participation

may have contributed to shaping identities, also what was ultimately gained or experienced from the process (Barnes et al., 2003). This was not a particular focus for the current research but may be useful to explore further.

It is recognised that there is a risk of assuming participatory approaches necessarily produces 'better' research (Holland et al., 2010). It should also be said that there is limited research undertaken to understand the experiences of young people involved in participatory research (Holland et al., 2010). This questions the motivating factors behind participatory practices. Therefore, it would be important to continue to build upon existing research to develop an understanding around what it means to undertake participatory research alongside young people. It is also recognised that triangulating the data would be useful, whether that is through qualitative, quantitative, and/or mixed methods. This could help strengthen the knowledge base and case for political proposals.

#### **4.6 Conclusions**

This research aimed to understand the experiences of six young people participating in the design and delivery of mental health services in the UK. From the accounts of young people, four broad stories were observed. These were stories of 1. Moving into social spaces and holding out a helping hand; 2. Having to become the 'right fit' for participation; 3. Repositioning from patient to person; 4. Strengthening alternative identity stories through relationships. These stories seemed to hold important narratives with implications for changes in identity, and how discourses around 'participation' and 'mental illness' are co-constructed. For some, there was an indication of redefining selves, and for others, a calling for change whether with services directly or society more broadly. The research introduces new insights into how language positions young people in mental health contexts. This research highlights the need to approach youth participation systematically and critically, acknowledging the

ethical and political impetus to engage young people accessing mental health services in the research process rather than just as providers of data. The clinical relevance and implications of the research identified key areas of focus and recommendations for future research.

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## Appendices

### Appendix A: Literature Review Process

#### Part One

The databases of PsycINFO, Scopus, CINAHL and Cochrane Controlled Trials Register were systematically searched between November 2018 and February 2019 for relevant articles published. A number of trial searches were completed to get a clearer idea of which terms would generate the most comprehensive searches. The search terms were used so as to cover broad and narrower regions of the literature. Inclusion and exclusion criteria, as displayed in Table 5 below, were applied.

Inclusion Criteria	Exclusion Criteria
<ol style="list-style-type: none"> <li>1. Peer-reviewed</li> <li>2. Written or translated English</li> <li>3. Concerning experiences of participation of young people in the design and/ or delivery of mental health services at the meta, macro or meso level.</li> <li>4. Studies making reference to the experience of young people aged between 10-24 years old in accordance with Association for Young People's Health (2015). Where the upper age exceeds this, this will be made clear.</li> <li>5. Young people's participation may have been reported by young people, researchers, their caretakers, health professionals or other stakeholder groups</li> </ol>	<ol style="list-style-type: none"> <li>1. Learning disabilities</li> <li>2. Involvement at an individual level only, concerning decisions about a young people's own mental healthcare</li> <li>3. Providing information to users</li> <li>4. User satisfaction surveys that were researched by the provider (which do not require users' partnership)</li> <li>5. General health services not specifically aimed at mental health</li> <li>6. Forensic services</li> <li>7. Services which are not health related, such as housing or vocational rehabilitation</li> <li>8. Commentaries, opinion pieces, or editorials</li> <li>9. Experiences of participation as part of discussion</li> </ol>

**Table 5.** *Inclusion and Exclusion Criteria*

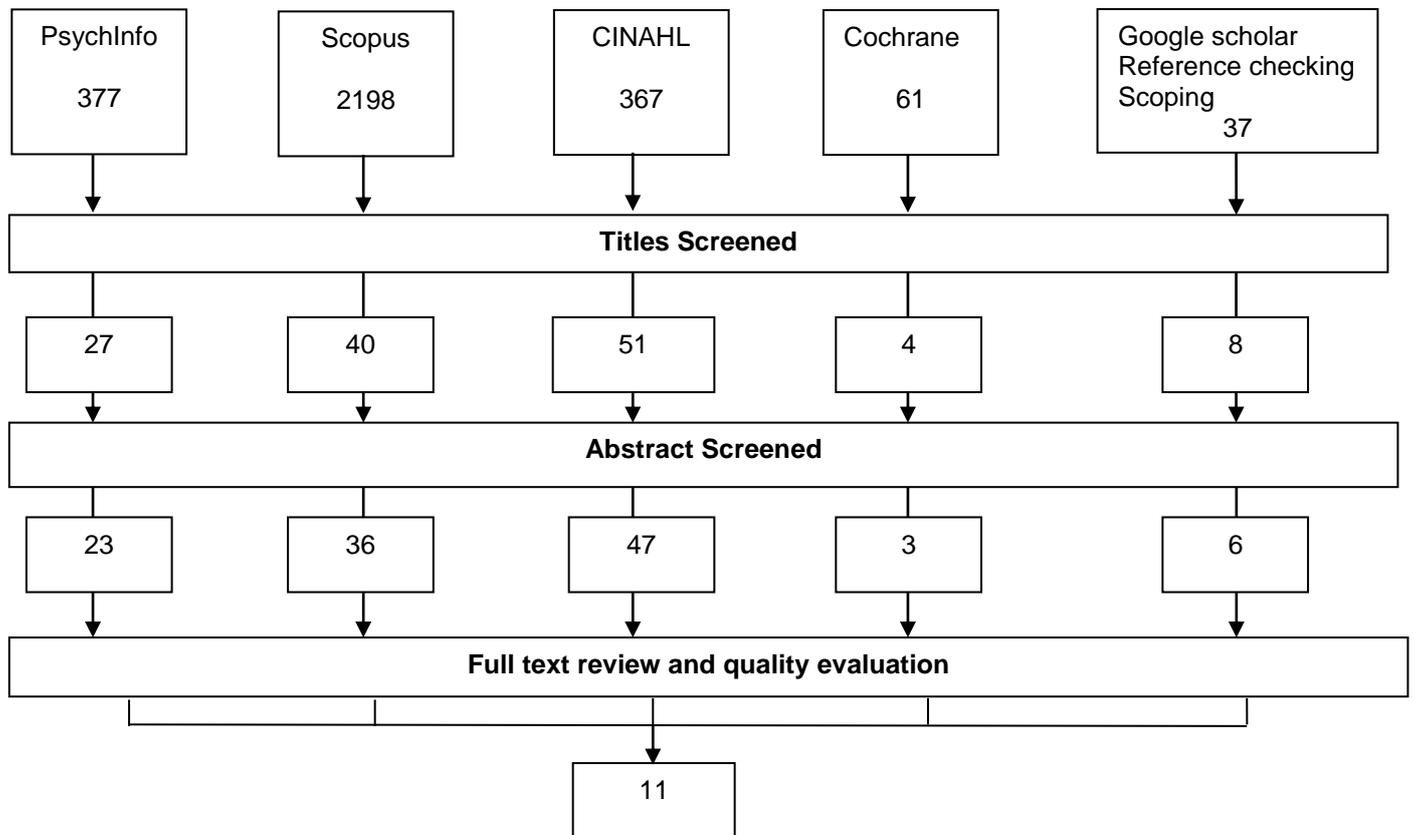
## Part Two

All papers which were relevant were checked to see if there were additional papers in their reference lists; in addition, Google Scholar was used to see whether each paper had been 'cited by' any other relevant paper published more recently. Also searched were: relevant NICE guidelines to the topic area, relevant book chapter's reference lists; publication pages of the websites of key authors in the field. This identified 36 further papers.

Database	Search Terms
PsychInfo	(inclu* OR invol* OR participat* OR "service-use*" OR "peer-lead" OR "peer-led" OR "co-produc*" OR "co-design*" OR "co-deliver*" OR "experts by experience") AND ("young people" OR "young person" OR "young adult" OR adolescen* OR teenage* OR child* OR youth) AND ("mental health" OR CAMHS OR "child & adolescent mental health service*" OR Psychiatr* OR "CYP-IAPT")
Scopus	(inclu* OR invol* OR participat* OR "service-use*" OR "peer-lead" OR "peer-led" OR "co-produc*" OR "co-design*" OR "co-deliver*" OR "experts by experience") AND ("young people" OR "young person" OR "young adult" OR adolescen* OR teenage* OR child* OR youth) AND ("mental health" OR CAMHS OR "child & adolescent mental health service*" OR Psychiatr* OR "CYP-IAPT")
CINAHL	(inclu* OR invol* OR participat* OR "service-use*" OR "peer-lead" OR "peer-led" OR "co-produc*" OR "co-design*" OR "co-deliver*" OR "experts by experience") AND ("young people" OR "young person" OR "young adult" OR adolescen* OR teenage* OR child* OR youth) AND ("mental health" OR CAMHS OR "child & adolescent mental health service*" OR Psychiatr* OR "CYP-IAPT")
Cochrane	(inclu* OR invol* OR participat* OR "service-use*" OR "peer-lead" OR "peer-led" OR "co-produc*" OR "co-design*" OR "co-deliver*" OR "experts by experience") AND ("young people" OR "young person" OR "young adult" OR adolescen* OR teenage* OR child* OR youth) AND ("mental health" OR CAMHS OR "child & adolescent mental health service*" OR Psychiatr* OR "CYP-IAPT")

**Table 6.** Search Terms for Literature Review.

A flow chart of the literature review is displayed in Figure 6 below.

**Figure 3.** *Flowchart for Literature Review Process*

**Appendix B: Framework for Quality Assessment (Elliott et al., 1999)**

Authors	Publishability guidelines shared by both qualitative and quantitative approaches														
	Publishability guidelines especially pertinent to qualitative research														
	Explicit scientific context and appropriate methods	Respect for participants	Specification of methods	Appropriate discussion	Clarity of presentation	Contribution to knowledge	Owning one's perspective	Situating the sample	Grounding in examples	Providing credibility checks	Coherence	Accomplishing general vs. specific	Resonating with readers		
Faithfull, Brophy, Pennell, & Simmons, 2018	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	✓		
Dexter, Larkin, & Newnes, 2011	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓		
Mayer & McKenzie, 2017	✓	✓	✓	✓	✓	✓	×	×	✓	✓	✓	✓	✓		
Coates & Howe, 2014	✓	×	✓	×	×	✓	×	✓	✓	×	×	✓	✓		
Coates & Howe, 2016	✓	✓	✓	✓	✓	✓	×	✓	✓	×	✓	✓	✓		



### Appendix C: Examples of Quality Evaluation of Literature Reviewed

An extract from a detailed table summarising the quality evaluation of the literature.

Authors	a.	Publishability guidelines shared by both qualitative and quantitative approaches					
	b.	Publishability guidelines especially pertinent to qualitative research					
	Explicit scientific context and purpose	Appropriate methods	Respect for participants	Specification of methods	Appropriate discussion	Clarity of presentation	Contribution to knowledge
Faithfull, Brophy, Pennell, & Simmons, 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	The paper includes background literature, aims of the study and an introduction to the method.	A general inductive approach was taken with the application of thematic analysis to explore experiences of youth mental health workers.	Ethical procedure detailed.  Participants were made aware that potentially identifiable information would be included in research. However, some aspects of demographic information was not included in order to protect anonymity.	The methodology is clearly defined, described and operationalised.  Sampling and recruitment described. Age and gender of sample not included but explanation given.  Methods described (semi-structured interviews). Analysis described and referenced: Thematic analysis	The discussion is appropriate, based on the findings, alongside some reflexive critiques around the potential influence of interviewer. Limitations and some recommendations for future working given.	Themes are clearly presented in results.	The study adds to the research literature, making similar findings, alongside useful contributions to the field. The research was conducted by a team of researchers that included a young person with lived experience enabling a lived experience perspective to make a central contribution.
	Owning one's perspective	Situating the sample	Grounding in examples	Providing credibility checks	Coherence	Accomplishing general vs. specific research tasks	Resonating with readers
No	Yes	Yes	Yes	Yes	Yes	Yes	
The study did not make an explicit	The sample is described in terms of	The authors frequently refer	All participants were offered member	The findings are presented within a	The study represents a general focus	Many aspects of the study could resonate	

	<p>reference to epistemology. There was an awareness of interviewer's dual role but no details around position taken. Introduction clearly focused upon benefits of participation without a critical component.</p> <p>The team of researchers for the included a young person with lived experience enabling a lived experience perspective, however the perspective was not explicitly shared.</p>	<p>having an academic position within Orygen and that the sample did not identify as young people with lived experience. There are no further details provided around length of position held. Demographic information is not given in order to protect anonymity.</p>	<p>themes back to participant quotes.</p>	<p>checking although no one took up this option.</p>	<p>clear and coherent conceptual framework, presenting perceived benefits and potential barriers of participation at individual and organisational levels. There was also the theme presented around making youth participation genuine.</p>	<p>around youth mental health research participation and why this may be lacking across research, providing barriers but also factors which can enable researchers to engage young people in their work.</p>	<p>with researchers looking into ways to engage young people in mental health research.</p>
	<b>Explicit scientific context and purpose</b>	<b>Appropriate methods</b>	<b>Respect for participants</b>	<b>Specification of methods</b>	<b>Appropriate discussion</b>	<b>Clarity of presentation</b>	<b>Contribution to knowledge</b>
Dexter, Larkin, & Newnes, 2011	<p>Yes</p> <p>The paper includes background literature, aims of the study and an introduction to the method.</p>	<p>Yes</p> <p>Foucauldian discourse analysis was used on the accounts of eight Clinical Psychologists who work with children.</p>	<p>Yes</p> <p>The researchers sought ethical approval from the National Health Service in order to undertake the research.</p>	<p>Yes</p> <p>The methodology is clearly defined, described and operationalised.</p> <p>Sampling and recruitment described. Age and gender of sample not included but explanation given.</p> <p>Details of the</p>	<p>Yes</p> <p>Findings related back to existing literature, with critical reflections on the research and future directions for research in this area given.</p>	<p>Yes</p> <p>Presentation of analysis given visually in terms of discursive objects and subject positions. Further detail is provided in the body of the text.</p>	<p>Yes</p> <p>Details of the psychology service and range of children seen by the sample was not included, details of which may help contextualise findings e.g. in context of adolescents etc.</p>

				<p>psychology service and range of children seen by the sample was not included.</p> <p>Methods described (semi-structured interviews). Analysis described and referenced: Foucauldian discourse analysis</p>			
<b>Owning one's perspective</b>	<b>Situating the sample</b>	<b>Grounding in examples</b>	<b>Providing credibility checks</b>	<b>Coherence</b>	<b>Accomplishing general vs. specific research tasks</b>	<b>Resonating with readers</b>	
<p>Yes</p> <p>Reflections are shared around the interview process a sharing of the author's awareness of the dynamic operating between the researcher and researched.</p> <p>Reflections also shared around the research overall research process and researcher's own position, interests and views relating to the research.</p>	<p>No</p> <p>Sampling and recruitment described. Age and gender of sample not included but explanation given.</p> <p>Details of the psychology service and range of children seen by the sample was not included.</p>	<p>Yes</p> <p>The authors frequently refer themes back to participant quotes</p>	<p>Yes</p> <p>Triangulation was used on the process of analysis. Roles of authors clearly stated, with second author providing a commentary on first authors analysis of transcripts.</p> <p>Reflection shared throughout research.</p>	<p>Yes</p> <p>The findings were presented within a clear and coherent conceptual framework with the presenting of each object in terms of ways it was constructed by the participants.</p>	<p>Yes</p> <p>The exploration of Clinical Psychologist's understanding of user involvement draws upon wider societal and political ideologies around involvement. The also goes on to explore the constructions around user involvement. The research draws less upon the 'how to,' with more focus on exploration of power relationships at play.</p>	<p>Yes</p> <p>This paper adds to the research literature, highlighting similar findings to the literature and provides a critical stance to involvement with interesting points around the impetus of involvement being at a senior level. This adds to the literature which tends to focus more on benefits of involvement.</p>	

## Appendix D: Research Ethics Committee Approval Letter

Lothian NHS Board

South East Scotland Research  
Ethics Committee 02



Waverley Gate  
2-4 Waterloo Place  
Edinburgh  
EH1 3EG  
Telephone 0131 538 9000

[www.nhslothian.scot.nhs.uk](http://www.nhslothian.scot.nhs.uk)

Date 11 September 2018  
Your Ref  
Our Ref

Enquiries to : Joyce Clearie  
Extension: 35674  
Direct Line: 0131 465 5674  
Email: [Joyce\\_Clearie@nhslothian.scot.nhs.uk](mailto:Joyce_Clearie@nhslothian.scot.nhs.uk)

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

07 September 2018

Dr Lizette Nolte  
Clinical Psychologist and Principle lecturer  
University of Hertfordshire  
Department of Psychology and Sports Sciences, School of Life and Medical Sciences  
College Lane Campus, University of Hertfordshire  
Hatfield  
AL10 9AB

Dear Dr Nolte

**Study title:** Young people's narratives of evolving identity through participation in the design and delivery of NHS mental health services  
**REC reference:** 18/SS/0107  
**Protocol number:** NA  
**IRAS project ID:** 244042

Thank you for your letter dated 26 August 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.



Headquarters  
Waverley Gate  
2-4 Waterloo Place  
Edinburgh EH1 3EG

Chair Brian G. Houston  
Chief Executive Jim Grayson  
Lothian NHS Board is the approved  
name of Lothian Health Board



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

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

#### **Confirmation of ethical opinion**

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

#### **Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

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

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

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

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

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

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

#### **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 8 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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

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

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

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

**Ethical review of research sites**



#### NHS sites

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

#### Non-NHS sites

#### Approved documents

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

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Project Proposal Feedback from Research Tutor, Dr Helen Ellis-Caird, Clinical Psychologist and Research Tutor, University of Hertfordshire]	1	26 June 2018
Copies of advertisement materials for research participants [Initial email to send out to potential participants. Version 2. 28.08.18]	2	28 August 2018
Covering letter on headed paper [Covering Letter. Version 1. Dated 28.08.18]	1	26 June 2018
Covering letter on headed paper [Cover Letter to REC Chair following request for clarification. Dated 26.08.18]	1	26 August 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Certificate. Dated 19.07.18]	2	19 July 2018
GP/consultant information sheets or letters [GP Letter. Version 1. Dated 22.08.18]	1	22 August 2018
Interview schedules or topic guides for participants [Interview Schedule Guide. Dated 26.08.18 Version 1]	1	26 June 2018
IRAS Application Form [IRAS_Form_01082018]		01 August 2018
IRAS Application Form XML file [IRAS_Form_01082018]		01 August 2018
IRAS Checklist XML [Checklist_07092018]		07 September 2018
Letter from sponsor [In principle approval]	1	20 July 2018
Letters of invitation to participant [Participant Invitation Letter. Version 1. Dated 26.08.18]	1	26 June 2018
Participant consent form [Participant Consent Form. Version 3. Dated 28.08.18]	3	28 August 2018
Participant information sheet (PIS) [Participant Information Sheet. Dated 28.08.18]	3	28 August 2018
Research protocol or project proposal [Research Proposal]	2	31 July 2018
Summary CV for Chief Investigator (CI) [Chief Investigator Research CV Version 1. Dated 02.07.18]	1	02 July 2018
Summary CV for student [Student CV. Version 1. Dated 30.07.18]	1	30 July 2018
Summary CV for supervisor (student research) [CV Dr James Randall-James]	1	30 July 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Debrief Form. Version 3. Dated 28.08.18]	3	28 August 2018

#### Statement of compliance

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



#### **After ethical review**

##### Reporting requirements

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

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

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

#### **User Feedback**

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

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

**18/SS/0107**

**Please quote this number on all correspondence**

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

Yours sincerely

A handwritten signature in black ink, appearing to read 'Lindsay Murray', written over a light blue horizontal line.

**Mr Lindsay Murray**

**Chair**

Email: [joyce.clearie@nhslothian.scot.nhs.uk](mailto:joyce.clearie@nhslothian.scot.nhs.uk)

**Enclosures:** "After ethical review – guidance for researchers"

**Copy to:**

## Appendix E: Health Research Authority Approval Letter



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[Research-permissions@wales.nhs.uk](mailto:Research-permissions@wales.nhs.uk)

Dr Lizette Nolte  
Clinical Psychologist and Principle lecturer  
Department of Psychology and Sports Sciences,  
School of Life and Medical Sciences  
College Lane Campus,  
University of Hertfordshire  
Hatfield  
AL10 9AB

20 September 2018

Dear Dr Nolte

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

<b>Study title:</b>	<b>Young people's narratives of evolving identity through participation in the design and delivery of NHS mental health services</b>
<b>IRAS project ID:</b>	<b>244042</b>
<b>Protocol number:</b>	<b>NA</b>
<b>REC reference:</b>	<b>18/SS/0107</b>
<b>Sponsor</b>	<b>University of Hertfordshire</b>

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

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

Following the arranging of capacity and capability, participating NHS organisations should formally confirm their capacity and capability to undertake the study. How this will be confirmed is detailed in the "summary of assessment" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

IRAS project ID	244042
-----------------	--------

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

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

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

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

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

**I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?**

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Ellie Hubbard

Tel: 01707284983

Email: [research-sponsorship@herts.ac.uk](mailto:research-sponsorship@herts.ac.uk)

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 244042. Please quote this on all correspondence.

IRAS project ID	244042
-----------------	--------

### List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Project Proposal Feedback from Research Tutor, Dr Helen Ellis-Caird, Clinical Psychologist and Research Tutor, University of Hertfordshire]	1	28 June 2018
Contract/Study Agreement template [Signed Supervisor Contract]	1	28 June 2018
Copies of advertisement materials for research participants [Initial email to send out to potential participants. Version 2. 28.08.18]	2	28 August 2018
Covering letter on headed paper [Covering Letter. Version 1. Dated 26.06.18]	1	28 June 2018
Covering letter on headed paper [Cover Letter to REC Chair following request for clarification. Dated 26.08.18]	1	28 August 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Certificate. Dated 19.07.18]	2	19 July 2018
GP/consultant information sheets or letters [GP Letter. Version 1. Dated 22.08.18]	1	22 August 2018
HRA Schedule of Events	1	20 September 2018
HRA Statement of Activities	1	20 September 2018
Interview schedules or topic guides for participants [Interview Schedule Guide. Dated 26.06.18 Version 1]	1	28 June 2018
IRAS Application Form [IRAS_Form_01082018]		01 August 2018
Letter from sponsor [In principle approval]	1	20 July 2018
Letters of invitation to participant [Participant Invitation Letter. Version 1. Dated 26.06.18]	1	28 June 2018
Participant consent form [Participant Consent Form. Version 3. Dated 28.08.18]	3	28 August 2018
Participant information sheet (PIS)	4	20 September 2018
Research protocol or project proposal [Research Proposal]	2	31 July 2018
Summary CV for Chief Investigator (CI) [Chief Investigator Research CV Version 1. Dated 02.07.18]	1	02 July 2018
Summary CV for student [Student CV. Version 1. Dated 30.07.18]	1	30 July 2018
Summary CV for supervisor (student research) [CV Dr James Randall-James]	1	30 July 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Debrief Form. Version 3. Dated 28.08.18]	3	28 August 2018

IRAS project ID	244042
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### Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

### Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	Non-substantial amendments were made to the Participant Information Sheet following the REC favourable opinion. This was to ensure compliance with the GDPR transparency requirement.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor intends that the Statement of Activities will be used to form an agreement with participating NHS organisations. No additional agreement is expected.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No external funding has been sought.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments

IRAS project ID	244042
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Section	Assessment Criteria	Compliant with Standards	Comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

### Participating NHS Organisations in England and Wales

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

There will be one study site type. Participants will be identified at site and may participate in an interview at site if this is the most convenient location for them.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra.approval@nhs.net](mailto:hra.approval@nhs.net) or HCRW at [Research-permissions@wales.nhs.uk](mailto:Research-permissions@wales.nhs.uk). We will work with these organisations to achieve a consistent approach to information provision.

### Principal Investigator Suitability

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

As per the Statement of Activities, a named local Principal Investigator has already been agreed at site. No training will be provided locally.

IRAS project ID	244042
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GCP training is not a generic training expectation, in line with the [HRA/HCRW/MHRA statement on training expectations](#).

### HR Good Practice Resource Pack Expectations

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

### Other Information to Aid Study Set-up

*This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.*

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

## Appendix F: NHS Trust Confirmation of Capacity and Capability

### IRAS 244042 - Confirmation of Capacity and Capability

Nolte, Lizette; Research Sponsorship; Cole, Laura; +3 more

Ethics



Download Save to OneDrive - University of Hertfordshire

Action Items



Dear All,

**RE: IRAS: 244042 -Confirmation of Capacity and Capability at**

**Full Study Title:** Young people’s narratives of evolving identity through participation in the design and delivery of NHS mental health services.

**Site PI/LC:**

This email confirms that [redacted] has the capacity and capability as a Research site. Please find attached the agreed Statement of Activities as confirmation.

[redacted] agrees to start this study on a date to be agreed when you as sponsor give the green light to begin. Please ensure the R&D office and local CRN contacts are provided with this date.

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

If necessary, Letters of Access for the research team should be arranged prior to the relevant team members conducting any study interventions.

Please note, in line with national HRA approvals process, you will no longer receive an NHS R&D Approval/Permission letter.

Kind regards,

**DETAILS REMOVED**

\*\*\*\*\*  
\*\*\*\*\*

## Appendix G: NHS Trust Right of Access Letter

Ms Laura Cole



Friday 21<sup>st</sup> December 2018

Dear Ms Laura Cole,

### Letter of access for research

This letter confirms your right of access to conduct research through

DETAILS REMOVED

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research [REDACTED] has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [REDACTED], you will remain accountable to your place of study [University of Hertfordshire] but you are required to follow the reasonable instructions of your manager in this NHS organisation [REDACTED], or those given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. You must



observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust [R&D department- 01707 253834 / occupational health- 01442 28 7576] prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that we accept no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the Trust or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

We will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager and the R&D office here in HPFT.

Yours sincerely

Human Resources Department

## Appendix H: University of Hertfordshire Sponsorship Letter



Dr L Nolte & Ms L Cole  
Department of Psychology & Sports Sciences  
School of Life & Medical Sciences

University of Hertfordshire  
Higher Education Corporation  
Hatfield, Hertfordshire  
AL10 8AB

Telephone: +44 (0) 1607 284000  
Fax: +44 (0) 1607 204115  
Website: [www.herts.ac.uk](http://www.herts.ac.uk)

18 December 2018

Dear Dr Nolte and Ms Cole,

**Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:**  
**RESEARCH STUDY TITLE:** Young people's narratives of shaping identity through participation in the design and delivery of NHS mental health services  
**NAME OF CHIEF INVESTIGATOR (Supervisor):** Dr Lizette Nolte  
**NAME OF INVESTIGATOR (Student):** Ms Laura Cole  
**UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER:** LMS/PGT/NIHS/02918

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements.

Permission to seek changes as outlined above should be requested from myself before submission to the Health Research Authority (HRA) NHS Research Ethics Committee (REC) and I must also be notified of the outcome. It is also essential that evidence of any further NHS Trust Management Permissions (formerly known as R&D Approval) is sent as soon as they are received. Copies of annual reports and the end of study report as submitted to the HRA also need to be provided. Please do this via email to [research\\_sponsorship@herts.ac.uk](mailto:research_sponsorship@herts.ac.uk)

**Please note that University Sponsorship of your study is invalidated if this process is not followed.**

In the meantime, I wish you well in pursuing this interesting research study.

Yours sincerely

Professor J.M. Senior  
Pro Vice-Chancellor (Research and Enterprise)



**Appendix I: Project Summary Report Sent to REC & Trust R&D****Health Research Authority****DECLARATION OF THE END OF A STUDY**

(For all studies except clinical trials of investigational medicinal products)

*To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination.*

*For questions with Yes/No options please indicate answer in bold type.*

**1. Details of Chief Investigator**

Name:	<b>Laura Cole</b>
Address:	<b>Department of Psychology and Sports Sciences, School of Life and Medical Sciences, College Lane Campus, University of Hertfordshire, Hatfield, AL10 9AB</b>
Telephone:	<b>01707284978</b>
Email:	<b>l.cole@herts.ac.uk</b>
Fax:	

**2. Details of study**

Full title of study:	<b>Young people's narrative accounts of participation in the design and delivery of NHS mental health services</b>
Research sponsor:	<b>Ms Ellie Hubbard, Research Information and Governance Manager, Research Office, University of Hertfordshire, AL 10 9AB Email: research-sponsorship@herts.ac.uk</b>
Name of REC:	<b>South East Scotland</b>
REC reference number:	<b>18/SS/0107</b>

**3. Study duration**

Date study commenced:	<b>Sept 2018</b>
-----------------------	------------------

Date study ended:	<b>July 2019</b>
Did this study terminate prematurely?	<i>Yes / <b>No</b></i> <i>If yes, please complete sections 4, 5, 6, &amp; 7.</i> <i>If no, please go direct to section 8.</i>

#### 4. Recruitment

Number of participants recruited	
Proposed number of participants to be recruited at the start of the study	
If different, please state the reason or this	

#### 5. Circumstances of early termination

What is the justification for this early termination?	
---	--

#### 6. Temporary halt

Is this a temporary halt to the study?	<i>Yes / No</i>
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	<i>e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.</i>

#### 7. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	
--	--

**8. Final report on the research**

Is a summary of the final report on the research enclosed with this form?	<p>Yes / <b><u>No</u></b></p> <p><i>If no, please forward within 12 months of the end of the study.</i></p>
---	---

**9. Declaration**

Signature of Chief Investigator:	
Print name:	<b>Laura Cole</b>
Date of submission:	<b>27.08.19</b>

[Address]

University of Hertfordshire  
Health Research Building  
College Lane Campus  
University of Hertfordshire  
Hatfield  
AL10 9AB

[ENTER DATE]

Dear [ENTER],

**RE: Young people's narratives of evolving identity through participation in the design and delivery of mental health services REC reference: 18/SS/0107 IRAS project ID: 244042**

I am writing to update you on the progress of the above research project. This project has now come to a close. I recruited 6 participants in total from two sites over an 8-month period. Please do not hesitate on contacting me if you have any questions.

Yours Sincerely,

Laura Cole  
Trainee Clinical Psychologist  
University of Hertfordshire  
l.cole@herts.ac.uk

## Appendix J: Letter to GP



Date:

Doctor  
Address:

Dear Doctor,

**Re: Young people's experiences of participation in the design and delivery of NHS mental health services**

**[Patient name and address]**

---

The above patient has kindly agreed to take part in a research project entitled: **Young people's experiences of participation in the design and delivery of NHS mental health services**. This is a qualitative study which will involve interviewing young people about experiences of service participation. The study, given favourable opinion by South East Scotland Research Ethics Service (REC reference number: 18/SS/0107).

The Chief Investigator for the study is: Dr Lizette Nolte, Clinical Psychologist and Principle Lecturer at University of Hertfordshire.

A copy of the participant information sheet is enclosed for your information. Should you have any questions regarding this study, please do not hesitate to contact me by email [l.cole@herts.ac.uk](mailto:l.cole@herts.ac.uk) or phone 01707 286 322.

Yours sincerely,

Laura Cole  
Trainee Clinical Psychologist  
University of Hertfordshire  
Health Research Building  
College Lane Campus  
University of Hertfordshire  
Hatfield  
AL10 9AB

Encl. Participant Information Sheet

Young people's experiences of participation in the design and delivery of NHS mental health services  
GP letter Version 1 Dated 22.08.18

## Appendix K: Information Sheet



### Information Sheet

You are invited to take part in a research study. Before you decide whether to do so it is important that you understand the research and what your involvement will include. Please take your time to read the following information carefully and discuss it with others if you wish. Feel free to ask us about anything that is unclear or ask for any further information you would like to help you make your decision. This study is part of an educational project and is being conducted as partial fulfilment of a Doctorate.

Thank you.

#### Project Title

**Young people's narratives of shaping identity through participation in the design and delivery of NHS mental health services.**

#### Who am I?

My name is Laura Cole and I am a Trainee Clinical Psychologist at the University of Hertfordshire.

#### What is the purpose of the study?

Participation of young people in the design, development and delivery of mental health services is a key part of current NHS policy. The current study aims to explore young people's experiences of participation. The researchers think it is important that young people's opinions are heard, and so this study aims to fill the gap in our knowledge regarding how young people experience service participation. We hope that this research will be useful for young people accessing, people working within and overall development of CAMHS

#### What does the project involve?

Your People Participation Lead will provide information about the study. If you then decide to take part, with your consent, your details will be passed on to me, the researcher.

I will arrange to speak with you on the phone to introduce myself and provide a space to answer any questions you may have about the study. I will then arrange a time and place to meet with you that suits you (e.g., your home or a CAMHS building).

When we meet I will ask you to sign a consent form if you are happy to take part in the research. I will then ask some questions such as your age, ethnicity, reason for and duration of accessing CAMHS. I will also ask about what type of participation work you have been involved in.

I would then ask you about your experiences of being involved in service development. Everyone has different experiences so there are no right or wrong answers. We would usually talk for about 1 hour, but we can stop or take breaks whenever you want.

**Are there any limitations of the research?**

The research will involve taking part in an individual interview, requiring a level of commitment from you. It is important to highlight that involvement in interviews etc. will have no detrimental impact on your access to services.

**What if I get upset during the research?**

The research is not intended to cause you any harm, distress or discomfort. However, talking about experiences such as mental health difficulties can be upsetting, and sometimes even meeting new people can be anxiety provoking. Therefore, I would encourage you to let me know if you are ever feeling worried or uncomfortable so that I can try and improve this.

There will be clear information about sources of support that you can access if you need to speak to someone in more detail outside of the research. However, if the researchers think you or someone else may be at risk of harm, we may need to tell someone else, such as your GP in order to keep you safe. We will try and let you know beforehand, but we may not always be able to do this.

**Do my parents or guardian have to know I am taking part?**

No. Young People over the age of 16 can consent to take part in research themselves. However, you can discuss this research with your parent or guardian if you wish to. If you don't want your parents or guardians to know, then you can still take part in the study.

**Will other people know I am taking part?**

If you agree to take part in the study, we will keep your information in confidence, stored in a safe locked location. The only people who could see this would be members of the research team, and people who monitor research to check that it is being done properly.

A brief letter will be sent to your GP to let them know you will be participating in this research if you agree to take part in the study. This will only include your name and address and a sentence to say you have agreed to take part in this research. It will not include any further personal information.

**What happens to the things I share? Will they be kept private?**

During the study, I will record our conversation on a Dictaphone and I may make some notes. The Dictaphone will be encrypted so that no one can access it without my password and it will be kept in a safe place. I will remove any information that might identify you such as your name, date of birth, the place where you live and so on from all aspects of the study.

I will type up our interview and remove your details giving you a 'pseudo name' to protect your privacy. This document will be kept, password protected, for up to 5 years to enable the study to be checked by others if they wish to do so. The recording will be deleted when the research is complete in September 2019.

Quotes and extracts from things you have shared may be used in the analysis of the research and the write up (this is common in this sort of study). However, no personal details

will be shared which would mean other people could identify you (e.g. your name or where you live).

A list of your names and contact details will be scanned and stored electronically as a secure password protected file which only the research team will have access to. This information will be kept only for the duration of the study (up to September 2019) in case we need to contact you.

Your data will be protected according to new GDPR legislation (see Appendix 1).

Anything you tell me will be kept confidential from friends, family and the CAMHS team involved in your care. The only limit to confidentiality would be if you told me something that made me believe that you or another young person was at risk of some kind. If you tell me anything that makes me concerned for your safety or the safety of someone close to you, I have a duty of care to tell someone about it in order to ensure you are safe. I will always do this wherever possible with your knowledge.

#### **Will I get anything for taking part?**

I hope that you will find the discussions with other young people interesting and helpful. If you need to travel to our meeting, the cost of this can be refunded. There will be a payment of a £15 gift voucher from a store of your choice for your time during the interview.

#### **Do I have to take part?**

No. You do not have to take part in this study and should not feel under any pressure to take part. If you do decide to take part, you are free to change your mind and withdraw from the study at any time. If you choose to withdraw from the study, there will be no disadvantage to you or any of the care you will receive from services.

#### **What happens if I withdraw from the research?**

Even if you decide to take part, you are free to stop at any time without giving a reason. Deciding to take part or not won't affect the care that you are receiving.

#### **Who are the research supervisors?**

There are three co-supervisors for the study: Lizette Nolte, Leann Stollenwerk and James Randall-James. Lizette Nolte is a clinician and Principle Lecturer and at the university. James Randall-James is a clinician within East London NHS Foundation Trust. Leann Stollenwerk is a young neuropsychology student and ex-service-user with expertise in service development.

All supervisors support me to carry out this research. This means if I have any questions, or if you have any concerns about how the project is being run, then you can chose to ask them to help you. The research has received formal approval from School of Psychology Research Ethics Sub-committee. This includes confirmation that I have passed the Disclosure and Barring Service (DBS) check, which is needed for anyone working with Young People.

#### **Who has reviewed the study?**

This study has been reviewed by: South East Scotland Research Ethics Service  
REC reference number: 18/SS/0107  
IRAS Project ID: 244042  
University of Hertfordshire protocol number: LMS/PGT/NHS/02918

**What next?**

Please feel free to ask me any questions you have. You can also talk with your People Participation Lead in CAMHS. If you are happy to continue you will be asked to sign a consent form before you can take part. Please keep this information sheet in case you want to look at it again.

If you have any questions or concerns about how the study has been carried out, please contact either:

Dr Lizette Nolte  
Health Research Building 1F421  
College Lane Campus  
University of Hertfordshire  
AL10 9AB  
Tel. 01707-268322  
l.nolte@herts.ac.uk

Dr James Randall-James  
Clinical Psychologist  
Looked After Children CAMHS Team  
East London NHS Foundation Trust  
9 Rush Court  
Bedford  
MK40 3JT

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University Secretary and Registrar.**

Sue Grant (Secretary and Registrar)  
s.c.grant@herts.ac.uk

**Independent Contact:**  
Dr Helen Ellis-Caird  
Senior Research Tutor  
University of Hertfordshire  
Health Research Building  
College Lane Campus  
University of Hertfordshire  
Hatfield  
AL10 9AB  
h.ellis-caird@herts.ac.uk

Yours sincerely,

Laura Cole  
Trainee Clinical Psychologist  
August 2018



**Thank you very much for reading this information and giving consideration to taking part in this study.**

## Appendix 1

### GDPR Information

The University of Hertfordshire is the sponsor for this study based in the United Kingdom, England. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Hertfordshire will keep your name, age, gender, ethnicity and contact details on a password protected electronic file for the duration of the study (until June 2019); information will be accessed only to contact you about the study.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the University of Hertfordshire Registrar Sue Grant (Secretary and Registrar) at [s.c.grant@herts.ac.uk](mailto:s.c.grant@herts.ac.uk)

The NHS site will collect information from you for this research study in accordance with our instructions.

The NHS site will use your contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Hertfordshire and regulatory organisations may look at your research records to check the accuracy of the research study.

The NHS site will pass these details to the University of Hertfordshire along with the information collected from you. The only people in the University of Hertfordshire who will have access to information that identifies you will be people who need to contact you about taking part or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. The NHS site will keep identifiable information about you from this study until after the study has ended.

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Data Protection Officer name and contact email: Ian Hanahoe; [dataprotection@herts.ac.uk](mailto:dataprotection@herts.ac.uk)

## Appendix L: Consent Form



### Consent to participate in the research study

**Participant ID:**

*[Contact details of person taking consent]*

**Please initial box**

- I have read the information sheet about this research study and have been given a copy to keep.
- I have had the chance to ask questions about this information and I understand what it is I am being asked to take part in.
- The researcher has also explained to me how I will be involved and what I will be asked to do.
- I understand that my interview will be audio taped.
- I understand that my involvement in this study, and any personal data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to identifying data.
- I understand the research will send a brief letter to my GP informing them that I will be participating in the research study.
- I understand that when a report is written and published about the study, quotes from my interview may be used, but all identifying information will be removed. I give permission for publication of these anonymised quotes.

- It has been explained to me what will happen once the research study has been completed.
- By signing this consent form, I am showing that I freely and fully consent to participate in the study, which has been fully explained to me.
- I understand that even once I have given this consent I have the right to withdraw from the study at any time without disadvantage to myself and without needing to give any reason.
- I understand that the relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Hertfordshire, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give my permission for these individuals to access my records.

Young Person's Name (BLOCK CAPITALS)

.....  
Signed

.....  
Date

Name of person taking consent (BLOCK CAPITALS)

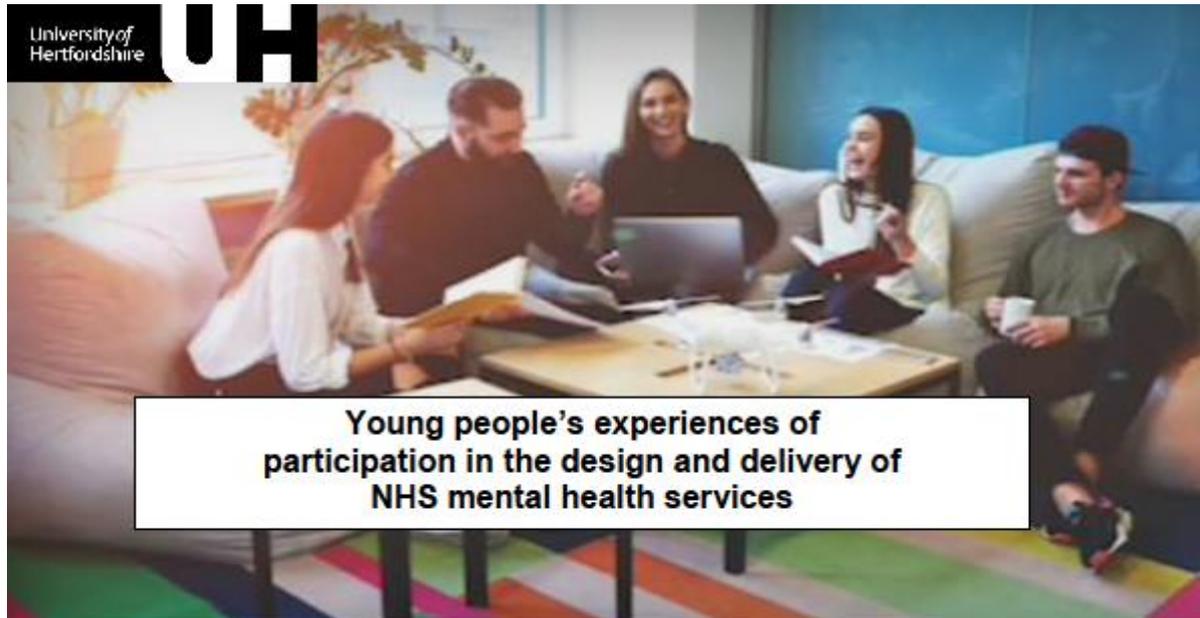
.....  
Signed

.....  
Date

When completed: 1 copy for participant; 1 copy for researcher

This study has been reviewed by: South East Scotland Research Ethics Service  
REC reference number: 18/SS/0107  
IRAS Project ID: 244042  
University of Hertfordshire protocol number: LMS/PGT/NHS/02918

## Appendix M: Debrief Sheet



*Thank you for taking part in the research project!*

Thank you for your generosity in giving your time to take part in this research project. Hopefully this research will help us better understand young people's experience of participating in services in different ways and help shape services to better suit the needs of young people in the future.

Hearing about young people's stories of their experience of actively participating in services can help other young people in similar positions, staff working in CAMHS and commissioners who make decisions about service design.

The information that you have provided will be kept confidential and the recordings will be destroyed after the interviews have been transcribed, analysed and reviewed.

### **Remember:**

If you feel upset after the interview and need someone to talk to you can:

- Speak to your parent or guardian
- Speak to your named CAMHS clinician
- Make an appointment to talk to your GP
- You can speak to someone at Child Line if you want to speak to someone who doesn't know you (0800 1111)
- Get Connected is a free confidential telephone and email helpline to provide support and advice to young people (0808 808 4994) [www.getconnected.org.uk](http://www.getconnected.org.uk)
- Samaritans is a confidential helpline for anyone experiencing any emotional distress. (08457 90 90 90) [www.samaritans.org](http://www.samaritans.org)

If after the interview you do not want me to use the information we talked about in the research interview then that is absolutely fine. You do not have to give any reason for this. I only want to use what you said if you think that is okay. Please speak to your People Participation Lead and they will help you to let me know.

If you have any further questions, or would be interested in being informed in the outcome of this study, then please contact me by email ([l.cole@herts.ac.uk](mailto:l.cole@herts.ac.uk))

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, you can contact Dr Lizette Nolte at [l.nolte@herts.ac.uk](mailto:l.nolte@herts.ac.uk) or alternatively you can contact the University Secretary and Registrar, Sue Grant at [s.c.grant@herts.ac.uk](mailto:s.c.grant@herts.ac.uk)

**Thank you again for your participation**

## Appendix N: Research Invitation Letter and Email

### Invitation Letter

Health Research Building  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
AL10 9AB

Hi,

My name is Laura Cole, and I am a trainee Clinical Psychologist at the University of Hertfordshire. I am doing some research to improve people's understanding of what it's like for young people to get involved in different ways in mental health services.

Since you are a young person who has been involved or is currently involved in Youth Participation Networks in the Trust, I'm hoping that you would be interested in taking part in this research. This would involve talking to me about your experiences of getting involved in service improvements or service delivery and telling me what things have been like for you.

DETAILS REMOVED

Attached is an Information Sheet for you, giving more details about the research.

Please read this, talk it over with your parent if you wish, and then feel free to ask any questions – either by talking to your People Participation Lead or by contacting me. My contact details are on the information sheets – including email address– and I would be very pleased to hear from you and/or your parent.

If you think that you might be interested in taking part, please could you or your parent contact me within the next few days. Alternatively, you can get in touch with your People Participation Lead to let them know, who could then pass your details to me to contact you. You can of course change your mind at any time without giving a reason, and your decision will not affect the health care you receive from the professionals within the Trust.

Thanks for your time.

I hope that this seems interesting to you, and hope to hear from you soon.

With best wishes,

Laura Cole  
Trainee Clinical Psychologist  
University of Hertfordshire  
l.cole@herts.ac.uk



My name is Laura Cole and I am a Trainee Clinical Psychologist conducting this research as part of my Professional Doctorate in Clinical Psychology at the University of Hertfordshire.

I would like to interview young people to hear their stories of participating in mental health services in different ways as part of my final year research project.

Since you are a young person who has been involved or is currently involved in Youth Participation Networks in the Trust, you might be interested in taking part in this research. This would involve talking to me about your experiences of getting involved in service improvements or service delivery and telling me what things have been like for you.

DETAILS REMOVED

**What are your thoughts?**

If you are interested in taking part, brilliant! Please - Read through the attached information first.

You can then contact either:

- email your CAMHS People Participation Lead:

DETAILS REMOVED

- email me, Laura Cole at [l.cole@herts.ac.uk](mailto:l.cole@herts.ac.uk)

I will then be in contact by email or telephone depending on what you would prefer.

Thank you for considering taking part in this research.

Laura Cole  
Trainee Clinical Psychologist  
University of Hertfordshire  
[l.cole@herts.ac.uk](mailto:l.cole@herts.ac.uk)

## Appendix O: Interview Guide

### Interview Guide

I plan to ask the young person what language they would prefer us to use as part of the story telling in relation to participation, explaining that this can often be called many different things such as user involvement, co-production, co-design, service participation. It is felt important to respect the language used by the young people telling their story of participation. I plan to ask at the end what may have drawn the young person to use the chosen term which may also help situate the use of language within the wider context.

<b>Main Areas</b>	<b>Prompts</b>
<p><b>General background</b></p> <p><i>I'm hoping to hear what it has been like for you to be involved in mental health services in different ways, but before we talk about service participation, it would be good to hear a bit about you and things you like to do if that is ok</i></p>	
<p><b>Main interview section</b></p> <p><i>I would like you to tell me your story of how you got involved in different ways within mental health services. I would like to hear about all of the experiences that have been important to you, and how your understanding of yourself has developed over time.</i></p> <p><i>I am aware that everyone's experiences are different and I would like to hear about good, bad, and neutral experiences you have had over time.</i></p>	<p>Could you tell me about the first time you had heard about participation groups?</p> <p>Could you tell me the story of how you became involved?</p> <p>And in what ways?</p> <p>What or who was main influence for participation?</p>
<p><b>As narratives are given, consider prompting further exploration of identity</b></p>	<p>If at all, how would you say you have changed, as a person, from your experiences of getting involved in service design and development?</p> <p>In what ways has your life over the last year been different as a result of being involved more actively in services?</p>

	<p>If at all, have there been any unhelpful things that have happened or challenges you have had to face as a result of participating in services in different ways. Have there been any positive things that have happened / that you've learned, as a result of your experiences?</p> <p>In what different or new ways do other people in your life see you as a result in being actively involved in services?</p> <p>How do you think your relationships with others have changed since you have been involved in service participation? E.g. With practitioners? With peers? With family members?</p>
<p><b>Ending</b></p> <p>Are there any other things that you think it is important for me – or other people – to understand about you, and your experiences with of actively participating in mental health services?</p> <p>If you could give a message to others, what would you tell them about being involved in services in different ways?</p> <p>I am curious to hear more about your choice to use the term (e.g. participation, involvement etc) and how you got to describe it in this way.</p> <p>What are your future plans around service participation?</p> <p>Any things that you want to say more about? Anything that you're feeling uncomfortable about having said? Any things that you don't want to be included in your account?</p> <p>How has it been, talking to me today?</p>	

### General prompts

When participants had finished responding prompt questions were used making sure they stayed close to the participant's narrative 'You mentioning..... can you tell me more about what happened/how you felt' etc.

Give positive feedback- 'we are about half way through the interview, I think some really useful things are coming out of what you are saying'

### Other prompts

- Chronology- and then... what next?
- Detail- tell me more about that, that's really interesting
- Clarification- I don't quite understand, can you explain that a little more for me
- Explanation- how come, why's that?

**Appendix P: Extract from Interview**

DETAILS REMOVED

## Appendix Q: Consent Form for Inclusion of Transcript

### Consent form for inclusion of transcript

**Title of Project:** Young people's narratives of shaping identity through participation in the design and delivery of NHS mental health services

**Name of Researcher:** Laura Cole (University of Hertfordshire)

Identification Number:

Within interview research it is necessary to be clear about how the researcher reached their conclusions about the main findings of the study. For this reason, I would like to include a transcript of your interview, in the appendix section of this study. If you agree:

- This would be fully anonymised with any names/identifying information (e.g., names of others, places etc.) removed/changed.

You do not have to say yes, this is completely up to you. You may find it helpful to discuss this with others before making your decision. Alternatively, if you have any questions to ask, you can contact me using the details below.

**Laura Cole**  
**Trainee Clinical Psychologist**  
**University of Hertfordshire**  
**College Lane**  
**Hatfield**  
**AL10 9AB**

**by email: l.cole@herts.ac.uk**

#### Agreement

If you are happy to give your consent for your transcript to be used as set out above, please sign below.

\_\_\_\_\_  
 Name of Young Person      Date      Signature

\_\_\_\_\_  
 Researcher      Date      Signature

Appendix R: Extract of Data Analysis Process

**Nodes**

Name	Files	Referenc
Being Heard listened to	0	0
Being valued	0	0
Content appreciated making a valuable contribution	1	1
Content being recognised by others	1	1
Content Being seen as a valuable contribution to the team	1	1
Content being seen positively through participation	3	6
Camaraderie	0	0
Content belonging	1	1
Content connecting through challenges	3	3
Content 'we' as a collective	3	5
Content a focus during difficult time	1	1
Content A story of coming through adversity, difficulties seemingly all	3	3
Content a story that needs to be told	1	1
Content acknowledging sense of vulnerability	1	1
Content acknowledging strength	1	1
Content Aligning self with awareness raising re mental health	1	1
Content Aligning self with human rights campaigns	1	1
Content Aligning self with those not accepted into society	1	1
Content anxiety taking part of self away, confidence	1	1
Content Attempt to consider identity in relation to participation althou	1	1
Content Becoming more confident about own needs and what works f	1	1
Content Being a passionate person about fitting into society	1	1
Content being brave through participation	1	1
Content Being home and cosy... contradiction between this and having	1	1
Content being transported to new domains of identity	1	1

YP2 Rowena    YP1 Ana    YP5 Jordan    YP6 Drew    YP4 Nadia

...Well make sure that the lift ...The place has a lift " you know (?) Like (,) it shouldn't be a negative connotation(,)

And it sounds like I'm being really harsh like "Oh (,) don't treat people the same." But actually I think it's just about making sure you're aware of actually (,) you know(,) you do have to treat people differently because people are dif ferent and that's just how it is (,)

[dog bark outside and dog on sofa jumps and runs to door]

YP6: Erm ...Oh-oh erm (,) so yeah so that was like quite a big thing for me and especially in the past I've really struggled with kind of trying to explain to people em. uh especially you know from an educational perspective about actually why should ...you know a lot of teachers would say to me "actually just have to get over it (,) you just have to deal with it." Well (,) you wouldn't say that to someone who'd broken their leg or you know had fallen down stairs and hurt their back (,) you wouldn't say to them (,) "You just need to get over it." You would be so lenient with them and you'd get them all the time they need(,) But with me you were telling me (,) "just to get over it (,) and to try and be happier (,) and to try harder (,) you know?"

All ...all ...it was the opposite (,) which kind of makes me laugh now if people would say (,) "Well (,) what do you have to feel stressed about (,) you're 12 (?) " Well (,) "what do you have to feel depressed about (,) you know (,) you're only 11 (?) " It's like (,) well (,) it's not like I'm sitting and choosing to have ...have those feelings (,) it's not quite how it works(,) Erm (,) thanks for your contribution anyway (,) but it's not quite how it works(,)

So for me I ...I was really (,) that really scared how I felt about a lot people and I think going to participation groups and actually be able to make a difference in that make me feel like I had ...it was very empowering (,) it was like actually I can change people's minds and I ...One of the conferences I did (,) erm (,) that was one of my old (,) erm ...What do they call them? Like ...It wasn't the SENCO (,) but she worked in the pastoral support team who's supposed to be looking after me and it just happened the whole presentation was about where education is lacking in terms of mental health support(,)

t: Hmmm

YP6: So I was there basically telling them all how I've been ...I've been to lots of different schools (,) but very ...how basically no ...no one school has ever supported me in my mental health illnesses(,) And they've never given me the right kind of support (,) they've always been really pressurising(,) And I ...I could go on about it for hours (,) but basically just how I really lacked in the right support and how my family was lacking the right support(,) Erm (,) they weren't giving the right support(,)

So afterwards she came up to me (,) and I thought I was gonna die (,) I didn't realise that she was like there (,) and I automatically was like (,) "Oh (,) my god ...what ...well ...oh my God no...no...this is not happening." Erm because something for me is confrontation (,) I can't do confrontation like full-on confrontation doesn't work for me so I'm very much like "Oh okay right [People Participation Lead] erm (,) can you take me home please? I mean this is not ...no." And she came up to me and she just said (,) "[Drew] I'm so so sorry." And I went "Ah (,) okay." I didn't quite know what to say to that(,) I really wasn't expecting that and she just said (,) you know (,) "I really thought I was doing the right thing (,) and I'm really sorry that ..." You know(,) I was like (,) "Okay (,) but do you realise why that wasn't the right thing?" And she went (,) "Yeah (,) I do(,) I do you realize that now."

### Combined Supervisory and Researcher Analysis

Annotations See Also Links Relationships Coding Stripes Highlight Code Code In Vivo Range Code Uncode Auto Code New Annotation Annotations Word Cloud Chart Compare With Explore Diagram Query This Document Find Edit

YP6 Drew

reach them in different ways(.)

I: Hmmmm

YP6: Yeah (,) so that's kind of what attracted me to it and that's why I try and ...It probably bored the hell out of my teachers by now (,) me coming in with like my (,) you know (,) my ...my poor cultural context teacher because every time she's like (,) "Okay (,) we need to look like this today." I'm like (,) "Right (,) okay (,) like bring up a subject like feminism." I'm like (,) "Right (,) okay (,) guys(.)We need to have a proper debate now (,) because you guys are not up-to-date with feminism knowledge."

I: That's great

YP6: Yeah (,) erm (,) so yeah (,) so I just like ...I don't know (,) I just kind of like [PAUSE] I think that some people think they're better than everyone else (,) and in my experience like nobody is(.) People can't be(.) Everyone to me is all the same (,) so actually if you want to be better than me then you need to have done something that's so amazing that like ... I got ...Like Rosa Parks (,) I would happily say she's about a woman than I am because I have a huge respect for her (,) you know (?) You know (,) for her I'd be like (,) yeah (,) definitely you're a better person than me(.)

But for someone in my class who just thinks they're funny or like ..(,)it's like (,) "oh (,) yeah (,) I'm not gonna do the work" It's like (,) "Well (,) okay (,) it's okay." So yeah (,) kind of (,) erm ..(,)Yeah (,) quite a mouthy gobby

I: [Laugh]

YP6: person(.) Just not good at like taking social cues(.) But yeah (,) so [PAUSE] that kind of is what sparked my interest as well(.)

I: It seems like you're quite an ideas person in terms of like how to put ideas into a way that people can like (,) you know (,) see new perspectives

YP6: Yeah

I: To learn some ...something about (,) but also you initiate good debates or initiate

Content Stating value re respect for others earned through th  
 Content A story of coming through adversity, difficulties seemingly all now in the past  
 Content immediacy of the change  
 Content Aligning self with human rights campaigns  
 Content loving person  
 Content Aligning self with those not accepted into society  
 Content appreciated making a valuable contribution  
 Content past tense used to be someone who struggled with low self esteem  
 Content Being a passionate person about filling into society  
 Content Taking a more academic position re difference film can make  
 Content limitations of that being only source of confidence  
 Performative dring on psychological pop psychology language, for my benefit  
 Content having a responsibility to tell people's stories the right way Also wrong ways to tell people's stories  
 Context First situating as student  
 Content unannotated name in confidence  
 Coding Density

## Appendix S: Evaluation of the Present Study

The criteria suggested by (Elliott, Fischer and Rennie (1999) and Mays and Pope (2000) were used to evaluate the quality of the research. A summary is detailed below.

<b>Criteria (Elliot, Fischer &amp; Rennie (1998))</b>	<b>Evidence for meeting criteria</b>
<i>Explicit scientific context and purpose:</i> The manuscript specifies where the study fits within relevant literature and states the intended purposes or questions of the study.	The literature review demonstrated that there was currently a paucity of research in this field, therefore the rationale for the present study was clearly identified.
<i>Appropriate methods:</i> The methods and procedures used are appropriate or responsive to the intended purposes or questions of the study.	The research set out to explore young peoples' experiences of participation, therefore the method was appropriate for this purpose. This rationale is clearly explained in the Method chapter
<i>Respect for participants:</i> Informed consent, confidentiality, welfare of the participants, social responsibility, and other ethical principles are fulfilled. Researchers creatively adapt their procedures and reports to respect both their participants' lives, and the complexity and ambiguity of the subject matter.	The consent procedures were thoroughly thought through, and clearly described in the Method chapter. In addition I reflected on my own position as a researcher within the psychology profession, being in a position of relative power throughout, and how this might implicate findings.
<i>Specification of methods:</i> Authors report all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis are also specified. This allows readers to see how to conduct a similar study themselves, and to judge for themselves how well the reported study was carried out.	The interview guide is shown in the appendices. The levels of narrative analysis are detailed in the Method section.
<i>Appropriate discussion :</i> The research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and } or practical domains, and are presented in appropriately tentative and contextualized terms, with limitations acknowledged.	The Discussion chapter focuses on how the findings fit with psychological theory, and with previous similar research. Clinical implications are tentatively suggested, and the limitations of the project are considered.
<i>Clarity of presentation:</i> The manuscript is well-organized and clearly written, with technical terms defined.	The terms used throughout the report are defined at the start of the first chapter. Efforts have clearly been made to organise the report in a logical and sequential manner.
<i>Contribution to knowledge:</i> The manuscript contributes to an elaboration of a discipline's body of description and understanding.	The study is unique within the literature and the findings can be seen as contributing to the experiences of young people participating in mental health service design and delivery.
<i>Owning one's perspective:</i> Authors specify	What drew me to this area of research and

<p>their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.</p>	<p>my epistemological stance is clearly stated at the start of the first chapter. Further reflections around the experience of participatory research methods has been included in the method section. An extract of my reflective log written throughout can be found in the appendices.</p>
<p><i>Situating the sample:</i> Authors describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant.</p>	<p>Adequate information about the young people taking part is given in the Method chapter.</p>
<p><i>Grounding in examples:</i> Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.</p>	<p>A wide range of example quotations are used throughout the Results chapter to illustrate the model.</p>
<p><i>Providing credibility checks:</i> Researchers may use any one of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, an additional analytic 'auditor,' or the original analyst for a 'verification step' of reviewing the data for discrepancies, overstatements or errors; (c) comparing two or more varied qualitative perspectives, or (d) where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data.</p>	<p>A number of methods were used assure the analysis had credibility:</p> <p>Attending narrative workshops facilitated by an expert in narrative inquiry alongside another Trainee Clinical Psychologist. We were also able to collaborate on analysing anonymised transcript extracts. Supervisors for the research independently analysed three interviews. Following this, we met to discuss and reflect on the similarities and differences in our analyses.</p>
<p><i>Coherence:</i> The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fits together to form a data-based story narrative, framework, or underlying structure for the phenomenon or domain.</p>	<p>The results are presented initially with each individual narrative account to situate the sample, remain client-centred, and introduce a key thread for each young person. Collective storylines across all of the accounts are then presented, with illustrative quotations, so nuances to the results are not</p>

<p><i>Accomplishing general vs. specific research tasks:</i> Where a <i>general</i> understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a <i>specific</i> instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances</p>	<p>lost.</p> <p>In the Discussion chapter I discuss the limitations of the project which could limit its generalisation to other people. The Method chapter clearly states why the number of participants was chosen.</p>
<p><i>Resonating with readers:</i> The manuscript stimulates resonance in readers } reviewers, meaning that the material is presented in such a way that readers and reviewers, taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.</p>	<p>The research has been carefully considered in order to be presented in an accessible and thought provoking way, using a critical stance to deconstruct concepts around youth participation. It is hoped this has expanded the readers' appreciation and understanding of the subject matter.</p>

## **Appendix T: Reflective Log Extract**

*A recurring reflection throughout the research process was the way in which young people are increasingly experiencing mental health difficulties but do not tend to make use of mental health services. I recognised the ways children are not valued, with their views not taken into account in the way services are run as much as they could be, including the Child and Adolescent Service I currently work within. If we are to think of young people as being the future generation and the future parents in our society, children and young people's wellbeing is everybody's business, and including them in decision making is key.*

*When thinking of youth participation, I continued to consider the benefits of this for individuals, services and wider systems. However, those 'allowed' or 'offered' a role in participation may be related to level of ability, social class and race, resulting in benefits only to select youth and communities. If this is the case, this would inevitably perpetuate a longer term trajectory of privilege or marginalisation. I continued to ask the question, does youth participation reduce or reinforce social inequality? I wondered if this may be a story told by the young people involved, or if might be less known to those taking part, and not shared.*

*I have attempted to step back and reflect upon the drivers behind my interest in this area. My experience across clinical settings has given me an insight into how distress can often be individualised with a focus on amelioration of individual symptoms with less consideration of inequality and social determinants of mental health. My values are aligned with a community psychology approach in the way that community psychology focuses on working with communities and macro socio-political systems rather than seeing difficulties as individualistic. Community psychology approaches utilises participatory research methods and social action oriented processes to work alongside people, creating contexts where individuals can develop a critical awareness of their social surroundings and take collective action to address community problems. This means privileging knowledge developed alongside communities and prioritising work with community groups using value-led and participatory work. I have attempted to contribute to a way of writing within the field of psychology which takes an active decolonial turn, moving away from the assumption that the person is the central focus of analysis whilst ignoring social, economical and political contexts.*

*A principal assumption of participatory research is that it redresses the power imbalance between adult researchers and young participants, however I continued to hold in mind post-structural theory which argues this might not be fully achievable, challenging the implication that adult researchers can empower young participants by "giving" them power. Working with Leann as a supervisor on the project has continued to be a learning experience. I have learnt through this process the importance of trust, honesty and scaffolding as a way to meet each other where we are at and provide a space to be acquainted with new ideas. It has also been a rich experience in being able to think together about the different ways in which the research can be of use to young people, making attempts to find creative ways to break the dissemination application barrier within the field of psychology, particularly with young people.*

*From the research inception, my relationship with the research area of youth participation within NHS mental health services has continued to be shaped by wider reading, engaging in dialogue with young people accessing services and clinical experience working within a Child and Adolescent Mental Health Service. I have continued to have opportunities to be involved in youth-led and co-produced projects which have had an impact in different ways on my views of participation in mental health services. I have become aware of my own decision-making around suitability and times when I think a young person may not find youth participation helpful, or if it may lead them to becoming more distressed, for example if they are in the midst of a crisis or have experienced a recent traumatic experience. I also reflected on my assumption that the young person may not think I am taking their difficulties seriously.*

*When Ana let me know she was nervous, I said I too shared these nerves and that she was the first young person I was meeting and felt pressure to 'get it right.' She spoke about how to let me know when she didn't understand and laughed at her initial apprehension of having to say the right thing and how we shared these anxieties. This helped bring a more human side of research and allow for honesty. Also, there were times I talked about being in a position of learning about a new type of research. This meant there may be times I might pause and think about my questions.*

**Appendix U: Letter/Summary of Stories and Storylines for Young People Taking Part**

[Address]

University of Hertfordshire  
Health Research Building  
College Lane Campus  
University of Hertfordshire  
Hatfield  
AL10 9AB

Friday 6<sup>th</sup> June, 2019

Dear [NAME],

At the start of the year took part in my research project: **Young people's experiences of participation in the design and delivery of NHS mental health services.**

You were kind enough to talk to me about your experiences of participation and were generous with your time to be able to share your story.

I am writing to you to say a huge thank you to you because without your help the project would not have been possible. From meeting with everyone taking part, I have been able to draw out main storylines and sub-stories shared across all the interviews with young people. I wanted to share with you a summary and have added this below. The stories represent stories which were shared across young people taking part, so may not represent your specific views. However, I hope that your views are represented within some of the storylines.

I hope this is of interest and captures experiences you hoped to share with me and others reading the research.

If you have any questions or would like to talk through the results, you can contact me by the details above. It was a pleasure to meet with you and I wish you all the very best for the future.

Kind Regards,

Laura Cole  
Trainee Clinical Psychologist  
University of Hertfordshire  
l.cole@herts.ac.uk

## Summary of Shared Stories

Story	Sub-story
<b>Moving into social spaces and holding out a helping hand</b>	Self as social "They kind of get me" Self as helping others
<b>Having to become the 'right fit' for participation</b>	Youth participation offered to those "well enough" Youth participation taken away: perpetuating power differentials Self as heard
<b>Repositioning from patient to person</b>	"we are both just people" Stepping in and out of an illness narrative Flipping the power imbalance
<b>Strengthening alternative identity stories through relationships</b>	Calling deeper on courage and stepping into new realms "Wow, I can actually do stuff" Empowerment and building confidence A message to you

### Moving into social spaces and holding out a helping hand

The process of being involved in service participation appeared to bring opportunities for young people to form a collective in shaping services. Young people spoke of this reducing social exclusion and contributing to their overall wellbeing. This appeared to bring about a valued social identity. Young people spoke of their relationships with others involved in service participation, who they perceived as people who genuinely cared, were non-judgemental and available in times of need, as core to their experience of participating in service design and delivery.

### Having to become the 'right fit' for participation

There were differences across accounts around how service participation became known and their experiences of others deciding when or if it should be taken away. There were stories of having to be seen as 'well enough' by young people to be able to get involved. There were also stories of having to be the 'right fit' for participation networks. Some young people spoke about being perceived as good fit for participation as they were good public speakers or held strong views on service delivery. Young people taking part spoke of participation being on a "need to know basis" and finding it difficult to find out about it.

### Repositioning from patient to person

There appeared to be a challenging of the assumptions underpinning the labelling and 'othering' processes arguably at work in the mental health system and the communities they sit within. There were stories of confronting perceived and actual societal stigma, with one person saying "*people seem to think we're called patients.*" "*Well I'm not a patient I'm just a person...like I don't need to be referred as a patient.*" Participation appeared to allow a shift in seeing the self as equal to others, with equal opportunities in work, particularly working with children or in mental health settings.

### Strengthening alternative identity stories through relationships

Stories of embracing vulnerability and being courageous appeared to be shared across all young people's narrative accounts. This seemed to transform the ways in which the young people viewed themselves, bringing new possibilities and frameworks of meaning. All young people taking part spoke of times in which they stepped into something new, such as speaking to large groups of people at events or conferences. Across stories there were narratives of the sharing of personal information with others. This seemed to provide opportunities to express thoughts and feelings, develop a sense of self, and build intimacy within personal relationships.

## Appendix V: Young People's Messages to Young People Accessing CAMHS

### Young People's Messages of Service Participation to Young People Accessing CAMHS

Drew:

*"Although they're getting something good out of it...like, you will do things and you will learn things about yourself you just didn't even know were there."*

*"...you get to give your opinion with people who have got so many more degrees than I will ever dream of having and you know...have all the experience in the world and for them to come up to you and say "Wow...that was a really great point, thank you so much."*

Jordan:

*"I think I just I realised that it is really important in your personal like, journey like the impact it can have on you. So participation can really really help you through your struggles personally. By sharing your experiences of helping others it helps you erm, I think that is not always seen. Sometimes I think its...you are helping others but help yourself first which is true but helping others can help yourself as well, so I think that participation is really important and it does really help you personally and change other people's experiences."*

Beth:

*"I would say if you can then get involved because it's it can literally change your life, erm...and if it's not for you, it's not for you. You have tried it. At least you can say, you know, that you did try"*

Nadia:

*"At the end of the day [you] don't have anything to lose because like even if it's not helpful to them like they tried, like they've tried." "There is no down side to trying but there's a lot of positives that could come from it, like you could make friends, you could become more confident in like, speaking in a group setting and stuff like that and you do get a lot of really amazing opportunities, like the video. I am really grateful to have had the opportunity to be involved in that so it's good to just try it. See if that's right for you, 'cause you could get some amazing opportunities. For that...there's no downsides really"*

Ana:

*"I guess it can seem really daunting but [PAUSE] you do manage to sort of help other people and you get to improve things that you didn't like, and it is really nice to know. It's like, even if you don't want to do it for anyone else do it for yourself."*

*"You do get something out of it, I mean I gained confidence and just helping people made me feel good." "You know if you don't want to help anyone else then do it so you sort of make friends."*

Rowena:

*"Definitely if you think you can, do it. If I can do it anyone can do it. Erm yeh definitely, to get involved in participation, and most people I meet say the exact same, like...I don't... I haven't spoken to anyone that has ever had it as a negative thing."*