

**A Participatory Action Research Approach to Participation with Young
People Within Mental Health Settings**

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ABSTRACT

Poor mental health is a growing issue for young people (YP) in the UK with 75% of all mental health issues occurring by age 24 (Kessler et al., 2005). YP are one of society's most oppressed groups (Sidanius & Pratto, 1999). Oppression disrupts potential for social equality, justice and wellbeing (Freire, 1973) and when already oppressed YP are faced with further oppressive structures in mental health settings their relative powerlessness is compounded (Dexter, Larkin & Newnes, 2012). Participation is a way of resisting such disempowerment and can contribute to wellbeing and recovery through empowering YP towards change (Taggart, Franks, Osborne & Collins 2013) and increasing YP's skills and competencies (Day, 2008). Services improve in quality and effectiveness when 'service-users' needs are met through 'participation' (Beresford, 1997).

Despite human rights, legislation and policy drivers (Department of Health, 2005, 2015, 2017) promoting YP's meaningful participation, YP's voice is not fully heard in mental health systems (Beresford, 2002). This research recognises gaps in practice and direct research with YP around YP's participation in mental health settings. Collaborating with YoungMinds, using a Participatory Action Research (PAR) approach, YP as 'co-researchers' shared their voice through cycles of dialogue, reflection and action towards (Baum, MacDougall & Smith, 2006) transformational change on varying levels.

This research is grounded in liberation practices and community psychology, utilising discursive ideas of power (Foucault, 1977, 1984, 1988). Thematic analysis (Braun & Clarke, 2006) led to four main themes developed, in collaboration with co-researchers, namely 'Power over YP', 'Hearing YP's voice', 'Safe Structures' and 'Participation as Fundamental to Wellbeing'. YP discussed professionals privileging their knowledge over them as problematic in YP's voice being heard and identified action towards shaping safe, ethical and meaningful participation in mental health settings. YP positioned participation as vital to wellbeing through connecting it to transformational processes and preventing harm. A reflexive stance towards evaluating the research is considered with future implications, including how this research may be taken forward by co-researchers beyond the scope of this thesis.

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1. INTRODUCTION

1.1. Overview

Young people¹ (YP) are among society's most oppressed groups, with limited voice² and distance from power (Sidanius & Pratto, 1999; Pratto, Sidanius & Levin, 2006). In mental health settings (MHS)³ YP's voice is often further marginalised (Valle, Payne, Gibb & Jellici, 2012).

Strong correlations exist between poor mental health in YP and high rates of social inequalities (Whitmore 1991). The majority of all mental health difficulties develop during childhood and adolescence (Oh et al., 2014) with 75% by age 24 (Kessler et al., 2005). The prevalence and incidence of emotional difficulties are especially high amongst YP (Patel, Flisher, Hetrick & McGorry, 2007) and a significant rate of mental health difficulties are related to adverse childhood experiences (Kessler, 2012). MHS do not appear to reflect the complex needs YP have, as statistics indicate that on average YP wait 10 years to receive effective intervention with 75% of YP with mental health difficulties not receiving intervention (Centre for Mental Health, 2016; Children's Society, 2008). Linked to wider systems such as the National Health Service (NHS) and funding, Children and Adolescent Mental Health Services (CAMHS) have historically been primarily designed by and around professionals, rarely with input from YP as the community they seek serve

¹ YP are defined in the age group of 10-24 (AYPH, 2015) years. This thesis uses this definition accounting for age beyond the commonly conceptualised term of 'teenagers'.

² Use of voice here is distinct from literal speech, conceptualised as including communicating one's experiences, expressions and ability to wield influence (Elbow, 1994).

³ "MHS" is also used interchangeably to describe mental health settings and mental health systems in the UK.

(McGorry et al., 2013). Further, YP are consistently positioned⁴ in MHS as both vulnerable and powerless (in contrast to parents and professionals) rendering YP 'less-than-ideal' candidates for their voice to be heard in MHS. (Dexter, Newnes & Larkin, 2011).

Meaningful participation practice can help redress inequalities through rebalancing power, leading to increased effectiveness and quality in mental health provision (Mayer & McKenzie (2017). 'Service-user' participation (SUP)⁵ is the process of involving 'service-users'⁶ in influencing healthcare and wider provision (Day, 2008). MHS designed with YP's voices at the centre with increased engagement towards truly reflecting and meeting YP's concerns, priorities and needs may improve outcomes (Day, 2008). Examples of YP's SUP include being involved in decisions relating to their care, developing information (Tindall, Hey & Linnell, 2003), service planning and development (Crawford et al., 2002), research (Rose et al., 2002) and staff training and recruitment (Millar, Chambers, & Giles, 2015). Participation also plays an important role in YP's control and influence over their recovery from mental health difficulties (Repper & Perkins, 2003). Therefore, YP's voices being truly heard and embedded in MHS is vital in making positive change towards meeting YP's complex needs, recovery and wellbeing.

A wealth of legislation, policy and documentation positions YP's SUP as an established fundamental right (United Nations Convention for the Rights of the

⁴ Positioning Theory (Harré & Van-Langenhove, 1999) is considered when using the term 'positioned'. The concept of 'positioning' is discussed in two main ways; as the attributes and identities of a person or group relevant to positioning and; sets of rights and duties (Harré, 2012).

⁵ Interchangeable term with 'service-user involvement', 'experts by experience' and 'patient and public involvement (PPI) initiatives', 'person centred care' and 'co-production'.

⁶ 'Service-user' describes people using services broadly conceptualised as the public, YP, adults, parents/carers and professionals. This research specifically thinks about YP as 'service-users' in MHS.

Child (UNESCO), 1989; NHS Act, 2006) and expectation within services (National Institute for Care and Excellence (NICE), 2010; British Psychology Society (BPS), 2010; Department of Health (DoH), 2003, 2004, 2015). Despite this and calls for meaningful participation in YP's MHS (NHS Confederation, 2011) participation is not systematically occurring or is often tokenistic (Beresford, 2002). YP are discussed to be infrequently involved in decision making, with their wishes and objectives often unheard in MHS (Gondek et al., 2017). Absence and tokenism are noted to leave YP feeling disempowered and linked to causing emotional harm (McNeish, 1999). Lack of meaningful participation undermines the implementation of YP's rights and the policy aims of MHS. Urgency is therefore needed to establish new ways of YP's participation, in enhancing wellbeing and preventing harm to YP in MHS. The disconnect between urgency driving YP's participation and practice calls into question systems, structures and power within MHS.

Participation is at the core of liberation and community psychology, currently seen as alternative approaches in clinical psychology. These approaches position power and its unequal distribution in society with central importance, towards understanding experiences and distress experienced by those who are historically marginalised (Nelson & Prilleltensky, 2010). Such approach is fundamental to creating new possibilities in the face of oppressive practices and structures. Deconstructing the 'problem' can demonstrate how multiple layers of context can inform future action. Appeals for YP as 'service-users' to participate in research are grounded in the acceptance of YP as a disadvantaged group (Ozer, 2016) and their active involvement in research leading to transformative action is a vehicle for empowerment (Chen, Weiss & Johnston-Nicholson, 2010). Recognising oppression as not just a site of domination but also a place of resistance (Afuape, 2011) moves towards engaging with creativity and acts of resistance towards liberation (Afuape, 2016). Liberation requires to be co-created through genuine participation, dialogue and action, it cannot simply be 'given' (Freire, 1973; Watkins & Shulman, 2008). This research recognises this through adopting a Participatory Action Research (PAR) framework as an alternative research approach, aligned with principles of liberation and community psychology.

As a professional, I continue to feel disconcerted and dissatisfied that through lack of voice, YP are being failed by systems which should protect and optimise their life trajectories. Working alongside marginalised communities and utilising approaches such as PAR, I believe clinical psychology can learn from how communities approach and act towards socio-political issues in reducing inequality leading to distress. Through this PAR project, facilitating YP's voice by taking a critical stance towards taken-for-granted knowledge, we can begin to co-construct new realities (Burr, 2003) to change meaning, knowledge and acts that are defined by YP as problematic.

YP's direct experience is also underrepresented in many areas of mental health research (Children's Society, 2008). The majority of the limited research on YP's participation in MHS is through adult observation and not YP's own perspectives. By providing opportunity for voices to be heard through participatory means, this research provides alternatives to problematic patterns of not placing YP voices at the centre of MHS and research, towards facilitating YP's empowerment. In a review of the literature on YP's participation within MHS, I consider definitions, models and political drivers relative to YP's participation. I will also examine what is known about the impact of participation and the facilitators and barriers to meaningful YP's participation in MHS, towards informing the research aims.

1.2. YP's Realities

YP realities are discussed to provide context to the environments YP operate in, as an oppressed group. Social dominance theory (Sidanius & Pratto, 1999; Pratto et al., 2006) highlights YP as an oppressed group by arguing that cross-culturally societies hierarchically position YP as having less value and societal power than adults. With strong correlations between poor mental health in YP and high rates of social inequalities (Whitmore, 1991) YP are also discussed as being in complex positions of disempowerment when they enter MHS, with their voices being entwined with intricate power issues (Dexter, Larkin & Newnes, 2012).

Globally, poor mental health in YP has been attributed to physical and sexual abuse, bereavement, war and difficult family relationships (Molnar, Berkman, Buka, 2001). These problems are often exacerbated by social inequalities such as poverty and lower educational achievement alongside stigmatisation (Patel et al., 2007). YP from disadvantaged backgrounds in the UK do worse than those from advantaged backgrounds by a significant amount (Machin, 2006). YP can be further disadvantaged when their age is layered with issues of gender, religion, ethnicity, (dis)ability (Burnham, Alvis-Palma & Whitehouse, 2008) and sexuality (Guasp, 2014; 2017). Intersectionality⁷ of social inequalities, often results in exclusion and discrimination on multiple levels (Crenshaw, 2012). It is important to note that YP are not a homogenous group and exercising caution against generalisations or representativeness can promote more authentic engagement, rather than tokenism (Sinclair, 2004).

Dichotomies of societal narratives of YP appear to prevail in western constructions (Berman, 2003), such as “YP being a symbol of hope for the future, while simultaneously being scored as threat to existing social order” (Giroux, 2012, p.17). YP are rarely positioned as a source of inspiration, often misrepresented and demonised in the media and by politicians (Clark, Ghosh, Green & Shariff, 2008). This research hopes to challenge this through providing alternative opportunities for YP’s voice to be discovered and heard.

1.2.1 YP Realities in MHS

Research indicates that diagnosed mental health problems in YP are growing (Jacobson, Churchill, Donovan, Garralda & Fay, 2002). 10% of children and YP (aged 5-16 years) have clinically diagnosable mental health issues (Children’s Society, 2008). Statistics indicate 13% of boys and 10% of girls (aged 11-15) in the UK experience mental health difficulties, with a particular rise in girls (Fink et al., 2015; Patalay & Fitzsimmons, 2017). 70% of YP experiencing mental health problems are estimated not to have appropriate interventions at a sufficiently early age (Green, McGinnity, Melzer, Ford &

⁷ The multiple layers of one’s identity, interacting at complex levels within many contexts.

Goodman, 2005). A high proportion of YP are not accessing or disengaging in MHS (Children's Commissioner, 2016). YP face increased vulnerability in relation to their mental health, particularly when transitioning into adolescence and early adulthood. These unparalleled stages of YP's lives are reinforced through MHS being set up with support according to arbitrary age ranges (Kozhimannil & Welch, 2014).

YP's MHS purport to understand, intervene and alleviate distress and suffering. Mainstream mental health is dominated by the medicalisation of distress (psychiatric diagnosis, medication and hospitalisation) and therapy. These models have been critiqued for locating distress in individuals by treating 'service-users' as passive recipients, limiting people's choice and preference (Boyle, 2011). This impacts on YP's sense of self and arguably discourages recognition of personhood⁸.

McGorry et al (2013) argue that MHS are currently fundamentally flawed, linked to the debate around MHS often being designed with professional models and knowledge in mind rather than the communities they are set up for. Furthermore, Szsaz (1994) contends that aspects of MHS serve as agents of social control. This sense of social control is arguably increased societally with YP (Baldwin, 2001; Breggin, 2001). In this context, MHS are more likely to misunderstand YP's behaviour as pathology as opposed to a communication of distress (Timimi, 2017). By not truly placing YP's voice and experience at the centre of their care and in turn exerting control over YP who are already in distress through professional models, results in MHS disempowering YP (Dexter, Larkin & Newnes, 2011).

⁸ Personhood describes attributes of being a person (Dewing 2008), e.g. sense of self, roles, behaviours and associations.

Current uncertainty in the UK's social and political situation exacerbates this social control through the NHS and other public services, being under increasing pressures with austerity measures and disenfranchisement (Pollock, 2017). YP's MHS are among services hardest hit by austerity cuts (Frith, 2016), with many in a state of crisis. Austerity measures implemented since 2009 correlate with increased mental health problems in the UK population and widening inequalities (Barr, Kinderman & Whitehead, 2015). The prevalence of people reporting mental health problems increased significantly between 2009 and 2013 compared to previous trends and was greatest amongst people with low levels of education, highlighting widening inequalities. This trend in reported mental health problems across England is noted to broadly mirror the pattern of increases in suicides and anti-depressant prescribing (Barr, Kinderman & Whitehead, 2015).

State-funded CAMHS turn away around a quarter of YP referred to them by concerned adults (Mental Health Task Force (MHTF), 2016). Longer waiting lists, spending reductions and higher thresholds for support deny YP adequate access to vital therapeutic support (National Society for the Prevention of Cruelty to Children (NSPCC), 2015). CAMHS professionals reported high rates of dissatisfaction and inadequacy linked to delays in appointments, high access thresholds, inability for service to meet demands of referrals and staffing issues (Teggart, & Linden, 2006). YP report lack of information and access to MHS, lack of continuity and medicalisation of difficulties, as problematic (Plaistow et al., 2013). In a qualitative study exploring YP's experiences of MHS, YP also identified a theme of 'being heard and seen' with YP highlighting opportunities for communicating more openly with professionals towards improving and making MHS more relevant (Persson, Hagguist & Michelson, 2017). This confirms a need for greater improvement throughout MHS, including increased collaborative models of practice and centralising YP's voice throughout MHS.

Non-tokenistic participation is a way to speak to and change these inequalities in MHS and YP's lives and has been pushed for in YP's MHS for many years (NHS Confederation, 2011; Ahmed et al., 2011). Clarke et al (2018) found that

YP felt participation was important in being treated equally in MHS. YP may be encouraged to actively participate in issues and decisions affecting them, such as their care and wider MHS issues, by not being positioned and treated as passive recipients of services or interventions (Walker, Thorene, Powes & Ganokar, 2010). Transformation plans for commissioning YP's MHS through CAMHS (DoH, 2015b) recommend being written with input from YP towards creating meaningful and relevant MHS. These plans also promote service models aimed at improving mental health in YP's settings and centralising YP's voice (e.g. Children and Young People's Improving Access to Psychological Therapies (CYP-IAPT⁹) alongside requirements to provide data and outcomes, 'evidence-based' intervention and cost-effectiveness.

Paying attention to power dynamics and challenging inequalities in YP MHS, this research focusses on researching 'with' YP rather than researching 'about them'. The PAR approach also signifies an act in challenging the status-quo and power imbalances in research and MHS towards change. YP will have the opportunity of being involved throughout several processes of this research to the degree they choose. Being co-researchers with 'medium-high' participation (Bakazar et al., 2004) at a 'collaborative' level' (Kirby, 2004), reflects the expected degree of control, commitment and collaboration. Other ways of working with YP include online forums argued as more relevant for YP (Bristow, 2014), providing flexibility and attending to power dynamics towards equalising power between researcher and YP (Kendon, Kesby & Pain, 2007) in creating dialogue and action.

1.3. Reflexivity

Reflexivity is central to PAR, through iterative cycles of dialogue, reflection and action which require flexibility. Critical and self-critical reflection is noted to allow us to access different kinds of knowledge about the observable

⁹ Initial IAPT models in adult MHS were developed as an economically-led initiative aimed at reducing unemployment (Layard, Clark, Knapp, & Mayraz, 2007).

processes in which we are engaged. Reflexivity therefore enables us to position ourselves (including our identities) within the collective process of PAR (Lykes & Hershberg 2012). Reflexivity enables us to examine how we and others view ourselves, which is important in PAR with an awareness that meaning-making and knowledge are situated in cultural, social and political contexts (Castro Romero & Afuape, 2016) and are therefore not neutral. Non-neutrality is fundamental to power imbalances and when working with YP. The inherent power imbalance with adults requires careful and ongoing scrutiny.

1.3.1. Self-Reflexivity

Self-reflexivity (Burnham, 1993) is the state of one's awareness of their contextual prejudices and assumptions (Falicov, 1996) and how this affects one's perceptions, actions and interactions and can be mobilised with me being an 'outside' researcher (Lykes & Hershberg, 2012). Self-reflexivity includes using self-awareness to do something differently (Burnham, 1993). Todd (2011) argues that liberation practices are constructed contextually, using experience as a starting place. By being a 'full person' (Castro & Afuape, 2016; Freire, 1973) in this research, my self-reflexivity aims to bring integrity to the research by embodying my contexts, set of values and personalising my ideas and knowledge, aided through transparency. Keeping a personal journal of my thoughts and experiences throughout this process also supports my awareness of specific assumptions and constructions throughout this research.

1.3.1.1. Why am I Doing This Research?

My experience as a user-participation lead in an inner-city CAMHS strengthened my beliefs about the value of challenging the status quo to encourage YP to co-produce knowledge and become active participants in decision making, community and social change. Studying at University of East London (UEL), critical approaches to psychology influenced and enabled me to further question society, practice and my values in this research. Learning from experience I am committed to actively raising awareness about issues of inequality leading to distress in my practice. Developing awareness of wider complex social, political and cultural structures has helped me adopt

perspectives and practices aligned with ‘the personal *is* the political’ (Dillon, 2011). This recognises that the personal cannot ever be other than the political. Linked to acknowledging our experiences, feelings and possibilities of our personal lives are not just private matters of personal preferences and choices, these are highlighted as limited and defined by the broader political and social context (Dillon, 2011).

In considering my personal history, I do not view my ‘identity’ easy to categorise but to situate myself, I can be described as having multiple ethnic and cultural influences (Scottish, Colonialised Indian and Irish), born female and brought up with catholic affiliations. I grew up in a Scottish town in a lone parent family where ideas and experiences of inequality were challenged and reinforced as important. My multiple identities and experience of transgenerational narratives of oppression in relation to skin colour and gender, makes me both emotive and motivated towards resisting oppressive structures and staying true to my values of equality and social justice. Throughout my life I have always been curious how I am afforded positions considered privileged; ‘middle class’ and growing up in a rich Westernised country. I am also curious at other times why in certain contexts my gender, age and ethnicity position me as less advantaged. The importance of adopting a participatory approach in this research, reinforces my belief that clinical psychology holds positions of power and leadership (BPS, 2010) with roles and responsibilities to create and support meaningful ways for YP’s voices to be heard (Novell, 2011). I believe that I can explore my own values further through working alongside YP, learning through reflexivity and addressing inequality further through this research.

1.3.2. Relational Reflexivity

Burnham (1993) terms relational reflexivity to describe how we become aware of and use our contributions to co-construct interpersonal interactions. It is important in PAR group settings for the group to become attuned to ethical issues such as power dynamics in order to critically reflect through use of dialogue towards transformative change. It is assumed that through increased self and relational reflexivity we can recognise what we bring to encounters

and modify interventions, actions and reactions. Through this we can more easily maintain curiosity (Cecchin, 1987) and guard against imposing our assumptions. This positioning was reinforced by my value that as clinical psychologists we should always be questioning knowledge and practices (Riley & Evans, 2017).

Relational reflexivity supports how we understand and interact with each other. Beginning to recognise and highlight differences, meanings and power differentials can position dialogue in this context towards recognising and opposing discrimination and oppression (Afuape, 2016). Through promoting relational reflexivity within the group, I hope to promote solidarity. Solidarity is noted to have the power to strengthen and stimulate individuals and groups towards social transformation, thereby threatening oppressive systems (Janis, 1982).

Relational reflexivity extends the idea of reflexivity beyond individual experiences into the relational context including the space in which this research is situated. YoungMinds¹⁰, as the collaborating organisation, being the United Kingdom's leading national mental health charity for YP, sits outside statutory services and can be viewed as an 'alternative' MHS. It is argued that for 'service-users' to make radical and emancipatory change in statutory MHS, they must sit outside the control of statutory services (Stickley, 2006). Power imbalances may remain if participation is set-up to be 'given' by hierarchies of power to those acting in the role of 'service-users' (Stickley, 2006). YoungMinds were recently commissioned to oversee wider participation throughout YP's universal health and education. In the context of supporting YP's voices being heard, an alternative environment further away from the statutory professional gaze may facilitate more open and critical

¹⁰ YoungMinds provided permission to discuss the organisation by name in this thesis however measures taken ensure anonymity of individual participants affiliated with YoungMinds.

dialogue and action. YoungMinds will also have their own organisational agendas, such as time and funding, which may impact this research.

The context of this research thesis is part of the clinical psychology doctorate programme at UEL, regarded as a socially critical and progressive training programme (Burton, Boyle, Harris & Kagan, 2007). This approach undoubtedly influenced and supported this particular research. UEL require me as 'lead-researcher' to have a written proposal with research questions before meeting and inviting YP to join the research. I initially felt uncomfortable with this, questioning my right to unilaterally determine key research questions and approaches. A recent PAR study in a comparable context noted YP reported they would have liked more structure and knowledge from the 'lead-researcher' (Templar, 2017). Therefore, in the context of this research being time-limited, initial structure and focus, still seeks to remain true to the values of PAR within this context.

In keeping with the 'action' element of PAR, exploring and deconstructing further contexts surrounding this research should increase awareness by examining assumptions within multiple levels of context, to inform action at any given time. Lykes and Hersberg (2012) discussed that institutional, professional and personal interests and choices are negotiated with a primary commitment to generate meaning, knowledge and actions towards addressing immediate social issues in PAR.

1.4. Participatory Action Research (PAR)

1.4.1. Historical Development of PAR

PAR is a subset of action research, defined as the "systematic collection and analysis of data for the purpose of taking action and making change" (Gillis & Jackson, 2002, p.264). Kurt Lewin (1946), a Prussian social psychologist and a Jewish refugee from Nazi Germany coined the term 'action research' (Gillis & Jackson, 2002). Lewin embodied the philosophy which considered that people would be more motivated about their work if they were involved in the decision-making about how the workplace was run (McNiff & Whitehead, 2006). This approach aimed to study a social system whilst attempting to

change it, highlighting the significance of person-orientated attempts at solving particular social problems (Gillis & Jackson, 2002). Action research therefore bridges disconnection between social science research and concrete problem solving in communities and society. Lewin's form of action research is noted to address problems of segregation, discrimination, and assimilation, in addition to assisting people in resolving issues and initiating change (Stringer & Genat, 2004).

PAR also is also connected to Paulo Freire (1973), a Brazilian educator and philosopher. He introduced ideas of critical pedagogy beyond limited intellectual academic exercises in relation to oppression being rooted in real and material experience. He termed the notion of 'conscientização' as the active process of reflection and action upon oppressive structures, being dynamic and at the core of liberation. Freire (1973) discussed dialogue as vital to encourage people to critically reflect on their experiences through a newly acquired critical consciousness allowing the mechanisms of oppression to become visible with new possibilities for liberating action to emerge. He also termed the complex interaction between reflection and action as 'praxis', advocating that in isolation both verbalism and activism make 'true' dialogue impossible. Ignacio Martín-Baró (1994), a Spanish Jesuit priest was also aligned to these ideas and the development of PAR. Martín-Baró discussed social suffering as systematically and unequally distributed in society, believing in preferential treatment for the poor (i.e. the *oppressed*) (Kleinman, Das & Lock, 1997). He was therefore instrumental in the move towards conducting research towards addressing unjust social conditions that oppress people. Another influential figure in the development of PAR is Orlando Fals Borda (1987) a Colombian sociologist, who saw science as a social construction subject to critique. Building on ideas of praxis in research he noted that we act based on new understandings and knowledge generated by research. He focused on practical (not abstract problems) and therefore did research *with* people who are participants.

1.4.2. Application of PAR

The advantage and explicit goal of adopting a PAR approach for this research is its potential to catalyse social transformation by engaging historically less powerful people in research (Whitmore, 1991). PAR adopts the position of knowledge being a source of power in itself and that participants themselves generate valid knowledge and are thus empowered. As philosophically collaborative, democracy, creating a safe space, working collaboratively, and attending to different levels of participation are considered crucial to PAR (Bergold & Thomas, 2012). PAR is a non-linear process thus methods emerge through the process which cannot be fully known at the outset (Greenwood, Whyte & Havarky, 1993). PAR aims to investigate 'real life problems' and create solutions for these challenges through an action-oriented intention (Fals-Borda, 1987). Challenging the distinction between 'researcher' and the 'researched' affords greater opportunity for active participation in research by considering issues that affect people and their communities (Gaventa, 1993) towards supporting changing defined situations for the better (Wadsworth & Epstein, 1998). Emphasising a collaborative research partnership, PAR focuses on research processes, reflexive engagement in the processes, and considers issues of power and knowledge sharing. PAR is therefore particularly relevant and effective in participation when working with oppressed groups in society. PAR and community psychology are discussed to reflect shared values of collaboration, democratic participation, self-determination and social justice (Lord, Ochocka, Janzen & Nelson, 2002).

Relatively few PAR projects within MHS actively involve YP in research (examples include; Chowns, 2008; Fattore, Mason & Watson, 2007; Jason et al., 2004; McLaughlin, 2005, Taggart, 2008, Afonu, 2016, Templar 2017). As co-researchers, YP were involved to varying degrees; collecting data about process; undertaking interviews supported by an academic researcher; and in disseminating research.

1.4.2.1. Action

In order to create a socially 'just' world in which power, resources and burdens are equally shared it is argued that we must engage in processes of social transformation (Nelson and Prilleltensky, 2010). Social transformation (or second order change) differs from first order change in that social transformation "strives to change the system and its assumptions" unlike first order change that is satisfied with "change within systems" (Nelson and Prilleltensky, 2010, p. 144). Therefore, achieving this change in the research process requires acknowledging 'action' from participants and researchers.

Response to oppression through action can take many forms, such as mental, behavioural, spiritual and physical (Afuape, 2011). 'Acts' can be implicit and explicit on personal and collective levels towards resisting oppression and moving towards changing what is defined as problematic. Wade (1997) discusses 'everyday acts of resistance' towards oppression through determined and creative 'acts' which are noted to provide a significant sense of self towards future acts of resistance. Wade (1997) purports that any act through which a person attempts to: expose; survive; repel; stop; prevent; abstain; strive against; obstruct; refuse to comply with, or oppose any form of oppression or the conditions that make such acts possible, can be understood as a form of resistance. Through the process of viewing acts through this lens, Wade (1997) reflects that individuals begin to experience themselves as more insightful, capable and stronger towards responding effectively to oppressive contexts. This includes recognising our pre-existing abilities we all possess to resist oppression.

Afuape (2011) views resistance as a type of poesis; creative freedom from tradition which can express difference and challenge norms, towards endless possibilities. Resistance as creativity is noted to be utilised by both 'service-users' and professionals in MHS in resisting various forms of oppressions. Therapists are noted to do so through resisting being positioned as the expert and the "arbiter of truth" (Afuape, 2011, p.41), in which this research seeks to challenge. Afuape (2011) urges both groups of humanity (i.e. 'service-users'

and professionals) to collectively work together against oppressive discourses, in which this research seeks to do.

1.4.3. Power, Knowledge and Language

Power is complex through being socially, culturally and historically situated (Patel, 2012) and is central to PAR. Power is highlighted as being integral in all of our lives, including in ongoing interactions (Afuape, 2011). Foucault's theories relating to power and PAR converge in considering interactions between people and exertion of different forms of knowledge (Schneider, 2012). Using a Foucauldian lens, the relationship between language and power (Foucault, 1988) is important when considering how power is constructed and positioned in enabling inclusion, exclusion and construction of realities.

Foucault (1977) rejects ideas of power being possessed and views power as pervasive, embodied everywhere through discourse¹¹. Interactions between people and practices of institutions are theorised to exercise different forms as knowledge through 'regimes of truth'¹² (Foucault, 1977) which inhibit and enable dialogue and action. Although often difficult not to assign blame to oppressors, oppression is best understood as originating outside of people

¹¹ Discourse harbours creating what is 'truth' and what is not, extending how 'truth' is sanctioned through procedures and techniques in discourse (Foucault, 1977).

¹² 'Regimes of truth' (Foucault, 1977) are the result of discourse and institutions, and are reinforced (and re-defined) constantly through social systems and ideologies. Therefore 'regimes of truth' are related to the rules in which objects are able exist (i.e. are true and false) within specific contexts and realities.

(Castro Romero & Afuape, 2016) dehumanising us all, as it disrupts potential for social equality, justice and wellbeing (Freire, 1973).

PAR fits with Foucault's (1977) theories of discipline as a mechanism of power to subtly regulate behaviour through 'acts of governing' (Foucault, 1977) and institutional practices such as hierarchies, norms and judgment. Historical contexts of MHS highlight power as 'exclusionary' (Foucault, 1977) with institutional practices of 'treating' people as 'unreasonable' until they became 'reasonable', through discourse defining these realities. Viewing power as pervasive includes power both being constraining and productive, thus opening up new ways of acting and thinking. This view defies the notion that power is held by the elite few with a large powerless majority (Foucault, 1977). PAR recognises this by aiming to change power dynamics in research through collaborative processes, challenging notions of the 'expert' and the 'researched' in opening new possibilities to privilege YP's voice in the production of knowledge and meaning-making (Usher, 1996) through participation at different tiers of this research. By becoming active in research agendas and increasing knowledge through reflection, YP may become more powerful agents.

Freire (1973) strongly advocated knowledge being most powerful when connected to possibilities for action and asserted that knowledge could only be termed 'true' if connected to the transformation of reality and human relationships. To increase understanding, reaffirm partnership working and avoid imbalances of power, professionals (such as myself as 'lead researcher') must work collaboratively with YP to communicate effectively and respond through a shared language that avoids jargon (Stickley, 2006). Sharing knowledge to bridge gaps, where I may hold more power, may increase YP's understanding and encourage their ownership in making decisions relating to the research (Mitra, 2004). By considering who has power and how it is used, I question the role academic researchers and psychologists play in maintaining the status quo of inequalities. I also see the importance of questioning by deconstructing and opening opportunities for change. From the outset, I have attempted to utilise the 'not knowing' position

(Anderson & Goolishian, 1992) to escape the 'all knowing' expert position, (Anderson, 1997) aware that I am always learning and can learn from others' unique experiences. This opens possibilities for co-researchers to deviate from established models and for them to make sense of their own experiences, supported by a non-judgmental and curious stance (Ceccin, 1987).

The academic requirement of this thesis is that it is written in language of an acceptable academic standard. To ensure inclusivity for YP, I commit to present and disseminate the findings of this thesis in ways that can be co-constructed and understood by other YP and those outside traditional academia. This is a step towards breaking down conventional hierarchies and encouraging social justice.

1.5. Alternative Psychological Approaches Leading to 'Empowerment'

Alternative psychological approaches, used in clinical psychology, namely liberation and community psychology seek to move away from mainstream models in understanding distress in wider socio-political structures and inequality.

1.5.1. Liberation Psychology

This research has been grounded in liberation practices and community psychology. Liberation is described as evoking freedom, choice, self-determination, equality and emancipation from oppressive social conditions (Moane, 2010). Liberation psychology is often used in the literature to describe liberation practices linked to wellbeing (Afuape & Hughes, 2016). Moane (2003) proposes a 'cycle of liberation', through conceptualising multiple levels (personal, interpersonal and political) of influence towards liberation. This model proposes laboratory practice at the level of individuals, groups and communities to transform people's lives. Although personal transformation is an essential element of liberation, the focus in this model is always on the collective. Each level of change requires connection with others who are similarly situated and this then sets the scene for dialogue to analyse, act and reflect (Moane, 2003).

Emanating from criticisms of traditional psychology, liberation practices aim to address inequalities through theory and practice, by challenging 'expert' positions and working alongside people towards developing their own strategies for transformation (Martín Baró, 1994). By recognising plurality of all knowledge liberation practices promote dialogue to enable awareness and change. Similar to PAR, liberation psychology is linked to cycles of reflection, planning and possibilities for action (Freire, 1973). PAR, as an alternative to 'expert-led' models, directly challenges the regulatory scientific approach of the researcher and is therefore an appropriate research approach in narrowing the gap between practice and research.

1.5.1.1. Historical Development

Liberation psychology is commonly considered to emanate from Latin America and attributed to Ignacio Martín Baró, a Salvadorian Jesuit priest and psychologist. Martín Baró (1994) proposed a vision of liberation could be made possible through processes of dialogue and transformative action. He argued that traditional psychological approaches did not locate psychological experiences within context and adopted neutral positions in relation to distress. His approach was unapologetically political, often referred to as non-neutrality, now a minority position in publicly funded health services (Burton et al., 2007). Martín Baró (1994) viewed liberatory approaches as the only ethical way to practice psychology and therefore tasked all psychologists with this approach (Montero, 2009). Paulo Freire (1973) is also a powerful inspiration to ideas of Martín Baró and liberation psychology through highlighting the possibilities of 'conscientização' and 'praxis'. These ideas and concepts are at the heart of this thesis, PAR is a form of 'conscientização' and 'praxis' in its attempt to raise critical awareness in research processes and connect people to the issues they feel need addressed within their communities. With PAR focusing on creating meaningful social action through the research process, this project intends to critically reflect and act upon YP's own realities (Kemmis & McTaggart, 2007) in order to create meaningful and flexible research and action.

Liberation psychology has earlier connections to African American philosopher, historian, sociologist, novelist and poet Dr W.E.B Du Bois. Strongly linked to critical and liberation theory, Du Bois used the term 'double consciousness' to describe oppressed individuals, having dual identities, viewing themselves both through their own eyes and the eyes of the society that oppresses them (Du Bois, 1994). Similarly, Freire (1973), discusses 'duality' of the 'oppressed' internalising the 'oppressor'. He warns against the 'oppressed' becoming the 'oppressors' through ambiguous 'duality'. This is noted through two possibilities; the 'oppressed' gaining power and using this to 'oppress' their previous oppressor and; the 'oppressed' gaining power over other oppressed people and becoming their 'oppressors' as they seek individual liberation. Freire (1973) claims that only the *oppressed* have the ability to liberate both themselves and their *oppressors* by re-establishing the humanity of both groups. This connects to this research in considering the language and positioning of 'service-user' participating in MHS. This arguably privileges and pushes 'service-users' to participate in the context of professionals' dominant discourse of theories, models, power and knowledge (McLaughlin, 2009) and not truly of (*the oppressed*) people accessing services. This arguably creates a confusing dichotomy in SUP where services simultaneously position people as passive receivers consuming from the service as experts (Stickley, 2006). The development of critical consciousness is liberatory in creating space to reflect on how we are shaped by our realities to see new possibilities as creative actors in our lives, rather than passive subjects (Martín Baró, 1994). This process regarded as 'humanising' leads to wellbeing and requires complete flexibility.

1.5.2. Community Psychology

Community psychology became established in the 1960's within contexts of social unrest in Western countries with demands for change in civil rights around gender, race, sexuality and disability equalities. In Britain, psychological models began to draw influence from liberation practices and move away from dominant and individualistic approaches towards questioning psychological practice by deconstructing wider societal structures (Burton et al., 2007). Placing distress firmly in wider material contexts recognises the

extent to which our feelings, thoughts and behaviour are shaped by economic and social circumstances (Smail, 2005). Therefore, actively engaging with wider circumstances which challenge inequalities can lead to positive psychological outcomes (Smail, 1994). Other theories are noted to also influence the development of community psychology, such as Ecological Systems Theory (layering social and environmental systems to understand individuals, Bronfenbrenner (1977)) and theories of empowerment (discussed in 1.5.4).

Community psychology, noted as difficult to define due to its flexible and responsive approach (Rappaport, 1977) is described as a diverse and at times conflicting discipline (Francescato & Tomai, 2001; Fryer, McKenna & Hamerton, 2000). Community psychology utilises a plurality of theoretical, research and action methods to work alongside psychological distress of individuals, communities and societies through collective action based on shared values. Orford (2008) notes 'empowerment', 'liberation' and 'social justice' as three core values of community psychology. Often categorised as an alternative psychological approach, community psychology is distinguished from other areas in psychology through specifically placing the 'person in context' (Orford, 1992). This pays attention to concepts of power by moving away from expert-led and individualistic interventions (Fryer, 2008) and attending to active engagement with wider circumstances (Kagan, Burton, Duckett, Lawthom & Siddiquee, 2011). In practice community psychology seeks to work with marginalised and oppressed members of society through a strengths-based approach acknowledging people are active agents (Fogg-Rogers, 2017) in relation to their historic, political and cultural contexts. Similar to liberation practices, community psychology has expressed dissatisfaction with traditional methods of research and psychology (Orford, 2008). Community psychology highlights that psychology can and ought to concern itself with pressing social and political concerns. Terms such as 'activist-practitioner' (Zlotowitz, 2013) have raised awareness that clinical psychologists, through social action, can address societal issues such as inequality that affect the overall mental health of the population. I believe our profession, with access to power and resources, has a duty to support local

and national actions that promote wellbeing of the population. PAR seeks to do this in many ways, examining power throughout to identify hierarchies and problem orientated action.

1.5.3. Barriers to Liberation and Community Psychology Approaches

The very nature of emancipatory psychological approaches is dynamically complex and with this comes limitations. Despite psychologists being inspired with visions to relieve suffering and help others (Parker, 2007), emancipatory approaches remain positioned as an 'alternative' and inaccessible for many. Current socio-political contexts place positive emphasis on 'evidence-based' practice. The National Institute for Health and Care Excellence (NICE) Guidelines are determined through a research hierarchy (NICE, 2006). This gives the lowest grade (Type V) to 'service-users' voices, with scientific measurements such as Randomised Control Trials (RCT's) having highest importance (Type I and II). Despite copious criticism of RCT's including many forms of bias and cherry picking (Moncrieff, 2013), this results in MHS being controlled and dominated by unreliable science which also neglects peoples' experiences and voices within this system. This, coupled with influence of the BPS, which is discussed as being arguably biased against alternative and non-individualistic psychological approaches (Burton et al., 2007), makes these alternative approaches difficult to access. With strong evidence linking social inequality to distress (Wilkinson & Pickett, 2009), I cannot make sense of this approach being marginalised as 'alternative', especially with connection to challenging how YP's voice is really 'heard' in MHS.

Considering the force of the mainstream (i.e. individualistic approaches to understanding distress), Parker (2007) argues that individualistic assumptions in western psychology can pervade community psychology, moving the focus towards internal processes and away from collective action. Parker (2007) suggests that many western psychologists are socialised with assumptions that they already know what the world is like and what is possible whereas many communities are just beginning to question what is possible, creating difficult and potentially misleading power dynamics. This linked to critiques of psychologists engaging with communities through agendas of 'social control'

rather than through empowerment, particularly in the context of funding pressures (Parker, 2007). Being aware that these limitations could potentially reside within this PAR highlights the importance of ongoing critical reflection to prevent oppressive practice in this research.

1.5.4. Empowerment

Empowerment is a multi-level and dynamic construct, linking individual wellbeing with the larger social and political environment. Through empowerment, individuals develop a critical understanding of their environment and strengths to access valued resources and decision-making capabilities (Zimmerman, 1990; 1995; 2000). Empowerment differs from psychological constructs of confidence and self-esteem as it involves critical reflection of our contexts (Zimmerman, Israel, Schulz, Checkoway, 1992), allowing greater access to and control over resources and participation (Rappaport, 1987). Empowerment is presented as a specific goal for community psychology interventions, being key to improving mental health and wellbeing (Harper & Speed, 2012).

Empowerment is defined within the hierarchies of power, including those intrinsic within MHS. It is argued that whilst professionals empower those acting as 'service-users', pervasive power imbalances are retained (the *worker* empowers the '*service-user*'). Empowerment therefore as a concept, in spite of its honourable intentions, is argued to reinforce the power position of those doing the empowering and maintained the dominant order (Stickley, 2006). Emancipation, however, is the potential for individuals to take power rather than to have it given. The construct of empowerment is further discussed as problematic recognising that traditional western psychology places emphasis on individual and cognitive processes. Riger (1993) argues this can lead to individuals feeling a sense of empowerment rather than having any actual increase in power, thereby being an illusion distracting from difficult historical and political issues without necessarily leading to more influence or control. Madden and Speed (2017) highlight the danger of framing power as located within an individual, both in the role of the 'patient' and that of the researcher. Conceptualising participation leading to

empowerment as personally determined ignores broader socio-political influences on the systems around an individual which can lead to division of responsibility and, in turn, tokenistic attempts at participation.

Empowerment, linked to disempowerment, can be understood as liberation drawing upon individualistic and critical traditions of autonomy (Lawson, 2011), opening new and different possibilities. As such, it can be part of an 'emancipatory' account focussing on the transformative capacity of active ways of learning and acting (Zyngier, 2007), which this research commits to. MHS need to be empowerment-orientated (DoH, 2004b). PAR and SUP can be described as having empowering potential, although it is clear that involvement does not necessary lead to empowerment (Radermacher & Sonn, 2007). PAR should be action-oriented otherwise it can become tokenistic (Beresford, 2002). Taggart et al (2013) discuss intrapersonal changes through PAR projects with YP experiencing empowerment in becoming honest, making sense of and accepting their difficulties with others. YP's participation is further discussed as linked to empowerment through facilitating a rebalance of power dynamics in YP's MHS towards a positive shift in sense of self, including moving towards being increasingly perceived by others outside of the 'patient' role (Mayer & McKenzie, 2017).

1.6. Literature Review: YP's Participation Within MHS

A review of the literature relating to YP's SUP in MHS provides further context. This was conducted across the following databases: Academic Search Complete; PsychINFO; PsychARTICLES, CINAHL Plus and Child Development and Adolescent Studies. The search terms used were: "user participation" or "user involvement" or "co-production" or "patient participation" and "young people" or "adolescents" or "young adult" or "teenager" or "child" and "mental health". The literature search was limited to articles written in English and no date ranges were implemented. In total 79 articles were considered relevant. Further relevant literature was located through using reference lists in articles of interest.

1.6.1. YP's 'Service-User' Participation

The literature highlighted numerous interchangeable terms to describe SUP (see footnote 4). Co-production is expressly conceptualised with more equal sharing of power and decision-making between 'service-user' and service provider (Mayer & McKenzie, 2017). All SUP terms encompass processes by which YP as 'service-users' can take part in and influence processes and issues affecting them, including their healthcare and wider service provision (Day, 2008) at all levels of MHS. YP's voice remains relatively unheard in MHS (Afonu, 2016) despite clear requirements for YP's views being heard and acted upon in everything affecting their lives, embodied in legal and policy frameworks (UNESCO, 1989; Children's Act, 1998; Human Rights Act, 1998, NHS Act, 2006). Nationally, Children's Trusts (established under The Children Act, 2004), which require all YP's services to centralise YP's voices at all levels (Street & Herts, 2005). YP's participation is at the core of many government strategies, policies and initiatives, such as 'Every Child Matters' (Children and Young People's Unit, 2001). Since 2001, all government departments are expected to involve YP in policy development (Badham & Wade, 2005). This expectation is reflected in YP's MHS and can be seen through recent initiatives such as 'CYP-IAPT', 'Future in Mind' (DoH, 2015a) and additional policy (DoH, 2003, 2004, NICE, 2010). Despite this, YP's participation is not systematically occurring, or is tokenistic (Beresford, 2002). Literature suggests that when CAMHS implements SUP, it is most commonly through service evaluation (Dexter, Larkin & Newnes, 2012). In the context of this research, 'participation' is broadly conceptualised in relation to how YP have 'participated' in MHS, such as individual therapy to wider service development.

Despite variances in practice, the literature is clear that to be meaningful involvement must be fed back in timely ways (Day, 2008). If not conducted appropriately, YP can feel coerced and tokenistic involvement can cause adverse effects such as emotional harm (McNeish, 1999) and damaging effects on YP's dignity (Bessell, 2011). This emphasises the need to safeguard against absent and tokenistic participation.

Many YP's experiences in MHS appear to directly contradict these key policy goals (Beresford, 2002), despite extensive directives and guidance produced to support professionals implementing safe, meaningful and ethical participation practices with YP in MHS. These include but are not limited to; Badham & Wade (2005); Department of Health, (2003); Lightfoot & Sloper (2001); Street & Herts (2005).

1.6.2. Models of YP Participation

Despite the plethora of publications relating to rights, models and theory of SUP purporting that services should fundamentally be built around 'service-users', In practice, varying degrees of participation are reflected in and across organisations. SUP in practice is often seen as a "bolt-on extra" (Riddell, 2010, p. 32) in MHS. Arnstein's Ladder of Participation (1969), adapted by Hart (1992) for YP's involvement is the predominant model used, particularly within statutory services (Tritter & McCallum, 2006). The ladder metaphor illustrates power levels between adults and YP (i.e. YP's level of authority and control increases as their level of participation activity increases on higher rungs of the ladder). This model has been criticised for implying a simplistic hierarchy (Hayward, Simpson & Wood, 2004) and for inferring failure if top level participation is not achieved. Although critiqued for positioning participation with the individual (Day, 2008), other models attempt to address this through conceptualising participation less linearly through considering YP's social, cultural and mental health needs (Sinclair, 2004) and wider organisational characteristics (Shier, 2001), as shown in Figure 1.

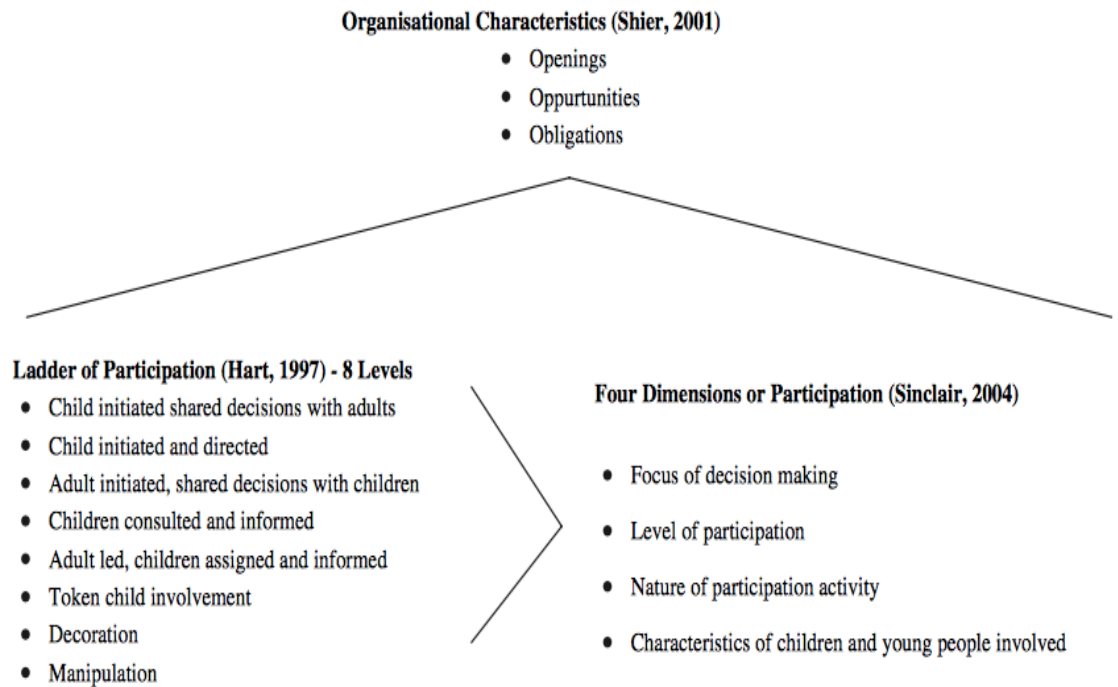


Figure 1. Models of YP's Participation

The 'nine participation priorities' (Great Involvement Future Thinking (GIFT), 2013) model in Figure 2, highlights levels and examples of YP's participation in MHS.

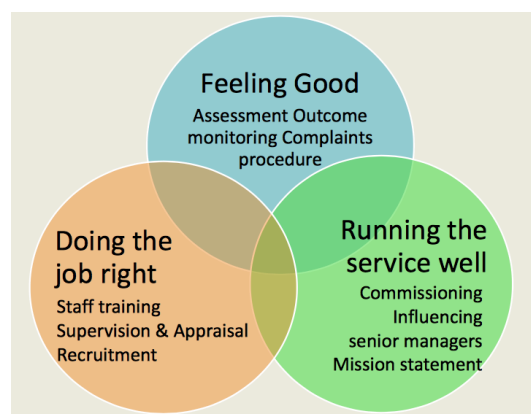


Figure 2. The Nine Participation Priorities (GIFT, 2013)

1.6.3. Impact of Participation

The impact of YP participating affects both YP and MHS in different ways with most initiatives discussed being driven by a combination of considering impacts for YP and MHS (DoH, 2004c; Kirby & Bryson, 2002; Sinclair & Franklin, 2000).

Literature indicates that YP's services improve in quality and effectiveness through 'participation' (Beresford, 1997) by eliciting the distinctive views of YP (Alderson, 1993). MHS provision can be improved through numerous levels of engagement in clinical decision making and interventions to more relevantly reflect YP's concerns and priorities (Day, Carey, & Surgenor, 2006; DoH, 2004c). Staley (2009) also discusses the recognition of involving YP in research, such as PAR, in improving quality by making the research more relevant and robust. Evidence also points to participation directly improving clinical outcomes, including higher rates of satisfaction among YP and professionals (DoH, 2004a; Guadagnoli & Ward, 1998). Participation is noted to make services more innovative, responsive and accessible to YP (Beresford, 1997). This is noted through challenging existing assumptions about YP's needs which also enhances service credibility (Mokwena, 2006; Revans, 2009) and reputation (Day, 2008). Participation is therefore discussed to have the potential to promote value, saving money in the longer term (Day, 2008).

The impact on YP of participation is noted to have many benefits through increasing YP's education, skills and competencies (Day, 2008). The impact of 'participation' explored directly with YP notes that participation supported YP to learn new information and skills, feel valued resulting in increased social benefits (Vromen & Collin, 2010) and facilitated wider social changes (Taggart et al., 2013). YP are noted to take part in wider decision-making in MHS for a number of reasons including a wish to make change and to 'give back' (Lightfoot & Sloper, 2001). These processes can in themselves help YP feel empowered (Day, 2008), respected, recognised and reinforce YP's personal knowledge about their health (Curtis & Singh, 1996). As a result, this plays an important role in YP's control and influence over their recovery from

mental health issues (Repper & Perkins, 2003). Hart, Saunders and Thomas (2005) discuss the process of eliciting participating views as being therapeutic, including in leading to the development of new CAMHS interventions. YP engaging in meaningful participation are noted to feel valued and have a strong sense of belonging which has been linked to positive mental health outcomes (Oliver, Collin, Burns, & Nicholas, 2006).

Wider communities are also noted to be impacted with 'empowered' YP becoming more likely to make positive contributions to society (YoungMinds, 2005). Community participation is noted as a strategy to reduce health inequalities as a key principle of UK health policy (DoH, 2017). Developing partnerships between community organisations (such as YoungMinds) and health services therefore moves towards eliminating sources of inequalities existing in the design and delivery of MHS (DoH, 2017).

A lack of rigorous empirical evidence of the impact of participation is discussed by Day (2008). Most evaluations utilise qualitative and participatory research methods (Kirby & Bryson, 2002). Many of the impacts, particularly on an individual level, are however 'evidenced' through adult observation rather than directly from YP's point of view. There now appears to be increasing research involving YP directly about the impact of participation, mainly conducted in Australia.

1.6.4. YP Participation in MHS as 'Service-Users'

In theory, YP being positioned as 'service-users' ascribes knowledge and experience of this role to them. YP's voices arguably exist in MHS in relation to this role. Through 'participation' YP could wield greater power within services and challenge the status quo (Dexter, Larkin & Newnes, 2011). YP should therefore be able to exert direct pressure on organisations (Day, 2008), although further complexities exist with many professionals being socialised to meanings of 'service-user' through the language of medical models (Harmer & Finlayson, 2015). Mental health professionals may unintentionally reinforce psychiatric labels to perpetuate stereotyping service-users as lacking competence to fully enact their rights and responsibilities

during participation. YP discussed participation as facilitating opportunities to rebalance their relationships with the system (Mayer & McKenzie, 2017).

YP's contributions play a critical role in creating person-centric service design and delivery in MHS which meet YP's needs (Rickwood, Van-Dyke, & Telford, 2015). This effectively positions YP as consumers and stakeholders (Day, 2008) and participation as personally determined, distracting from the broader socio-political influences and leading to a division of responsibility in MHS. Positioning YP as consumers arguably reduces them to a 'commodity' (Stickley, 2006). Therefore, 'participation' may serve as an empty signifier which changes its value, based on the policy drivers of the time (Stewart, 2012). This highlights that YP's 'participation' can serve alternative functions for those with power, potentially removing motivation to develop broader engagement levels of the public in meaningful ways. Applying consumer models towards participation is formulated as problematic, including a risk of treating people in unstable ways (Diamond, 2010). This is of particular concern for YP involved within MHS being typically amongst the most subjugated members of society (Patel, 2010) and in most need of stable support. Limited opportunities for resistance in relation to oppression (such as participation) are likely to impact on maintaining individual psychological distress (Rogers & Pilgrim, 2003).

1.6.5. Barriers and Facilitators to Meaningful Participation

Seeking to realise benefits of participation described in literature and policy drivers, serves to question incongruent practice and absence of participation in YP's MHS. Exploring barriers to implementing meaningful participation led me to consider the relative force of facilitators towards these barriers. This is in the context of structural power relationships in MHS which can produce stigma through culture, power and difference (Parker & Aggleton, 2003). Staff attitudes, competence, recognising YP's contribution, communication, rigid structures, representation and mental capacity are highlighted throughout the literature and discussed below. Interestingly, I found the majority of literature appeared to focus on wider YP's participation in MHS and less so on participation at individual levels within YP's own healthcare.

1.6.5.1. Power Dynamics

Power dynamics may reflect the disparate activity within YP's participation (Kirby, Landyon, Cronin & Sinclair, 2003; Sinclair, 2004) with wider dynamics of mental health stigma being a barrier to YP's voice in MHS. YP's preconceptions about mental health (with associated stigma) and previous experiences within MHS is noted as a barrier to engagement and, in turn, participation (Simmons et al., 2013). YP are noted to be particularly susceptible to stigma linked to peer acceptance making them less motivated to access MHS (Kranke, Floersch, Townsend, & Munson, 2010). Stigma is also noted as a barrier to participation in MHS. Stigma can produce feelings of shame and raise concerns about being positioned as 'weak' (Moskos, Olson, Halbern, & Gray, 2007). Being positioned as 'weak' can lead individuals to internalise or externalise this narrative. In wider contexts, this can be linked to gender norms and expectations (i.e. boys are strong and girls are emotional) resulting in boys being less likely to access MHS than girls (Chandra & Minkovitz, 2007).

YP's capacity to be involved in decision-making, due to age and severity of 'symptoms' were raised as key barriers to participation by professionals, 'service-users', and carers (Idenfors et al., 2015; Oruche et al., 2014; Tam-Seto & Versnel, 2015). Professional power dynamics are noted as a barrier through YP reporting feeling intimidated with low confidence to share their voice, paired with lacking faith their views will be heard and acted upon (DoH, 2004a) in MHS.

Professionals reported a lack of expertise in involving 'service-users' in care and decision-making (Abrines-Jaume et al., 2014; Bee et al., 2015). Day (2008) discusses that increased participation in YP's MHS implies that adults now work with YP rather than separately and autonomously. Participation challenges existing discourses such as 'adults know best' with evidence demonstrating YP's developmental competence of reflection and ability to contribute to decision-making in sophisticated ways (Clark & Moss, 2001). Discourse in MHS includes some clinical psychologists believing increased SUP would decrease the need for or remove their roles (Soffe,

Read & Frude, 2003), highlighting professionals' fears in viewing participation as a threat. Another study revealed that CAMHS staff positioned YP as both vulnerable and powerless (Dexter, Larkin & Newnes, 2012), positioning YP as 'less-than-ideal' candidates to participate and act in wider MHS planning. Dexter, Larkin & Newnes (2012) discuss this finding within a context where parents (and professionals) were positioned in contrast to YP as being perceived to offer a more straightforward option for participation in MHS.

To avoid an imbalance of power, professionals require to work collaboratively alongside YP communicating effectively and being attuned to the language they use, responding through shared dialogue that avoids jargon (Stickley, 2006). Clear communication towards recognising YP's contribution, treating YP with respect and acknowledging their input was noted as integral (Day, 2008). This was discussed through the literature as closing feedback loops by following up with YP and also through remuneration for wider level participation (Coates & Howe, 2016). Remuneration is debated in the literature. National Children's Bureau (2003) guidelines suggest that remuneration should not be used as a coercive incentive to participate however YP should be compensated for their time, knowledge and participation appropriately (Kirby, 2004). Actively and meaningfully engaging with YP in all organisations and recognising YP as 'educating the educators' is required (Fallon, Warne, McAndrew, McLaughlin, 2012). Consequently, many higher education institutions, such as mental health and social care professionals, now introduce 'service-user' perspectives and teaching into their curriculum and research agendas (Amitav, 2008).

1.6.5.2. Flexibility

Flexibility, being central to PAR, can increase possibilities for action and is key to facilitate YP's participation (Coates & Howe, 2014), with rigid structures noted as a barrier towards meaningful participation. A systematic review (Gondek et al., 2017) concluded that professionals, 'service-users' and carers reported limited resources and a lack of information as barriers to participation, making flexibility difficult. YP's participation must recognise YP's dynamic lives with commitments (such as education and employment). MHS

require to take these into account (Coates & Howe, 2016), centralising YP's experience and culture (Beresford, 2005). One study suggests that YP involved in participation initiatives found informal environments more inclusive and appealing, with YP being invited to own processes instead of formal structures being imposed (Vronmen & Collin, 2009). Studies considering wider participation practice, suggest that organisations require to 'go beyond' normal practices towards ensuring meaningful participation (Abrines-Jaume et al., 2014; Buckley et al., 2012; Oruche et al., 2014). The National Youth Participation Strategy (2008) for Australian mental health discusses a 'continuum of participation model' or 'tiered model' to support varying degrees to which YP participate depending on projects and YP's availability, choice and interest level. Having a tiered approach to participation allows YP to progress through their knowledge, abilities and confidence (James, 2007) and ensures that all YP are offered the same opportunities.

1.6.5.3. Representation of Voice

Another pertinent issue to consider is who participates and how. Questions have been raised about the representativeness of YP involved in participatory activities (Day, 2008). The literature is clear that SUP is more likely to involve adolescents than younger children (Kirby, 2004; Oldfield & Fowler, 2004), despite recommended developmental adaptations and capabilities for young children to be involved (Clark & Moss, 2002).

Inclusive representation also extends to further marginalised groups including but not limited to: physical disability (Bailey, Boddy, Briscoe & Morris, 2016), learning disability (Mitchell, 2012); neuro-disability (McAnuff et al., 2017); males (Raeburn, Walter, & Cleary, 2015); homeless YP (Claveirole, 2004); looked after children (Davies & Wright, 2008); and YP under sections of the Mental Health Act (2007). YP falling into these groups are found less likely to be involved, although when their participation is successfully established many of these YP report feeling over-consulted (Oldfield & Fowler, 2004). These studies acknowledged adaptations are required to achieve meaningful participation with these YP groups tending to be less involved than other YP located outside of these groups. Noted complexity and sensitivities with these

groups should not be a barrier to participation in itself (Coates & Howe, 2016). Consultation with YP not explicitly involved in MHS is also noted as useful but discussed as potentially difficult to access because of stigma YP feel is associated with having mental health difficulties.

Considering what is known of participation in MHS through this literature review highlights gaps in direct research working with YP towards YP's voice being heard in MHS. This research aims to address this as laid out below.

1.7. Research Aims

This research aims to actively to establish and investigate YP's experiences of participation within MHS through a PAR framework with YP as 'co-researchers'. With PAR being an ongoing process of reflection, dialogue and action (Baun, MacDougal & Smith, 2006), initial questions around this topic are set out to guide the broad research aims, namely:

- What benefits do YP identify by being 'service-user participants'?
- What encourages increased YP participation practices in MHS?
- What barriers do YP identify in their role as 'service-user participants'?

To reflect the dynamic nature of PAR, these questions will be adapted and adjusted to reflect YP's questions and preferences throughout the process. Qualitative research methods were utilised in relation to a PAR framework and the research aims. This is explained in detail in the below methodology chapter, alongside the philosophical assumptions of this research.

2. METHODOLOGY

Based on my experiences and values, I was drawn to PAR, which is described as a “philosophy of engagement” (Schneider, 2012, p.2) centred on cycles of reflection, data collection and action. Differing from other research approaches utilised in clinical psychology, PAR is aligned with principles and values typically emanating from community psychology approaches, paying attention to socio-political contexts and raising critical consciousness of ‘realities’ to drive varying action to promote change (Grundy, 1987). PAR actively involves community members in generating knowledge about issues concerning them through promoting personal and social action to bring about health equality, citizenship and social justice (Baum, MacDougall & Smith, 2006). With this research aiming to explore YP’s participation in MHS, it was fitting to invite YP to become ‘co-researchers’¹³ to participate at different phases of this research, towards understanding and action (Montero, 2000). In this research, I adopt PAR as a “democratic process” (Reason & Bradbury, 2006, pp.1) by upholding commitment to YP participating as ‘co-researchers’ and respecting all YP’s knowledge, with attention to YP in MHS as a marginalised group and action to promote social justice for YP and others alike (Reason & Bradbury, 2006). To operationalise this, I adopted ongoing reflexivity with regular consultations with Director of Studies (DoS), YoungMinds and co-researchers. Framework documents (Appendices A-F) and reference guidelines on involving YP in research (e.g. Kirby, 2004) were used. I provided workshops to ensure co-researchers were fully briefed on ethical and other aspects of research (Appendix G).

In this chapter I will outline and rationalise the epistemological and ontological position informing the use of qualitative data and methods of analysis. I will

¹³ Agreed term chosen with YP in this research.

then outline the method and 'phases of the research' which emerged through co-construction with YP as 'co-researchers'.

2.1. Philosophical Assumptions

In determining the research aims and methods, ontology and epistemology are of key relevance. Ontology relates to questions fundamental to 'reality' or existence (Burr, 2003). Epistemology relates to the philosophy of knowledge and how we obtain this, with questions about how and what we can 'know' about 'reality' (Burr, 2003). Both ontological and epistemological positions can be found on a continuum of 'naïve realism'¹⁴ to 'extreme relativism'¹⁵ (Willig, 2013; Harper, 2011) to describe the extent to which data is seen to reflect reality.

Ontology, as the existence of phenomenon or 'reality', is important to consider in this research as it includes hidden public discourse which is arguably the crux of YP's participation and how YP voices are able to 'exist in MHS'. Epistemology in considering how knowledge is produced is critical to PAR, as this research seeks to construct knowledge through YP's active role as co-researchers. This will question who produces knowledge and how within MHS, this is fundamental to YP as an oppressed group. In PAR knowledge is acted upon new consciousness, which is crucial in creating meaning, and new knowledge towards change.

2.1.1 Epistemological Position: Critical Realist Social Constructionist

Harper (2011) suggests a 'critical realist social constructionist' epistemological position draws upon critical theory and is defined as ontologically realist with an epistemologically relativist position. Elder-Vass (2012) argues the potential of social constructionism is best understood when distanced from an anti-

¹⁴ The belief that the world is 'rule-bound' and that data collected mirrors this reality (Willig, 2008).

¹⁵ Extreme relativism rejects concepts of 'truth' and 'knowledge' altogether (Harper, 2011) advocating that data has multiple valid interpretations.

realist ontological stance. An explicit realist ontology can increase coherence and consistency of connection to material reality (such as MHS) to increase clarity and plausibility in enabling connections between accounts and social entities that shape these (Elder-Vass, 2012). Critical realism (Willig, 1999) acknowledges that wider social contexts impact on our meanings through a degree of 'reality' that exists. This position recognises the importance of studying qualitative data by going beyond the 'text' to include broader historical, cultural and social contexts (Harper, 2011). Social context is central to PAR (Kagan et al., 2011) as is the concern of change. I argue that to enable change, there must be an acknowledgement of reality and that a critical realist position can highlight pre-existing accepted practices that work to distort realities (Glesne, 1992).

This epistemological position affords deeper layers of interpretation in broader historical, cultural and social contexts, such as drawing upon ideas from Foucault's ideas relating to power (Harper, 2011). This position can allow researchers to make ontological claims about pre-existing material practices that can influence discourse (Harper, 2011), such as policies and procedures used in YP's MHS. PAR and Foucault's ideas share relevance and converge in many ways (Schneider, 2012). As discussed in 1.4.3 Foucault (1977) was interested in how discourse defines the 'reality' of the social world, and it being an institutionalised way of communicating about a reality that defines what can intelligibly be thought about and what cannot. Therefore, PAR opens new possibilities by aiming to change power dynamics in research through collaborative processes and challenging notions of the 'expert' and the 'researched' by privileging YP's voice in the production of knowledge and meaning-making (Usher, 1996). YP positioned as 'co-researchers' allows space for voice that is not normally heard (Lather, 1991). This acknowledges engagement of researcher and co-researchers as co-creators of a shared reality.

2.1.1.1. Power

Extending ideas relating to power (in section 1.4.3), as pervasive (Foucault, 1997) and integral to our everyday lives (Afuape, 20110) and PAR, it is

important to note that not all action research has historically attended to issues of power (Glesne, 1992). I aim to attend to power issues through this epistemological stance highlighting the role of language, social and cultural contexts and dominant and oppressive conditions through processes of praxis and conscientização (Freire, 1973). Through this, I resign my 'expert' position and assumptions towards facilitating change. In line with critical theory, this epistemological position will not provide neutrality (Martín Baró, 1994). As an act against inequality, alongside YP, I aim for this research to open new possibilities against the status quo of MHS. This critical realist approach within a social construction framework understands political stances as entwined with both epistemological and ontological positions (Glesne, 1992), i.e. there is a 'reality' to what is socially constructed through this research. Therefore, this epistemological position supports this research as a form of social action (Burr, 2003) and a political act (Usher, 1996) by inviting researcher(s) to reflect on issues of power and through understanding YP's perspectives. Orford (1993) argues it is impossible to adopt the orthodox stance of complete neutrality and impartiality within research, aligned with community psychology's strong stance on social justice. Through this lens, I seek to re-politicise mental health through recognising YP 'exist' in the realities of their personal experiences in relation to wider social and political contexts (Dalrymple & Burke, 2006) as discussed in 1.2. This research is explicitly constructed in YP's social environments with attempts to move away from 'false generosity'¹⁶ (Freire, 1973) to curiosity within this research process.

The blend of ontological and epistemological positioning is noted to have potential for a greater degree of reflexivity and moves towards challenging practices that reinforce dominant discourse (Brown, 2012). Therefore, the

¹⁶ False generosity occurs in structures comprising oppressors and oppressed where some oppressors feeling genuine compassion towards oppressed suffering move to isolate or aid that suffering rather than address the root cause societal structures.

epistemological position enables flexibility and transparency which are key to PAR (Kemmis & McTaggart, 2007). In line with ongoing reflexivity throughout this research, this epistemological position attempts to replace the objectivist ideal with an ongoing critical lens (Hoffman, 1990). This includes the way YP are perceived and positioned in society and the way many MHS are set up around such beliefs and practices. By deconstructing dominant discourses, assumptions and normative rules, this research seeks to create space for non-dominant and often unheard narratives in order to reconstruct new narratives and possibilities for action alongside YP (White & Epston, 1990). Elliot (2005) discusses one's sense of self and personhood (see footnote 10) as shaped by society and culture. Possibilities and meanings for some YP may feel limiting within MHS, especially when diagnosis is used in subtle and explicit ways as a weapon of oppression and marginalisation (Wakefield, 2013) by arguably pathologising human suffering and distress (Boyle, 2006) and limiting individual choices (Boyle, 2011). Application of PAR with oppressed groups, fits with social constructionist arguments that people's narratives are often marginalised, subjugated and denied in favour of the dominant belief system that pathologises those who do not meet its expectations (Rapmund, 2000). Social constructionist lenses move away from individualistic narratives and single accounts of reality, paying attention to patterns in the social world around these for the development of problems, meanings and possibilities (Zimmerman & Dickerson, 1996).

A social constructionist epistemological stance notes YP have complex and ever-changing identities and understandings of their experiences (Chadderton, 2011). Therefore, this research cannot capture the views of YP at any one point in time and cannot represent all YP nor remain static. However, while this position is not concerned with searching for the ultimate 'truth', it does seek to question who defines it (Brown, 2003; Wilson & Beresford, 2000). Therefore, this research does not aim to make generalised claims (Willig, 2008).

2.1.1.2. Language

While paying attention to power dynamics, this epistemological stance also pays attention to language. Glesne (1992) highlights the role of language in the construction of supporting and maintaining conditions of inequality, oppression and exploitation which this PAR framework seeks to address. From a social constructionist perspective, language validates, connects and sustains societal ideas about one's existence (Burr, 1993). The ontological position acknowledges a 'reality' to this existence, such as MHS. In this research knowledge and meaning are constructed through understandings of dialogue and communicative action. Therefore, this epistemological stance positions perceptions of 'reality' as existing through being constructed within the constraints and regulations of possibilities around what can and cannot be said (Sims-Schouten, Riley & Willig, 2007) within historical, cultural and social contexts. This research also positions language as opening possibilities of 'giving voice', aligned with the view that "there is no such thing as the voiceless, there are only the silenced and the deliberately misheard" (Roy, 2004, pp.54).

2.2. Methodology

2.2.1. Qualitative Data

Qualitative methodology¹⁷ was chosen as the most fitting approach towards inquiring into subjective meanings within socio-political contexts (Yardley, 2001). Qualitative methods indicate the specific research techniques used in this research (Silverman, 1993). Aligned with the epistemological position, qualitative research supports the core values of community psychology (Orford, 1993); diversity, importance of context and notion of empowerment through hearing directly from people about the reality of their lives and experiences (Banyard & Miller, 1998). Participants telling their stories through their own language and feeling 'heard' when neglected areas become

¹⁷ General approach to exploring research areas concerned with meaning and how people make sense of their experiences (Willig, 2008).

explored, supports YP in this research to consider their differences in novel ways (Banyard, 1995). 'Giving voice' does not necessarily transform one's experiences (Stein & Mankowsk, 2004) and PAR is aligned with notions of social transformation. Therefore, this qualitative research draws on inter-related actions of asking, witnessing¹⁸, knowing and interpreting using the understanding of processes to contribute to change and social action.

2.3. Analysis

Despite highlighting Foucault's ideas relating to language, power and institutional practices (1977, 1984, 1988) as very relevant to PAR (Golob & Giles, 2013), a decision was taken not to utilise Foucauldian Discourse Analysis (FDA) (Willig, 2013). This decision was to enable YP to collaboratively partake in the analysis process as co-researchers. Thematic analysis (TA) (Braun & Clarke, 2006) was considered more accessible to arrive at patterns in the data alongside co-researchers. Recognising concerns about undertheorising power within PAR highlights possibilities of marginalising co-researchers within the research (Chambers, 1998; Kemmis & McTaggart, 2000; Pain Kindon, Pain, 2007). This research attempts to move away from enacting problematic power dynamics through challenging deep-rooted power inequalities further, utilising Foucauldian ideas in TA. Foucault's theories of power, identity and discourse (1977, 1980, 1984) will be applied in order to gain a deeper analysis, including how YP 'talk about' and are 'talked about' in positioning YP's voice and ways of being at the centre. TA will also be utilised to explore how experiences, realities and meaning-making are constructed through the effects of social context and discourse.

¹⁸ Observing events, dialogue and action through validation, listening and observation. 'Outsider witnessing' practices, included in this definition, support us to identify expression, describe change, embody responses and acknowledge transport of where this witnessing takes us and others (White, 2002). This thereby decentres ourselves and provides opportunities to listen and observe challenges and difficulties to be shared (Fredman, 2014).

Taking a critical realist approach to language enabled me to explore how YP's voice reflects underlying material structures.

TA can identify, analyse and report patterns to organise and represent meaning within the data set (Braun & Clarke, 2006) relating to the research aims (Boyaktzis, 1998). Being both a direct and adaptable analytic method (Braun & Clarke, 2006) in qualitative data, TA was also chosen to fit with the flexible, dynamic and complex nature of PAR and its compatibility with critical realist social constructionist positions towards providing a rich, detailed and complex account of data (Braun & Clarke, 2006). In TA, themes are identified when recognised for importance in relation to the research aims and questions (Braun & Clarke, 2006) and are not selected based on frequency of the theme in the data. Themes presented should be considered 'in context' whilst reflecting the content of the entire data set, rather than themes being selected based on the preference of the researcher (Joffe, 2012). The research aims were broadly about experiences of how YP participate in MHS to capture the breath of dialogue, likely to be discussed in the context of PAR. Anything that was not captured under these broad themes was noted and discussed with YP, including how the group might take these ideas forward after this project (further discussed in 4.4.6).

Attending to power imbalances, it was important to me to promote equality and meaningful collaboration, through ensuring the analysis process was accessible to co-researchers with different levels of education and 'ability'. TA is a simple approach to analysis but not basic and unsophisticated (Braun & Clarke, 2006). TA does not require detailed theoretical and technical knowledge in comparison to other qualitative approaches. It can offer increased accessibility for those relatively unfamiliar with qualitative methods (Braun & Clarke, 2006; King, 2004), which many co-researchers reported to be. TA is also suitable for group analysis, noted as useful for examining the perspectives of different research participants in highlighting similarities and differences, and generating unexpected insights (Braun & Clarke, 2006; King, 2004).

This research utilised Braun & Clarke (2006) six-stepped process to TA, using both inductive and deductive approaches. It was deductive given the research group's awareness of the research aims when analysing data, generating codes and ideas closely linked to the data. It was inductive in that some of the themes chosen reflected co-researchers' and my theoretical interests based on our experiences (Braun & Clarke, 2006) produced through group processes and analysis.

2.4 Ethical Considerations

Ethical considerations are central to PAR and risk of harm was of critical importance throughout the research process. This is of particular importance when working with subjugated members of society, in considering nuanced ways of understanding power and empowerment (Kindon, Pain & Kesby, 2003). Detailed risks and responses were identified (Appendix A) including possibilities of distress, coercion and manipulation in the process.

Ethics approval was granted from the School of Psychology Research Ethics Sub-Committee at UEL (Appendix B) and agreed as sufficient by YoungMinds. YoungMinds had an additional layer of organisational safeguarding policy with a staff member appointed as a point of contact and present in all correspondence and meetings with co-researchers. In line with ethics, importantly all sessions were optional and I checked consent with YP at the beginning of all sessions.

2.4.1 Risk

Ground rules (Appendix C) co-constructed with the group in phase 1 were used for reference. Risk considered from the outset (Appendix A), was further minimised through transparent and continuous discussion and summary, encouraging and gaining ongoing feedback with DoS, YoungMinds and co-researchers. Keeping a reflective diary helped me recognise my own assumptions, thoughts and feelings which might impact on the process and research, taking care not to fall into traps of manipulation and cohesion to meet time pressures of the thesis.

Ending social action research before it is decided as 'complete' is discussed as exclusionary and unethical (Tait & Lester, 2005). PAR is a dynamic and continual process and therefore having an 'end' may be contradictory. Linked to ideas of 'giving psychology away' (Miller, 1969) utilised in community psychology, I have offered to remain available as a resource following this focussed thesis to a workable extent the group choose. It is hoped co-researchers can sustain this project through leading dialogue and further action.

2.4.2 Informed Consent

Initially, I informed YP about the project verbally when in YoungMinds premises and circulated information via email through YoungMinds' staff members. After having time to consider the project, YP were provided with an information sheet, Terms of Reference (ToR), and co-researcher consent and confidentiality agreement forms (Appendices D-F). These were completed by all co-researchers before taking part in the research. Separate documents prepared for YP under 16 years, were not required due to all co-researchers being aged 16 and over. Co-researchers aged 16 and over were encouraged but not obliged to inform their parents/guardians. Aware of power balances, all information (written and verbal) sought to be transparent and presented in accessible language and format for YP. Co-researchers were also informed throughout the PAR process that they could withdraw from the research (including text extracts from transcripts that YP did not want to share) at any time (before write up) without having to provide any explanation. Co-researchers were provided details of DoS and encouraged to speak to me or a named individual at YoungMinds at any time if any concerns arose.

2.4.3. Confidentiality and Anonymity

All signed documentation and research data were kept confidential through use of a secure online forum, a password protected computer and ensuring data was anonymised. Co-researchers were informed from the beginning that confidentiality would only be broken, in consultation with YoungMinds and DoS, if there were safety concerns about a co-researcher or a member of the public, and would be discussed with the YP where possible. Confidentiality

was maintained throughout the entire research process, and no issues occurred. Only the research team (who all signed confidentiality agreements) supervisors and examiners had access to data. Data collection took place in 'focus groups' and via social media through a private online collaborative workspace ('Slack'), which only consenting co-researchers had access to. Data was not entirely anonymous within the group as YP already had knowledge of what was said in discussions they participated in. 'Slack' is an online workspace application which securely enables group communication, discussions and file sharing. This online application was utilised for organisation, communication, data collection and information sharing.

YP's dialogue and actions were noted, discussed and summarised after each focus group session. Focus group transcripts (from consented audio recordings) were transcribed by me, preserving anonymity and circulated to the group for their information. Identifying information was anonymised in transcripts and thesis extracts through the use of pseudonyms (many chosen by co-researchers). PAR participants have the right to waive anonymity and be publicly recognised for their contributions (Kindon, Pain & Kesby, 2007) however anonymising all data in this write-up recognises academic requirements. For future dissemination of this research, I aim to revisit anonymity and carefully consider this with co-researchers.

2.4.4 Online Safety

An online workspace, 'Slack', set up by YoungMinds for this research enabled YP's dialogue, information sharing and data storage. The use of closed and secure online groups can provide flexible and enabling ways for 'co-researchers' to participate in activities (Templar, 2017) and was a preferred method for dialogue and data collection for some YP. Documentation relating to the project was centrally stored and shared on this space, affording equal access to knowledge for all co-researchers.

Co-researchers were requested to keep conversations relevant to this topic on this forum, maintain confidentiality and reminded of safeguarding policies and procedures. Online group discussions were set up at designated times allow myself and a YoungMinds staff member to be present. This felt

important to ensure online safety such as managing any potential difficulties, such as inappropriate content or cyberbullying that could have been posted at any time (this did not occur in this online space). Safeguarding measures were taken, aligned with guidance (Sharkey et al., 2011) ensuring no personal or contact information was shared or could be obtained on the forum, (apart from YoungMinds email contact). Forum rules were available from the outset on the online forum with a report procedure for co-researchers for anything deemed inappropriate. Balancing online safety with the set-up of this online space and within the context of time restrictions (with this research being part of the doctoral thesis process) may have censored how voice was expressed in this forum.

2.5. Procedure

To provide framework and clarity around the dynamic nature of the project I conceptualise the procedure in terms of distinct 'phases' of the research. Table 1, below, provides an overview of these phases. Due to the multi-faceted processes of this research, phases and processes of designing, developing and analysing research became parallel, overlapping and intertwined. Non- tokenistic dialogue and action, which cannot be anticipated, occurred at varying levels throughout all phases. These phases were constructed within the group within different contexts (individual and collective) over time. During all 'phases' the online workspace enabled communication between monthly meetings and held summaries of meetings and all relevant documents including the thesis proposal, information sheets and anonymous transcripts of focus groups. Transparency in sharing information felt important in providing equal access and attending to power dynamics.

Timeline	MONTH									
	Pre - month 1	1	2	3	4	5	6	7	8	9 →
Phase 1 Set up	Agreements with Young Minds (YM)	Initial engagement								
		Recruitment								
Phase 2		Slack online workspace available								
Data collection		Co-researchers Meetings: groups and Slack live chat								
Phase 3									Slack online discussion	
Analysis									Analysis workshop	
Phase 4 Interpretation and write-up									Write-up	
Phase 5 Dissemination and Continuation of PAR group										Dissemination
Forum	Meetings, emails and telephone calls	YM Monthly Meet-up	YM Monthly Meet-up	Research Workshop	Focus Group	Focus Group	Focus Group	Analysis Workshop	Slack live Discussion	Continued space for PAR group
Attendees	YM Staff members	YM staff member Poppy Scott (2 YP who signed up but did not actively engage after this time)	YM staff member Poppy Sarah (2 YP who did not actively engage after this time)	YM staff member Poppy Ally Sarah Esther	YM staff member Poppy Anita Ella Esther Emily Scott Sarah	YM staff member Poppy Helen Scott Sarah Jay Hope	YM staff member Poppy Anita Jamie Esther Emily Matt Rachel	YM staff member Poppy Anita Matt	YM staff member Poppy Anita Esther	YM staff member Co-researchers

Table 1. Method Timeline and Activity

2.5.1. Phase 1: Engagement and Initial Set Up

Involvement of YoungMinds organisation in the research was negotiated through a series of meetings and communications as the initial step. I was allocated a slot at monthly ‘meet-ups’ attended by YP volunteering nationally through a YoungMinds ‘Young Activist’ Programme¹⁹.

For three months, prior to research groups emerging, I attended these ‘meet-ups’ and began engaging YP with the opportunities and possibilities of the

¹⁹ This Programme is open to all YP aged 14-25 who want to improve the status quo for YP with experience of mental illness in the UK and aims to be as diverse and representative of YP as possible, to ensure YoungMinds represents varied voices of YP in the UK on the topic of mental health. The programme has development opportunities such as paid positions on participation projects and providing references to support with education and employment after volunteering for 6 months.

proposed research. This included facilitating group exercises and providing information to inform and engage YP in this research. I saw value in the 'well begun, half done' approach (Lang & McAdam, 1996) providing opportunity for thorough understanding, informed consent and meaningful engagement through in this phase. This included informing and understanding contexts and building relationships with YP and the organisation at this early stage. Freire (1973) also advocates that before we enter into dialogue the context for doing so must include care and commitment. Throughout this 'phase' recruitment began to take place with documentation about the project (information sheets, co-researcher agreement and consent forms) made available.

2.5.1.1. Recruitment

Inclusion criteria included YP aged 14-25, who were part of YoungMinds organisation, specifically within the Young Activism Program, and able to communicate in English. This is the age range YP are commonly referred to in health and social care settings (Association for Young People's Health (AYPH), 2015) and connected with the age group of YP available for recruitment within the Young Activist Program. YoungMinds' established relationships and structures supported YP, such as always having a staff member present attuned to YP's preferences and needs. Therefore, there was no explicit exclusion criteria for additional communication needs (such as learning disabilities).

Although recruitment began in this initial engagement phase, the recruitment stage evolved into an open 'rolling' process. This involved 'young activists' attending and signing up to become 'co-researchers' in each session. In line with participatory approaches, it felt ethically important that no YP participating in these monthly meetings became excluded. Allied with the principles of PAR, I did not want to cause harm through marginalising any YP further. This open flexible recruitment process also recognised YP's existing lives, commitments and that participation in this project was unpaid. This research presented an opportunity for 'young activists' to further participate in changing MHS. Linden et al. (2007) note practices of offering equal options,

such as open and ongoing recruitment, are important when working with oppressed groups to safeguard against exclusion. It is noted that open-designs can result in research being less biased and more valid, with a wider and more diverse pool of voice and experience (Linden et al., 2007).

I provided information and updates at the beginning of each group and ensured informed consent was carefully considered through establishing a framework of engagement through terms of reference (Appendix D) and co-researcher confidentiality and consent agreements (Appendix E), before participating. At the beginning of each session it was made clear verbally that being part of sessions was optional and entirely voluntary without disadvantage or having to give reason. This aimed to reduce potential for power imbalances within the group, with me as lead-researcher and new members joining the group.

2.5.1.2. Co-researchers

The term 'co-researchers' was established with YP to define YP participating in this PAR project. Fourteen YP aged 17-24 signed up to become 'co-researchers' of which 12 (eight females, four males) actively participated. Of these YP, nine identified as 'White British', one as 'Black African', one as 'Indian' and one as 'Other'. Co-researchers decided how actively involved they became based on their personal preferences and the level of time and commitment required. Table 1 indicates co-researcher (using pseudonyms) involvement at different times. Involvement activities during online discussion forums and monthly face-to-face focus groups included:

- Data collection: gathering voice (which included problem-posing²⁰) through dialogue and action.
- Analysis: co-construction of production of knowledge with regard to the project.

²⁰ The term problem-posing coined by Freire (1973) describes a method of facilitating critical thinking towards liberation involving: listening, dialogue and action towards problem-solving.

- Ongoing decision making about research process: ongoing collaboration and praxis.
- Future scope of the project: further dialogue, action and disseminating our research to others.

During this phase I delivered a research workshop to all ‘young activists’ interested (Appendix G for slides). Existing ideas and beliefs about research were discussed and information was provided about research processes, PAR and the proposed project. At this stage, many co-researchers appeared to conceptualise research as a dull and tedious process and through learning about these existing beliefs, I strived to create an alternative narrative through briefing about the history of PAR, generating activities and providing as much opportunity for this research to be shaped by co-researchers as possible.

During this phase through workshops and groups, we utilised the social GRRACCEESS²¹ (Burnham, 2012) framework to consider the intersections of social differences. I attempted to model transparency and build relationships by sharing intersects of my identity with the group which I hoped could also enable the group to attend to self and relational reflexivity, and provide more equal sharing of voice in the group. Additionally, towards this we considered our ‘wildest hopes and dreams’ (Appendix H) for the project and any questions and ideas to inform and develop this research together. It was hoped these exercises which felt powerful in opening new possibilities, could begin to raise critical consciousness and instil the endless possibilities of YP’s action. Many co-researchers reported that they had not considered nor been privy to this experience before with power being un-interrogated through many years of experiences in the MHS.

²¹ Acronym which includes Gender, Religion, Race, Ability, Age, Culture, Class, Ethnicity, Education, Employment, Sexuality and Spirituality.

2.5.2. Phase 2: Data Collection Sessions

In line with PAR framework, 'data collection' was an opportunity to gather voice about YP's experiences of participation in MHS. In addition to gathering broad experiences about participation this included learning what was defined as problematic (i.e. the barriers to participation in MHS) through problem-posing and action. 'Data' was explicitly collected in this phase through dialogue from monthly focus group discussions, which were audio recorded with permission. All interactions informed and constructed each data collection method.

To provide the discussed structure, I initiated the first recorded focus group discussion, as the first data collection method. On reflection, I felt pressured by traditional research methods at this stage. However, I felt it important that YP had participation and choice around future data collection methods. I therefore gave choices about further data collection, through polls in 'Slack' and in meetings. Options included group discussions (focus group), PhotoVoice²², designing an online data collection method for other YP within a secure online platform within YoungMinds or any other ideas co-researchers had. Co-researchers chose focus group discussions for all data collection methods. Reasons for choosing group discussions were reported by some co-researchers as easier to utilise in relation to the open-design, allocated time and this feeling more familiar than the other options.

For the first focus group, I devised a discussion schedule (Appendix I) to broadly consider my research questions. Again, on reflection, I felt pressured by time limitations and traditional research methods through devising this initial structure and prioritising my aims. This did however feel useful during the early stages to provide initial structure and direction, within time restrictions. I also ensured I kept questions broad so as not to restrict responses. YP co-researchers in a similar project (Templar, 2017) reflected

²² PhotoVoice can be utilised as a research method where participants use photography towards producing positive social change.

that a degree of direction was helpful at this stage. It was also reflected as useful to set expectations, in a similar way, for the group to begin dialogue and action. Seeking to promote transparency, I acknowledged my interest in exploring the research aim(s) initially, seeking permission from the group to begin with these ideas and questions while actively encouraging YP to raise further ideas and questions throughout the discussions, towards the co-construction of the research.

For the second and third focus groups, I opened by summarising previous discussions explicitly setting out that these were my understandings of the discussions while encouraging other understandings and sign-posting YP to revisit the transcripts held on 'Slack'. After setting up the groups in this way, I promoted open discussion about YP's experiences of participation within MHS to provide space for YP's voice outside my interpretations and towards further co-construction of the research. Data collection from 'Slack' online discussion forums followed a similar process with active participation encouraged.

2.5.3. Phase 3: Process of Joint Analysis: Co-construction of Meaning-Making and Production of Knowledge

It is vital that qualitative researchers provide clarity about what they are doing, why and how (Attridge-Stirling, 2001). Research dependability requires researchers to ensure the process is logical, traceable and clearly documented (Tobin & Begley, 2004) in a reflexive manner. Being clear about the rationale and positioning of the research aided through self, relational and group reflexivity extends towards recognising this, in this research. Braun and Clarke (2006) six-stage method for TA was utilised namely Stage 1: Familiarising yourself with data; Stage 2: Generating initial code; Stage 3: Searching for themes; Stage 4: Reviewing themes; Stage 5: Defining and naming themes; Stage 6: Producing the report.

Researcher judgement is necessary to determine themes. Alongside co-researchers (Braun & Clarke, 2006), I argue that sharing judgement with co-researchers can strengthen trustworthiness of determined themes by reducing potential for bias by challenging assumptions and seeking diversity of flexible possibilities and positions. Prolonged engagement is argued to close gaps

between participants' views and researcher's interpretation of them, enhancing the credibility of the research (Tobin & Begley, 2004).

This phase was ongoing with co-researchers as they had access to transcripts after data collection sessions and were 'in' the data. Therefore co-researchers were likely constructing ideas of codes and themes throughout. Three co-researchers, who participated in one or more of the three focus group discussions and had read the transcripts in between sessions, attended an analysis session. During this session, I briefed co-researchers on TA (Braun & Clarke, 2006) and how I felt it fitted with the research. The aim of this session was to inform YP about analysis and begin to collectively code, synthesise and name themes together. There was also opportunity for discussion to inform my approach to interpreting the data, which I alone was responsible for. Through briefing, I became aware of using and disseminating my academic knowledge which I initially felt uncomfortable by somewhat taking an 'expert' position over YP in this process. However, on reflection it was important to brief YP to enable YP to participate meaningfully in this analysis session, within time constraints.

2.5.3.1. Generating Initial Codes and Synthesising Themes

During the analysis workshop, co-researchers and I selected combined elements of 'theory-led' analysis, as described below. This included considering the themes based on group discussion and our own ideas. This analysis is also noted as 'experience-led' analysis (Templar, 2017) with co-researchers being both 'in' the data experientially, and 'analysts' of the data. Below, I detail the process of generating initial codes and synthesising themes together. Braun and Clarke (2006) six-step process is highlighted throughout:

- 1) In the analysis session, we read through the scripts individually (at different times; outside of sessions and together in the analysis session) annotating these with our own ideas and thoughts (step 1: familiarising yourself with the data).
- 2) We then discussed and paid attention to the language we chose to generate codes together (step 2: generating initial codes).

- 3) Due to time and engagement, as a group we decided to go through the second and third group transcript together. I had already annotated some ideas which were jointly discussed with YP (step 2: generating initial codes).
- 4) We jointly captured and noted the development of codes (step 2: generating initial codes).
- 5) In parallel, we began to group these codes into broad themes (step 3: searching for themes) and discussed these themes together (step 4: reviewing themes), as demonstrated in Appendix J.
- 6) We then began naming these groups as 'themes' (step 5: defining and renaming themes) together. This was useful in bringing different perspectives to my own, that I may not have considered. This truly highlighted the power of YP participating in the analysis of their own words and conversations they were a part of. It also gave particular power and credibility to the TA with co-researchers having more explanation and understanding of their own language and experiences which arguably reduced assumptions and bias in relation to the analysis.
- 7) After these steps in this joint analysis session were concluded, the group agreed that I would type up the codes and themes and return to the data to consider any further ideas. This was to ensure the rigor of the data and particularly so that dialogue and action from other YP (who were not a part of this session) did not become lost. Part of me felt that while this was essential to the research process, I may have been imposing my agendas in doing so within the time-limited context, which I openly discussed in the session. I then repeated the process iteratively through reviewing the joint analysis by revisiting the six-stepped process. I ensured that extracts associated with each identified theme were reviewed for coherence and fit, towards developing a coherent narrative about the data (Braun & Clarke, 2006) whilst keeping YP's language and ideas in the joint analysis session alive in this process.
- 8) After this iterative process, I brought the typed codes from the joint analysis session with my new analysis added (generated through 7 above), to the group's attention over 'Slack' for discussion. I used different coloured text (exemplified in Appendix J2) to differentiate my ideas,

ensure transparency and offer opportunity for disagreement from all co-researchers (i.e. including co-researchers who were not involved in the analysis session) about decisions relating to the themes. This felt important in order to respect all YP's input and minimise power imbalances within the group.

2.5.4 Phase 4: My Interpretation and Write Up

After the joint analysis session, due to time limitations and placing manageable and realistic expectations on YP and with this thesis write-up being my responsibility, I term this phase as my interpretation. Through continuing transparency, I let YP know about this process and named their ideas which were essential to informing this phase. With many YP expressing interest in viewing the outcome, I agreed to send a copy of the thesis write-up upon completion to the group to increase transparency.

Guidelines for good qualitative research were used which include a clear rationale for methodology and methods supported by integration of theory (Henwood & Pigeon, 1992), such being complemented with Foucauldian ideas. As discussed, Braun and Clarke (2006) guidelines were also used at this stage, including step 6 of 'producing the report'. For example, quotes reflected data codes and were sorted thematically, which is reported to evaluate the robustness of the research (Braun & Clarke, 2006). A coded transcript example can be found in Appendix K, alongside evidence of the development of the codes (Appendix L). Further, Elliott (1999) advocates good quality qualitative research should include: awareness and consideration of the researcher's perspective and relationship to the topic; situating the sample in examples of the data; validity of data via multiple sources of interpretation (credibility checks); coherence and integration. YP actively participating in research, through 'data collection' and partaking in analysis, in relation to issues which affect them is highlighted to increasing the validity of the research for the communities it serves (Ozer, 2016).

Acknowledging YP's knowledge and meaning-making as valid in its own right, I will therefore propose an option for the interpretation to be reviewed together, after this write-up (step 6: producing the report) to minimise risk of my

interpretation (which is laden with additional theory and literature) supplanting YP's own dialogue and action in future dissemination.

2.5.5. Phase 5: Future Development of Project

In line with the research aims, it is hoped this research will lay the foundation and create space and possibility for further dialogue and action led by YP to take forward as chosen by the group. The results and discussion chapters below seek to inform this phase towards future possibilities of this research.

3. RESULTS AND DISCUSSION

3.1. Overview

Results and analysis, inextricably linked with issues of power and social inequalities, are set out in this chapter. Endorsing the validity of YP's voice, meaning-making and knowledge through this research, seeks to align with a psychology that challenges psychologists' positions as experts (Martín Baró, 1994). Therefore, through data collection and analysis YP themselves define their experience of YP participation (including defining what is problematic in relation to action). I see YP's knowledge and meaning-making as valid in its own right, using relevant theory and literature in this chapter, such as Foucault (1977, 1984, 1988), to confirm and exemplify YP's own insights and consider issues of power. Wishing to stay close to data comprising YP's own words, I discuss my reflections in the next chapter, to ensure my words do not deflect from YP's.

Readability of data extracts is enhanced by use of ellipses when quotes have been shortened and information is inserted in [square brackets], to help make sense of quotations. For clarity, the references for extracts are GD=Group Discussion, SLD=Slack Live Discussion.

3.2. Themes

The four selected themes which emerged overlap and are interconnected, as might be expected given the dynamic nature of PAR (Templar, 2017). YP talked about the construct of power, which became implicitly and explicitly present throughout all themes. In recognising power being at the core of this PAR research, we decided to identify 'power over YP' in MHS as a key theme. Four core themes and nine sub-themes (presented in Table 2 below) were chosen by co-researchers and myself to reflect our analysis of the data and its connection with the research aims. Coding information and thematic maps are included in Appendices J-L.

Global Theme	Sub-theme
Power Over YP	YP as the Other
	Solidarity
Hearing YP's voice	Gender
	Assumptions
Safe Structures	Professional Responsibility
	Practical Aspects
	Staff Attributes
Participation as Fundamental to Wellbeing	Dehumanised to Humanised
	Preventing Harm

Table 2. Table of Themes

Co-researchers named the themes; 'solidarity', 'gender', 'assumptions', 'safe structures', 'professional responsibility', 'practical aspects' and 'dehumanised to humanised'.

3.3. Theme 1: 'Power over YP'

'Power over YP' in MHS describes YP's experiencing power produced by professionals privileging their knowledge, models and theories over YP's experiences and voice. Excluding and minimising YP's voice and creating a hierarchy of knowledge, separating employees from YP produces YP as powerless objects in MHS, resulting in 'YP as the Other' which became a sub-theme. A second sub-theme, 'solidarity', aimed to capture YP's productive use of their own power in MHS to counteract 'power over YP' with acts of resistance through individual and collective actions.

3.3.1. YP as 'the Other'

Not being treated as equals and as 'the other' (Keszinger & Wilkinson, 1996) within MHS was defined by YP as problematic.

The professional is very much the professional and it can be very difficult for the professionals to...step out of that idea of...I know what to do and you don't because if you knew...then you wouldn't be in treatment. But in terms of participation and youth participation I know what to do and they don't because...they have no experience from the other side (Poppy; GD1, 206-210).

Poppy highlights YP experiencing professionals as people who think they have superior knowledge and understanding of mental health issues. YP also talked of experiencing professionals equating their knowledge with the 'truth', which is then lauded over YP. Foucault's 'regimes of truth' (1977) point to 'acts of governing' by hierarchies of professional judgement and normalised ways which positions YP in MHS with constrained power. Further, Poppy discusses that professionals dismissing YP's voices goes against what professionals aim to do in supporting YP.

Yeah, a fully defined person [YP] with opinions and value and it can sometimes be talking to people who are so dismissive of the value of participation...because if you have a little respect for the people you treat...you can't effectively treat somebody if you are looking at them like they are less than you and...worth than less than you (Poppy; GD3, 387-392)

The importance of sense of self and personhood in MHS is discussed as being dismissed by professionals' knowledge being viewed as the 'truth', reducing YP believability in this space.

Like, we know what we are going through...and none of that matters apart from what like they have learned in like the academic route most of the time (Esther, GD3, 878-879)

Discussion of medical language highlights discourse in MHS that medical models are used to shape YP's identities (Harmer & Finlayson, 2015). Foucault (1977) notes such discourse as institutionalised ways of creating narratives and identities by hierarchies that seek to manage 'health and

illness' within larger social bodies and through language this becomes normalised.

They are not taking us seriously [Helen: yeah literally], they are not using our words...all the words are just medical (Jay; GD2, 476-477)

Privileging professional knowledge is exemplified as problematic when YP talk about professionals' preferences for YP's voices to remain silenced in MHS.

Poppy: They don't like it when you're right.

Emily: Professionals don't like it when you come with solutions or potential reason for something because it...

Anita: It's like it takes away their power

Emily: It takes away their power...They want to be the one finding it and telling you your diagnosis...I think the problem lies that people are worried that people with mental health problems are making them up for attention or are making it up for some sort of bizarre reason (GD3; 570- 586)

Through dialogue YP appear increasingly critical of collective experiences of practice that allow professionals to maintain and increase 'power over YP' by not allowing space for YP's voice and creating a 'culture of silence' (Freire, 1973). Pilgrim (2005) discusses two groups of humanity (Professionals and YP) with a 'them and us' split in MHS. Frequent use of 'they' by YP when talking about professionals may indicate YP regard professionals as a separate group, with YP holding on to their own sense of self as an act of resistance towards the problematic nature of positioning YP's voice in MHS. When YP have power through participation, they highlight professionals feeling that their power is taken away thus positioning power as a finite resource. By personalising power differentials as professionals being the powerful face of the system highlights separation of YP as a disempowered group (Sidanius & Pratto, 1999) and professionals as the powerful.

Anita: It's just we are like numbers isn't it, "we [MHS] have children"...it's sad but it's true

Lucy: You did a little tick there, like ticking the box?

Esther: Yeah, [by saying] "we have children and young people shaping our services"... but in reality, they don't have any power
(GD1;79 -86)

Use of the word 'have' struck me, connected to ideas of MHS *having* YP as possessions or commodities and how this can act to dehumanise others (YP and professionals) in a pursuit of '*having*' rather than '*being*' (Freire, 1973, pp.33). This highlights *the oppressed* (YP) being under constant control and objectified through tokenistic engagement to meet the needs and obligations of the institution. These tokenistic attempts, potentially to meet legal and policy drivers (Day, 2008), are highlighted by YP perceiving they hold no power. This is exemplified by Sarah who discusses feeling that she and other YP feel as if they hold no power in relation to 'confidence' when participating in wider levels within MHS.

...Sometimes the young person doesn't feel that power even though they do have power (Sarah, GD2, 401)

Dialogue was used to understand social realities better, such as YP's histories and contexts of distressed being overlooked. Through producing new knowledge about the conditions of power over YP, pejorative power became located in professionals and in MHS structures.

Yeah, the system is designed to trip you up...clearly everything beforehand all of the other stuff is ignored (Helen, GD2, 469-471)

YP also discussed ways in which professionals maintain power over YP in MHS by professionals becoming desensitised to YP distress, losing empathetic connection with YP.

The phrase “I want to die” is a really frightening thing to hear a child say and I think they’ve heard it so many times that it doesn’t mean anything to them anymore (Poppy, GD2, 483-484)

Privileging professional knowledge and becoming desensitised can also be connected to unconscious ways of dealing with anxieties relating to the nature of the work (Menzies, 1960). YP acknowledged that professional practices acting as barriers to YP’s voices being heard and privileged in MHS, were occurring through systemic practices and “learned behaviour” (Helen; GD2, 369). YP started to open up possibilities of pejorative ‘power over YP’ being pervasive (Foucault, 1977) and considered oppression occurring systemically, such as “CAMHS is overstretched” (Esther, GD1, 172). This highlights the impact of the political context, namely austerity (Barr, Kinderman & Whitehead, 2005), in how YP participate in MHS.

A lot of workload...and...financial pressures (Scott, GD1, 49)

Recognising professional’s humanity and the importance of authenticity, YP identified this becoming lost in the system and being a barrier towards YP being treated equally and being heard.

Poppy: Because they [professionals] are people

Hope: Yeah exactly and if you [professionals] just be honest about it. I think that if you are a young person you know immediately if someone is being honest or not and...it’s underestimating that actually that young person will be like yeah it’s ok... but they [YP] will be understanding because they will tell if it’s genuine or not...I guess that’s what gets lost in the system, you lose that face to face (GD2, 229-235)

YP’s dialogue moved towards further action through their observations of professionals’ power over YP being shored up by other systems. This included professionals being seen to be above the law and an absence of accountability or repercussions.

It does come a lot down to power...particularly when they have the legal ability to strip you of most of your rights there's a limit to how much you can do (Poppy, GD2, 289-290).

They get away with saying it and nothing is done about it
(Helen; GD2, 327)

By their voices being excluded, YP experience frustration, helplessness and despair.

Yeah, so what do you do? So, saying your experiences and probably most young people [would]...probably [say]...that happened to me too and what do you do with this and knowing there is no consequence to that. Otherwise what's the point in saying [anything]...they will just get away with it...if you needed a little somewhere you could go with your views to make things better for yourself and obviously with YP that will come after you then maybe...it's worth saying something. But I think at the moment as you said, it's just like they're not listening... they win
(Helen, GD2, 111-117)

"They win" is significant, in positioning professionals as not on the same side of YP and highlights an indictment of professionals doing harm and not working to promote healing. YP also began speaking about a "loss of faith" (Hope; GD2, 177) in professionals and the system, which can be seen as an act of resistance to 'power over YP' in MHS. YP expressed views that the lack of consequences for professionals excluding YP's voice resulted in severe consequences for YP.

Yeah, it's so damaging to feel like you have not been heard for a very long time. I feel like I have too many experiences of this...they [professionals] hadn't done what they could have done...like when I finally got my diagnosis at 17 me and my mum were in like tears ...because it was like oh my gosh this has taken so long [11 years] and we have finally been believed...this could have been prevented...Who does it take to say something for a professional to listen? Like how high

do you have to be for a professional to listen? It makes no sense
(Anita, GD3, 412-440)

Anita talks about not being believed as “damaging”. Anita also speaks of conceptualising her experiences through the medical model, namely psychiatric diagnosis, and many years of her voice being overlooked and ignored. Anita appears to uncritically adopt professionals’ models and theories and highlights the role of YP participating in MHS as ‘patients’ with diagnosis. Diagnosis can be a mechanism of oppression by locating the ‘problems’ in people (Boyle, 2006), increasing stigma and worsening one’s long-term prognosis (Timimi, 2014). It is also noted that medicalising and psychologising mental health, further positions YP as the ‘other’ (Johnstone, 2000). YP indicated another consequence of feeling ignored, was to adapt their experiences to fit with professional ways of knowing in order to become heard and receive support. Anita also raises important questions about whose voice is privileged and how in MHS.

If you have this like higher psychiatrist force there overlooking...everything you do, you don’t feel you can be honest...the problem in participation when people do ask for your views...you are so scared of what to say because there is such strict guidelines and...it just leaves you feeling like you have to be a certain way or actually get nothing and unfortunately that is the case, it’s like so rubbish
(Emily; GD3, 642-647)

Emily talks about how a form of surveillance through the gaze of professionals determines her actions and voice. This suggests that professional models of distress and language may seek to control YP’s voice and promote ‘norms’ of how voices can be heard and what can be said in this space. This includes expectations of being a ‘patient’ with MHS. Emily’s quote illustrates how disciplinary power (Foucault, 1977) in MHS socialises YP into censoring their voice and meaning to that of professionals’ knowledge. Emily also highlights the gap between the invitation for YP to participate and their experience of participating.

Many YP expressed doubting their own meanings of their experiences, possibly due to such oppressive conditions reducing their capacity to act (Moane, 2003). Below Helen talks about being invited to participate but being met with a hierarchy that renders YP as unequal and ineffective in their own lives. This further highlights the question of who do you have to be in order to be heard in MHS?

One of the reasons that YP don't participate with professionals is that the professionals don't treat the young people as equals because they think that they are inexperienced and what they are thinking is wrong...because they are not treating the young people as equals, creates that sort of friction and it will put people off wanting to participate. Why should you participate when you're not going to be treated equally? I think it's always going to be about power and equality (Helen; M2, 311-321)

Disciplinary power maintaining the 'regime of truth' and 'culture of silence' with professionals' knowledge positioned over YP's suggests that YP become silent or use adapted language to conceptualise their knowledge, meaning and experience in MHS. This then becomes a social mediator between professionals and YP in maintaining problematic 'social order' for YP (Martín Baró, 1994). This also highlights another act of resistance against not participating in systems where YP feel rejected and not treated YP as equals in MHS. YP reveal consequences of harm and patterns through 'power over YP', with YP also expressing another consequence of feeling excluded by not wishing their voice to be heard in these oppressive systems.

Although you are removing brainwork from the professional [through participation] they have to figure out what is best for you, and then you're mad and we've come around full circle [*group laughter*] (Poppy; GD2 62-63)

This identifies circularity of interactions maintaining the 'problem' (Palazzoli, Boscolo, Cecchin, Prata, 1980; Cecchin, 1987) of YP's voices being unheard in MHS. To summarise the defined problem in this theme, this circularity is

further hypothesised in figure 3, within the context of societal disempowerment of all YP as an oppressed group. This does not aim to reify complex power dynamics and relationships but illustrates understanding from YP's perspectives in an attempt to highlight YP's definition of the problem (Martín Baró, 1994).

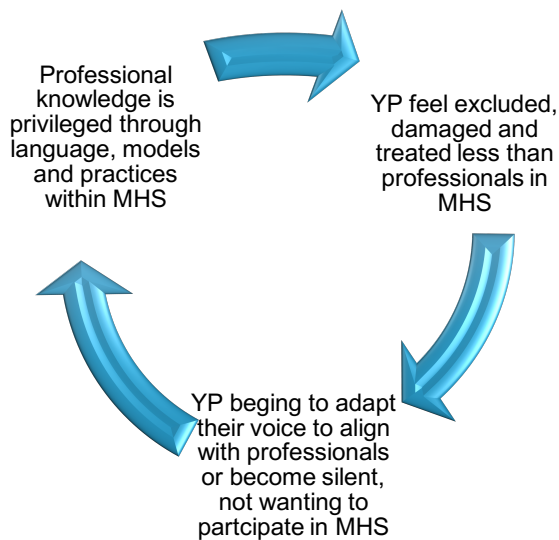


Figure 3. Hypothesised Circularity of 'YP as the Other'

3.3.2. Solidarity

This sub-theme describes acts of resistance towards 'power over YP' through 'solidarity' by recognising resistance against becoming 'othered' on personal and collective levels. Foucault (1977) advocates 'there are no relations of power without resistances' with power being a necessary, productive and positive force (Gaventa, 2003). Freire (1973) emphasises necessity of action to change oppressive conditions towards liberation. Moane (2003) discusses personal strength and collective resistance within 'cycles of liberation'. YP described personal acts of resistance building strength and survival of their experiences of distress and treatment.

Poppy: I lodged a complaint

Helen: Yeah, I did the same (GD2;137)

These acts of resistance standing up to the system, utilise a formal structure permitted by the social control of the system. YP continued to express resistance through holding onto their experiences and meaning despite adversity of power doubting the validity of their voice.

Because I know what is best for me, but you've still got like professionals trying to like brainwash into you (Helen, GD1; 316-317)

Helen demonstrates critical consciousness of professionals exercising 'power over YP' showing further strength in maintaining her own meaning against this oppressive force. Esther also demonstrates personal strength and resistance by validating the believability of her own and others' experiences, thus increasing capacity to act through this strength (Moane, 2003) on individual and collective levels.

That person knows what is going on inside of them...like, we know what we are going through (Esther, GD3, 876-877).

Through recognising their own and others' strength, YP began to discuss 'solidarity' against the constraining 'power over YP' and how other YP, with similar experiences, might resist in explicit and implicit ways. Collective strength with others is noted as the 'interpersonal level' of making connection in cycles of liberation (Moane, 2003). YP discuss forming explicit 'solidarity' in psychiatric inpatient units and the value of sharing voice and experience to support each other. YP thereby highlight possibilities of transformative action towards 'YP as the other' through productive power.

Immense solidarity between inpatients is quite common...The friendship is probably the most important thing about inpatient and you probably do more treating of each other than the staff do...you support each other in ways that you won't let the staff support you (Poppy; GD1, 436-470)

Through positioning herself with other YP and resisting professionals supporting her, Poppy describes acting against dominant discourses (i.e. that

she needs to be treated by professionals as a patient in MHS) that define her alongside other YP. Poppy thereby produces new meanings and narratives of her 'self' and other YP through shaping discourses outside the 'norm', resulting in professionals as somewhat redundant in this setting. Reference to a "community" of YP within MHS (Esther; GD1, 450) further highlights YP's 'collective power' (Martín Baró, 1994). YP talked about shared, collective experiences allowing YP to make sense of the construct 'mental health', so as to include new possibilities outside of professional models and language. This highlights participation as an articulation of voice enabling the development of a shared understanding of mental health difficulties and then playing this forward by sharing understanding.

It stops you feeling...screaming into a void...it stops you feeling like your anger is unfair because you can now be like everyone else and it must be real (Poppy; GD2, 510-512)

Participation within...a group can help me understand mental health more I guess...people can have different views around mental health, it's not necessarily one definitive thing so it ebbs and flows. Hopefully what I have said in the past has helped others and what other people have said has helped me (Jamie; GD3, 142-145)

Jamie's quote suggests the importance of a sense of giving back (Lighfoot & Sloper, 2001) and contributing in the hope of supporting others. He also describes participation as a way to make further meaning of his experiences (Taggart et al., 2013). This also highlights processes of 'conscientização' and 'praxis' (Freire, 1973) towards creating new possibilities of new meanings around mental health experiences and collectively supporting other YP in MHS.

Sometimes I just open my mouth and keep talking...I'm like I didn't even realise that was a thing that I thought and then I'm like but I really did [group laughter] then everyone takes it seriously and I'm like thanks guys (Poppy; GD3, 157-162)

YP also talked about having connection, validation and strength in ‘solidarity’ with other adults such as parents and professionals who were ‘exceptions’ to ‘othering’ YP. This included both mainstream and alternative mental health spaces, like YoungMinds, towards supporting YP’s voices being heard and highlighting the power of collective dialogue. Myself and a consistent YoungMinds staff member, who were part of this dialogue, further witnessed, validated and joined YP’s resistance towards collective action, thickening this ‘solidarity’ in the PAR group. Freire (1998) discussed ‘conscientização’ as a ‘twofold unveiling’ (p.507) where *oppressors* and *the oppressed* collaborate in examining the dynamics of oppression. Through adults allying with YP, they become “committed to eliminating a form of oppression from which they benefit” (Goodman, 2011, p. 157). By utilising opportunities to learn more about other people’s experience of oppression, adults such as mental health professionals, can then act on what they learn (Bishop, 2002) in resisting positioning ‘YP as the other’.

That’s one of the best things about charities like YoungMinds that it lets you build your confidence in a really safe space and you know that if something goes wrong there is no way that the members of staff facilitating are going to let anything, basically, happen to you....there is no way that member of staff is going to just abandon you and that lets you be confident enough to make some mistakes to really take a risk, knowing that then there is someone there who has done this 100 times before will not let anything go that wrong and that’s massive for young people’s confidence (Emily; GD2, 403-410)

Afuape and Hughes (2016) discuss solidarity as central to liberation. These connections and acts highlight ‘solidarity’ as transformational action towards YP’s voice being respected and heard within MHS, through a shared desire and movement towards this change.

3.4. Theme 2 - Hearing YP's Voices

This theme explores ways in which YP talked about how their participation and voice is heard within MHS, being based on 'gender' and 'assumptions'.

3.4.1. Gender

This sub-theme discusses the significance of gender in shaping how YP's voices are heard and participation is shaped in MHS. Boys are less likely to access services than girls (Chandra & Minkovitz, 2007), with around 2% more young females than males accessing MHS (NHS Digital, 2017). In this research, nine of the fourteen co-researchers were female and YoungMinds estimated that 60-70% of YP participating in the organisation are female (personal communication, 2018). Spaces for formal voice to be heard within MHS, such as 'participation groups' were discussed by YP as generally female dominated and one of the few spaces where women may hold more power, constructing new possibilities outside of wider dominant societal structures (i.e. patriarchal structures)

Emily: Within mental health and care, women are like the majority and that's kind of like one of the only areas where we are

Anita: Like an alternative reality

Poppy: In that sense, it's prestigious

[group laughter]

Anita: But it's strange the way it works...

Scott: If you tried to do this thing with anything other than mental health you'd be like why didn't we get more women (GD1; 546- 555).

Through YP connecting the wider socio-political context (inequality of women), participating in MHS is highlighted as a potential space for reversal of mainstream power dynamics for females. By situating themselves in their

context, action of challenging inequality of the wider patriarchy through this space can be seen in developing alternative discourse. This highlights transformational change towards subverting wider historical, cultural and societal structures through a different positioning of female voice through these spaces in MHS. YP highlighted further gender inequalities through discussing stereotyped gender norms and roles as pervasive in society and through psychiatric diagnosis positioning males and females in MHS in certain ways.

Neurological conditions tend to be associated with men whereas emotional difficulties with women (Anita, GD1, 599)

These gender stereotypes position females as being more “emotional” (Ella; GD1, 654) and males being “strong” (Poppy; GD1, 602) when respectively internalising and externalising their voice. This also highlights the gendered nature of psychiatric diagnoses (Rosenfield, 1999). Participation spaces were discussed as reflecting and reinforcing these gender norms, in male voices being heard through these stereotypes.

Participation...it’s literally always YP sat in a circle and it’s like generally and I’m not just saying it because it’s happening now, the girls talk loads (Scott; GD1, 618-620).

Elements of the dominant western model available to males of ‘hegemonic masculinity’²³ (Courtney, 2000) were posed as problematic through YP’s discussion as a societal barrier to young male voices being heard and equal in MHS. Timimi (2011) talks about this as the ‘boy-code’ model in

²³ Hegemonic ideals, such as stoicism and strength, position men as more powerful and less vulnerable than women to reinforce societal beliefs that men are more powerful, efficient and less vulnerable than women. This therefore positions help-seeking and caring for one’s health as becoming ‘feminine’ (Courtenay, 2000).

emphasising dominant Western cultural beliefs through socialisation and acts. These include the promotion of physical strength and aggression and the discouragement of displays of affection and distress.

Anita: It's still very much ingrained in our society.

Sarah: Yeah, it's like to participate they would get labelled like you're doing this because you're doing that and there's that whole stigma.

Anita: Also, maybe there's that idea of lack of awareness like men aren't taught to be introspective...not taught to help themselves...like women are always taught to feel, get in touch with yourself and how you feel (GD1; 500-507)

YP acknowledged homogeneity of gender and discussed the importance of not assuming all males want to participate in certain ways. Towards equality in representation of voice (Day, 2008) in MHS, YP discussed the need to have more space to create different possibilities for male voice and began to act towards this change. Ella suggested that a starting point would be to change conversations to break down these structural barriers.

So, the way I see men's mental health conversations that you are not necessarily going to change the structural issues of women being emotional and men being physical but you can get men involved in that by changing the ways that you are having conversations...if you talk about sports psychology or something boys are more likely to join in the conversation. It's like a bit more in their territory (Ella, GD1, 654-655)

Esther also talks about ways she witnessed engagement encouraging more male voices in MHS.

My CAMHS...brought a footballer in last week and I was just thinking where did all these boys like come from...all these boys that I've never seen in any participation group suddenly all these boys pop up (Esther; GD1, 273- 276)

Increased visibility and contact is seen to decrease stigma (Ahemdani, 2011). Scott who identifies as male, talked about men being more likely to participate within MHS if this was the case.

If more guys were doing it, more guys would do it (Scott; GD1, 528)

Gender was also discussed relative to professionals making assumptions about the nature of YP's experiences and meaning.

I have ADHD and it took me 17 years to get my diagnosis because I was always compared to this little boy who runs around and hits things and I'm not like that (Anita; GD1, 581-583)

Anita's voice links to discourse defining 'reality' as existing by being constructed as offering constraints and regulations on the possibilities about what fits with what can and cannot be possible about her experiences, within medical frameworks (Foucault, 1988). Therefore, this discourse shapes YP's experiences and voice being ignored outside of professionals' 'norms' associated with diagnosis, in which YP's voice becomes unheard by the hierarchical relationship of professionals' knowledge judging versions of the 'truth'.

3.4.2. Assumptions

This sub-theme captures assumptions connected with 'YP as the other' and seeing YP as a 'whole'. This theme is discussed in relation to assumptions of homogeneity operating in how YP's voice is heard in MHS.

I guess GRRACCEESS is the answer (Esther, GD1, 262)

Esther's response to me asking about barriers to YP's voices in MHS highlights the significance of intersectionality in these assumptions.

At the end of the day it comes down to power because as a young person with a mental health problem, like a young person full stop is not going to be believed over an adult but when you have got a mental

health problem and they are a professional looking after you
(Poppy; GD2, 278-280).

In this extract, linked to 'YP as the other', Poppy expressed awareness about not being taken seriously and "believed" due to both age and mental health status, highlighting these intersects as significant in how voice is heard. YP talked about discrimination they faced in mental MHS through professionals' assumptions based on gender, ethnicity, class, culture and this shaping how they were perceived and how their voices were heard.

The thing is assumptions in care...when you're trying to get your point across and when people have preconceived ideas about what your family dynamic looks like it can be really difficult. Because I'm like an Indian Muslim girl, a lot of the time it was just assumed the reason that I was so anxious was because my parents were putting so much pressure on me and they absolutely don't...I guess because of the family dynamic that my Dad is this scary man like constantly trying to get me married off [group laughter] which is like nonsense. So, like when you have people with those pre-existing assumptions it's really difficult to...get across what's actually going on (Anita; GD2, 718-728)

Anita highlights her voice being excluded, and discriminated against, over assumptions being made about her family background, ethnicity and culture. Stereotyping is discussed as a further way to exert control, dominance and justify the status quo (Fiske, 2000). Medical models are also discussed to highlight invisible power operating in maintaining a 'culture of silence' (Freire, 1973) and YP's voices being constructed as unheard by the MHS 'acts of governing' (Foucault, 1977).

If you are not presenting [in] a certain way then they just don't take you seriously (Emily; GD3, 604-605)

When YP's experiences are not convergent with professionals' norms and expectations, such as "atypical presentations" (Poppy; GD1, 586), their needs and voice become overlooked. It is suggested that professional practices

produce power over YP's voice, meanings and personhood which become distorted through socially constructed assumptions and discourse (Foucault 1977). By locating YP within their socio-cultural contexts, YP explored being socialised into feeling disempowered or "not...good enough" (Hope; GD2, 57). Through social order YP become conditioned to their voices being unheard before entering MHS.

The context of where YP are coming from, so there might be YP coming from cultures or even specific families where challenging authority isn't necessarily welcomed...that can make it difficult for people to then go and talk about participation in settings and to speak their mind as much as they otherwise would because if you haven't been listened to before...then there's no reason for you to expect it to be now (Poppy; GD2, 43-52)

Expectations for YP to share voice and participate in MHS must be questioned for those already marginalised and socialised into roles of not being heard. This may impact on YP feeling as if sharing their voice is not possible, thus creating a barrier to YP's voices being heard. YP also discussed occasions when they were not acting in the stereotypical role of the 'patient' in MHS and having difficulties being heard in MHS.

It's just really difficult to get across how you are feeling when you sound as if you are fine...it's not a conscious thing but I am always making an effort to be like my best self and even when I am like at my very lowest I will still be sounding like I am my best self. I get told so often by professionals, you sound so articulate you sound like you really know yourself, you're so self-aware. Yeah, I'm self-aware but I'm also suicidal (Anita; GD1, 397-401)

YP also discussed the role of the 'patient' in determining how seriously their voices are heard in MHS. This includes YP considering possibilities of their voice being excluded in relation to the severity of their role as the 'patient', even in spaces dedicated for participation through this role.

There's definitely a worry like with YoungMinds, if I had a crisis would I be told I couldn't volunteer anymore? (Poppy; GD1, 867-868)

YP's voice is considered in psychiatric inpatient settings, Emily highlights added complexity in this space which typically excludes YP from society.

I think that the state of someone's mental health can really effect the validity of what they are feeding back because...if [professionals say] we are going to listen to you, what do you want to say and if...[YP] are really not in a good place, their feedback will be biased in the sense that they some of the time don't know what is best for them...I have been in that position where I have been given the opportunity to say what I think is best for me and I've said the complete opposite because I didn't know...you'd need that medium to know whether or not someone does know what is best for them and can effectively feedback for the greater...cause (Emily, GD1, 307-314)

Emily shows strength in talking about providing feedback for the "greater cause" of others and highlights the complexity of sharing voice at these times of distress. Pervasive 'power over YP' through institutional practices can produce self-discipline and self-doubt (Foucault, 1977), including YP's ability to know what they want to say to professionals. Emily acknowledges believability issues when YP are given voice at these times of distress (such a suicidality) however she also recognises the importance of professional support in keeping her and other YP safe.

3.5. Theme 3 - Safe Structures

This theme explored participation structures which YP discussed should be enabling, safe, meaningful and ethical in MHS. During the analysis phase, YP talked about a 'checklist' towards 'doing participation right'. By YP providing clarity for professionals and the system about what must be done to enable safe, meaningful and ethical participation represents action. This challenges existing structures towards safeguarding against further harm in MHS and opening new possibilities for themselves and others.

3.5.1. Professional Responsibility

'Professional responsibility' as a sub-theme explored discussions around a need for professionals to take responsibility for YP's voice being heard, learned from and respected. In exploring ways YP have been treated and positioned, YP saw professionals taking responsibility within MHS as fundamental towards a transformative change in MHS. YP talk about difficult feelings, including anger about professionals' mistakes of seeing 'YP as the other' by not respecting and hearing YP.

Experiences...with such extreme reactions from mental health professionals like they come out with like appalling things and they're allowed...nothing is done about it (Helen; GD2, 83)

Acting against the defined problematic nature of YP's voice within MHS, YP highlighted professionals as pertinent to any transformational change.

If [professionals are] not really willing to hear that anger, you can't improve your service (Hope; GD2, 220)

This anger described could be an expression of injustice and distress in the face of oppression. Holding onto this anger can also be viewed as an act of resistance towards retaining a sense of power and control in the face of oppression (Afuape, 2011). Anger is noted as relational and this highlights YP's dissatisfactory and unsafe relationships with MHS. Therefore professionals (the *oppressors*) validating these feelings in MHS is positioned as imperative in order to truly move forward and prevent oppressive experiences from happening and to improve MHS. Through dialogue, further action was considered towards professionals' mistakes.

Lucy: I was really struck by someone saying what does it take [to be listened to by professionals in MHS]? The question to the whole group is - what is it going to take?

Emily: Listen to us, please...by dismissing people...saying no and having that sort of confrontation makes the problem worse...
(GD3, 630-637)

My open question which included inviting action from within YP towards solving the problem of YP's voice being ignored by professionals, may have felt wrong to Emily. Here she pleads for professionals to listen to YP in changing the structures and discourse silencing YP's voice in MHS. Through this communicative act Emily demonstrates resistance against problematic ways of YP being dismissed in MHS. Towards this change, YP talked about professionals taking ownership of previous mistakes including apologising and being willing to learn from YP.

Helen: It has to be a meaningful apology it can't be like we're sorry we upset you our intentions were good

Hope: Otherwise it's going to go into the black hole with all the other...
(GD2; 155-158)

YP's voice in the above extract highlights potential for meaningful processes of 'rupture-repair' (Bordin, 1979). This is discussed in the context of professionals acknowledging their oppressive actions towards YP and communicating their responsibility to YP. YP considered this as an essential element of resisting oppressive practices and professionals' 'power over YP' with possibilities for different meaning-making for MHS staff.

For professionals to work effectively you need a working relationship, it needs to exist and when they make a mistake it damages that and the only way to really repair it is to admit that they have done something wrong because that isn't like diminishing them, it isn't diminishing their knowledge, it's them showing that they are constantly increasing it which means more than just like oh no I'm infallible and I'm always right because the YP does know (Poppy; GD2, 197-202)

Linked to the sub-theme 'solidarity' with adults, YP began to demonstrate further action through highlighting the importance of professionals challenging each other. Professionals adopting non-neutral positions alongside YP and recognising their responsibility to use the power could enable YP's voice to be heard and taken seriously in MHS. This is also highlighted in alternative mental health spaces, such as YoungMinds.

Sometimes another young person saying you are not listening is not enough. Sometimes you need a professional or a member of staff or a charity like YoungMinds to be like hey you can't talk to them like that (Poppy; GD2, 349-353)

YP defined a barrier of meaningful participation with YP's voices being tokenistic in MHS at times. Sarah talks her experience of formal policy and procedures to embed professional responsibility and accountability in positioning YP's participation in meaningful, safe and ethical ways.

[YP's Participation Organisation] actually came up with agreements where any visitors or adults had to sign...and if they didn't agree to it then they just wouldn't be accepted because obviously one of the things at [YP's Participation Organisation] is...young person holistic, it's all about the young person and now it's changed because we put something in place...actually it works really, really well now (Sarah; GD1, 188-187)

Considering attachment theory (Bowlby 1969; Ainsworth & Bell, 1973) which describes the enduring emotional bond between people (Bowlby, 1969), driven for the need of belonging and the motivation to seek proximity to attachment figures in the time of need. YP suggest that 'professional responsibility' through a 'secure base' (i.e. professionals being sensitive and responsive to YP's needs and being a source of safety for YP) would strengthen attachment towards both YP and professionals in YP sharing voice and participation within MHS. YP's action towards change in 'professional responsibility' resembles a form of liberation practice in working 'alongside' rather than 'for' YP. As communities change in this way, this presents

opportunities for solidarity and collective action with professionals and YP in MHS.

3.5.2. Practical Aspects

This sub-theme was named 'practical aspects' to capture the structural practicalities around enabling and encouraging YP's participation at different levels throughout MHS. Naming this sub-theme can be seen as a form of resistance by YP towards acting against YP's voices not being heard in MHS. This act moves towards YP providing safe structures for themselves and others to participate in MHS. 'Practical aspects' towards meaningful participation reflect safe spaces with flexibility (Coates & Howe, 2014) and "YP friendly" (Scott; GD1, 889) language (Stickley, 2006). This highlights flexibility in allowing new and different possibilities towards change.

Even just knowing...there is flexibility makes you feel...you are more listened to because you know they are thinking about exactly what it is or...about the way you might feel about a process in itself is more comforting than just thinking this is the way it is and if that doesn't work for me then that doesn't work for me (Hope; GD2, 67-72)

YP also highlighted the importance of services sharing best practice and contributions, such as receiving remuneration (Kirby, 2004) and "ability to pay travel costs" (Poppy; GD1, 893). YP also highlighted the importance giving consideration of YP's social locations and commitments (Coates & Howe, 2016) when determining spaces for wider participation towards enabling accessible ways to participate in MHS.

Time people have, like people are busy with school and stuff, like I know the NHS...they are always setting dates at like two in the afternoon or a weekday and it's like no wonder no-one is participating...everyone is at school, it's just really dumb. And like the time young people give up when busy with exams and school and uni they don't have the time to commit and because they're not getting paid (Scott; GD1, 882-885)

3.5.3. Staff Attributes

The sub-theme of 'staff attributes' describes staff skills and competence in enabling successful facilitation towards sustaining YP's voices being heard in MHS).

It was just such a positive environment and they were all so committed to listening to us and respecting us and properly engaging with what we were trying to do with them that it did make me feel a lot better about what I had done in the past and it made me feel like that is something that I want to continue doing (Poppy; GD3, 313-316)

Staff attributes included staff qualities and skills such as; honesty, humour, encouragement, compassion and kindness (Day, 2008). This also included staff demonstrating motivation and willingness to learn from YP beyond their knowledge, highlighting the importance of YP as 'the educators' (Fallon et al., 2012).

They [staff] really did want to listen to us and to hear what we wanted to say... they wanted to then take that practice and put it into what they did... they were really engaging...they really wanted to get involved...it was really nice...it...let me feel like I'm not in the wrong place (Ester, GD3, 290-300).

Ester further highlights that these qualities from staff members provided her with a sense of connection and feeling as her voice was respected and integral to professionals practice and development (Day, 2009). This also empathised the importance of YP and professionals collectively working together (Afuape, 2011). YP reflected the set-up of this PAR group, which was constructed collectively and collaboratively with professionals, supported their voices to be heard with this research process creating 'safe structures' towards opening new possibilities towards action.

Anita: I think the openness really helped in getting the most out of everyone 😊

Poppy: ...I think the space feeling equal made what was said more honest...Yes Anita! (Anita, Poppy; SLD)

Staff competence and skill is discussed to support YP sense of safety and trust, towards enabling YP voice being heard in meaningful ways in MHS.

3.6. Theme 4: Participation as Fundamental to Wellbeing

This theme describes participation as central to wellbeing and presenting endless benefits when positioned in meaningful, ethical and safe ways. Participation was described as bringing bi-lateral benefits for both YP's mental health and recovery and MHS.

Actually, participation is kind of the golden goose...because it just keeps giving, giving and giving (Poppy; GD2, 379).

3.6.1. Dehumanised to Humanised

This sub-theme captures the transformational process YP discussed of feeling 'dehumanised to humanised' through participation and ways YP have acted and changed as a result of their voice being heard. YP describe being treated as inferior as the 'other' in MHS and chose this language for this sub-theme, to describe the process of participation as 'transformative action' for both YP and professionals. Freire (1973) theorises dehumanisation, as a result of oppression, distorting the human condition and proposes critical reflection and corresponding action to liberate. This consciousness through dialogue transforms "semi-humans" (Freire, 1973, p.77) into human beings capable of transforming limiting situations. YP discuss this process as having meaningful opportunities to share voice with others and participate in their own and other YP's care and MHS. Emily discusses feeling behind her peers and sees participation as a transformative tool, empowering her with opportunity for new narratives and experiences beyond mental health difficulties.

If you come out of hospital settings or even just a long period of illness you are not at the same level as your peers in competency in a variety of things whether it's social skills, academically or...other activities...so

being in a situation where you are the expert and you are competent and you are not behind because of your problems is really valuable and it gives you a chance to be more than just your experience (Emily; GD3, 350-355)

‘Defetishisation’ (Marx, 1981), the process of humanising people by increasing visibility of one’s strengths and resources, is exemplified below through reframing mental health experiences and creating new possibilities.

Allowing people with mental health problems to not only get back into society but to...sort of excel perhaps...it [participation] can give you something like special and important but also something that is objectively impressive, so rather than mental health problems being a weakness they can be a strength and be used in a positive way (Poppy; GD2, 106-110).

Participation is seen as a transformative tool towards change by creating a new context and narratives for YP to connect with and uncover their strengths and possibilities. Participation was also discussed as raising critical consciousness and increasing possibilities through opportunities of sharing voice. In this process, YP discussed discovering things about themselves they were unable to express. This process may be an indirect way to reach part of their voice and selves that may have been difficult to reach or consider before.

Poppy: You learn more of things about yourself like you never... you know before you’re kinda surprised with just how wise, not wise, how articulate you are.

Lucy: So, finding out about things that you knew but you didn’t know about yourself?

Poppy: Yeah, like it was hidden (GD1;11-16)

Poppy exemplifies how participating and sharing voice enabled her to view herself in unexpected ways, which highlighted new possibilities about herself and her strengths. The recognition of personhood is discussed as raising

critical consciousness in staff. YP talked of professionals' skill improving by seeing YP beyond the 'other', rather than positioning YP as 'patients' in MHS, highlighting different possibilities through participation.

It makes for better staff...because particularly staff involved in user participation it lets them see the young people as not just a problem (Sarah; GD1, 151-152)

Through this change, services were also discussed as being more person-centred and tailored to YP's individual needs thus opening space for YP's voice to be heard in MHS.

Services would not work if there was no input from the people that they are serving because otherwise it would just be a textbook, generic form of how you deliver help or like deliver services and having input from young people keeps everything kind of patient and person centred (Emily; GD3, 362-367)

Participation was discussed within the group as having numerous benefits towards mental health (Repper et al., 2005) including being perceived beyond mental health status. Through this process of discussed empowerment, YP also located transformative change in their recovery and mental health.

I think it can be quite...empowering when you are accessing a service...to get help and they want your view and...it can kind of make you feel that you have more purpose rather than being told just what to do and yeah it can...give you that purpose of what I say is important and that can go on to benefit your mental health so it's kind of a win-win situation (Emily; GD3, 134-138).

YP's dialogue revealed that sharing voice at all levels benefits YP and their mental health by facilitating positive outlooks towards their sense of self, others and the future. Tangible outcomes were discussed to include making YP feel "capable and competent" (Emily; GD3, 349), supporting YP to gain "skills and experience" and participation being "good for the CV and getting

jobs in the future” (Scott; GD1, 24). These discussions highlighted increased power across several domains which can be linked the technique of ‘power mapping’ (Hagan & Smail, 1997, illustrated in Figure 4). ‘Power mapping’ can be used to make sense of an individual’s distress and wellbeing by relating experiences to negative and positive proximal sources of power (Hagan & Smail, 1997). Proximal sources of power are grouped in domains for; material resources, personal resources, social life and home and family life. Within this, domains of friendship, relations, associations, confidence, understanding of the past, leisure and intelligence were discussed by YP as increasing. YP validated that an increase in proximal power can positively impact on wellbeing (Smail and Hagan, 1997).

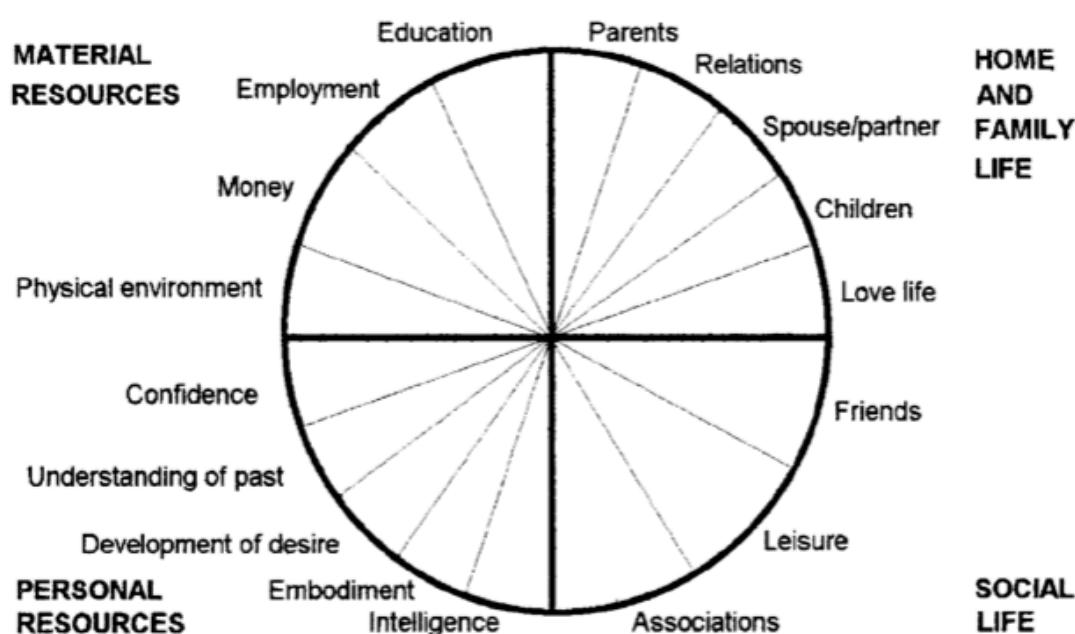


Figure 4. Terrain of Proximal Powers and Resources (Smail & Hagan, 1997)

3.6.2. Preventing Harm

This sub-theme explores the impact of meaningful participation in preventing harm. This is discussed in relation to the damaging effects of YP not being able to participate and YP’s voice not being heard. Many YP spoke of how earlier participation could potentially have prevented difficult experiences from occurring over many years of their lives including experiences of distress and

a “damaging” (Anita; GD3, 412) impact of not being heard and taken seriously in MHS.

Poppy: nobody listened to them [Poppy’s partner] but also nobody listened to me...and it had a huge knock-on effect for me and also, it’s six years of your lives and of your adolescence where nobody cares and things could have been done that could have changed that so much earlier

Lucy: And like you were saying, really damaging these experiences...

Anita: Absolutely, it is so preventable that’s the thing and the thing that makes it preventable is your experience. Your experience counts for something. It should count for something (GD3; 500- 513)

In this extract, Poppy and Anita talk of their voices not being heard by professionals resulting in long periods of missed opportunities to hear their others voices, understand their experiences from their perspective towards supporting them in helpful ways. This highlights the oppression YP face in MHS and the harm that can be caused by not listening, respecting and including YP voice in MHS. Linked to ‘assumptions’, Anita reinforces YP’s not being heard causing harm.

It’s really hard especially if you have a certain idea about what someone looks like...it’s putting you at harm when someone is seen as sort of beyond kind of questioning (Anita; GD1, 757-759)

Through communicative action YP highlight mechanisms of control in the system, including a lack of consequences, as being deeply problematic for them and other YP. YP uncovering and defining this problem, highlights a new and alternative ‘truth’ about MHS and a desire and movement towards change to transform MHS to prevent harm by active YP participation. Benefits of early intervention and prevention is highlighted suggested through YP’s experiences and hypotheses about if they were listened to in MHS in the past.

4. FURTHER DISCUSSION, EVALUATION AND IMPLICATIONS

This chapter builds upon analysis and discussion in the previous chapter through further reflections which evaluate this research and consider implications with recommendations. I also discuss reflections in relation to the four main themes selected as relevant to participation in MHS ('Power over YP', 'Hearing YP's Voice', 'Safe Structures' and 'Participation as Fundamental to Wellbeing').

4.1. Revisiting the Research Aims

This PAR research aimed to actively establish and investigate YP's experiences of participation within MHS with YP as 'co-researchers'. The specific questions that initially guided this research included:

- What benefits do YP identify by being 'service-user participants'?
- What encourages increased YP participation practices in MHS?
- What barriers do YP identify in their role as 'service-user participants'?

To reflect the dynamic nature of PAR, research questions were adapted to include YP's additional research questions including:

- How do the PAR group understand accessibility and representation of YP's participation in MHS towards generating action?

Other questions YP raised which could not be fully explored in this research may lay the foundations for possible future dialogue and social action for YP to continue this project beyond this thesis (see section 4.4.6).

4.2. Further Discussion of Themes

4.2.1. 'Power Over YP'

This theme highlights significant barriers to YP's voice and participation within MHS by highlighting YP being objectified as the 'other'. Figure 3 (see 3.3.1) illustrates the harmful and problematic circularity YP defined as preventing and disempowering them from participating freely in MHS, through systemic practice. In collectively naming this pejorative power within MHS alongside YP, I felt it important not to dilute or sanitise YP's experiences and stay true to YP's voice. A YP's PAR project (Taggart, 2013) also highlighted oppressive systemic practices in MHS and in producing stigma. Some of these practices currently appear 'normed' (e.g. medicalising distress) by professionals with MHS, raising significant professional and ethical issues in our duty of care to safeguard against such harm.

Professional conceptualisations of distress, including psychiatric diagnosis is a challenging issue. Many YP accepted diagnosis as validating their experiences of distress. Watts (2018) discusses diagnosis as both structurally violent and a life-saving tool for many. YP highlighted the set-up of current MHS includes a hierarchy that renders YP as unequal and ineffective in their own lives which restricts how their voice is heard. Therefore, adopting tentative relationships to professional models when considering YP's voice as valid in assessment, formulation, intervention and evaluation of distress could contribute to minimising 'power over YP' within existing practice. This is noted to be challenging within the wider contexts of NICE guidelines and service models. However it emphasises the importance of connecting with YP as human beings on a human level. Tentative relationships would mean considering psychological and professional models of distress as tools (Patel, 2011) within the context of humanity, towards supporting YP as human beings. Opportunity for this exists through current principles in professional models that promote collaboration and YP voice (including but not limited to; narrative therapy (White & Espton, 1990) and open-dialogue (Olsen & Seikkula, 1995)) towards placing YP at the centre of MHS. Respecting YP is a professional expectation and raises questions about what would actually be

lost if hearing YP's voice was truly implemented in MHS. This also strengthens arguments for increased alternative psychological approaches such as liberation and community psychology practice throughout YP's MHS.

YP's analysis locating professionals as the face of power in 'othering' YP, was coded by the group as 'professionals vs YP'. Further, within MHS, Johnstone (2000) discusses 'them and us' splits in MHS, where most power is granted to those professionals who comply and are therefore potentially invested in sustaining this dynamic. This highlights the need for all staff, particularly those in leadership positions (such as in management and commissioning) to attach increased importance to YP's meaningful participation in MHS. Reflexivity throughout this research towards change underscores the importance of continuous reflective practice for professionals in MHS on individual and groups levels when working alongside YP. Further PAR with professionals could support identifying further possibilities and sustaining change towards addressing findings of professional practices being a barrier to YP's participation within MHS. The finding of 'solidarity' could also support action towards overcoming barriers in MHS with staff acting alongside YP.

Increased availability of open and 'free' space for participation both within and outside MHS (e.g. peer support, therapeutic groups and participation forums) may also strengthen this 'solidarity'. Solidarity is linked to compassion (Watts, 2014) and humanity which YP highlighted as important to facilitate participation in MHS. Providing opportunities for YP to validate their experiences with limited professional gaze and judgement supports staff visibly working alongside YP towards their voice being truly heard in MHS. Collective action has the power to galvanise and boost social transformation, thereby acting against oppressive structures in MHS where YP discuss feeling 'othered'. In MHS increased 'solidarity' with YP is noted to also promote participation, reflection and provide foundations for further action (Afuape, 2011).

Approaches to 'solidarity' also requires us to act outside of the therapy room by attending to wider social circumstances (McCarthy, 2001). Sickley (2006) suggests any significant change by people who use MHS must be outside the

control of the psychiatric system. In hearing YP express how they felt treated in system, I felt angered and saw strength in the creative and collective acts YP discussed in navigating the oppressive system. Hearing YP describe their use of silence and adapting their ways of being I also felt saddened by the impact of this on limiting YP voice and experiences. I questioned how powerless YP felt compared to adults in MHS where 'service-user' movements historically aimed to completely change the system through radical action. I wondered how possible this felt for YP, highlighting a significant gap in radical social transformation towards this issue, particularly when considering the overwhelming statistics relating to 75% of mental health issues starting before the age of 24 years (Kessler et al., 2005).

I was struck by the lack of consequences YP discussed for professionals 'othering' YP and extent to which YP believed the legal system supported this, such as professionals' use of the Mental Health Act (2007). YP talked of professionals' legal power but not of their own, contained in extensive legislation confirming YP's human and legal rights of being heard (discussed in 1.6.1). Maintaining this imbalance raises questions when an increased awareness for YP of their legal rights may support YP's voice being heard and taken seriously both inside and outside MHS. This highlights possibilities towards YP's power and further action in YP's participation in MHS and this research offers this as a potential action YP could take.

4.2.2. 'Hearing YP's Voice'

This theme speaks to YP's own research question about accessibility and representation of YP's participation and how YP voice is heard and shaped in MHS. Gender was discussed as a significant barrier to how YP's voice is heard in MHS with males less likely to participate in what is seen as a female dominated space. Gender is particularly complex in current contexts of surging gender identity referrals in YP (Carmichael, 2017) and in considering gender as binary. While acknowledging wider structural issues around access and referrals, engaging more males in wider level participation was discussed as an action towards solving this problem. Importantly, this finding and noted action from YP, moves towards the potential to support increased male voice

in MHS. This is considered important in the context of high male suicide rates (a main cause of death in men under 45 years (Samaritans, 2016)). Due to the generalisability of this research (i.e. this research does not make generalised claims), this could be investigated further through future research.

The complexity of intersectionality and a plurality of assumptions operating at different levels highlighted how YP's personhood and individual voice and is often not seen or heard. YP highlighted that additional consideration and care is required to safeguard against unwarranted assumptions which create YP voice and participation being heard in problematic ways. This research highlights how pervasive power existing in 'assumptions' prevents YP authentically participating, particularly on individual levels in MHS. Therefore, this research challenges assumptions in policy and models of participation that a higher and wider level of participation is preferred. Indeed, the numerous interchangeable terms associated with 'participation' reflect language shaping the marketisation and fragmentation of YP's voice in MHS, reinforcing ideas of YP as commodities, serving the needs of services and staff through wider participation. This maintains the defined problem of 'YP as the other' in MHS.

4.2.3. 'Safe Structures'

This sub-theme highlights barriers to participation when systems and structures do not feel safe, trusted and accessible. Action towards enabling, safe, meaningful and ethical participation in MHS could increase meaningful participation practice at all levels. YP discussed professional responsibility towards enabling 'safe structures' through 'practical aspects' and 'staff attributes' to build contexts of safety and trust. This highlights training opportunities for staff working in YP MHS, ideally with YP as the 'educators' (Fallon et al., 2012).

YP recommend further action towards new agreements, policy and procedures to safeguard their voices being heard at all levels in MHS. Extensive policy and regulations are noted as barriers to participation due to inflexibility in meeting YP's complex and individual needs (Idenfors et al., 2015; Pelto-Piri et al., 2013; Tam- Seto & Versnel, 2015). New policy must

therefore take account of other policies towards placing YP in the centre, and ideally be written and disseminated by YP as 'educators' towards implementation and promoting urgency of YP's voices being safely heard in MHS. Limited implementation of this existing policy highlights the need for further social transformation (Romero Castro, 2016), which this project aims to sustain and build upon.

4.2.4. 'Participation as Fundamental to Wellbeing'

YP's dialogue in this research positioned participation as central to wellbeing, going beyond the initial question of the benefits of participation. By positioning participation as fundamental in MHS, YP describe processes of empowerment by considering participation as a transformative tool. YP discussed how their voice being heard and acted upon facilitated change benefitting their levels of distress and outlook within oppressive social, cultural and mental health contexts. Chinman & Linney (1998) note that YP feeling 'empowered' moves towards preventing emotional distress and increasing YP's quality of life both in the short and long term.

'Preventing Harm' is a significant issue underlined in all professional code of ethics (e.g. Royal College of Psychiatry, 2014; BPS, 2018). However, YP conveyed throughout that not being taken seriously or listened to may have resulted in them not receiving the most appropriate support and feeling 'damaged' by MHS. 75% of YP lack appropriate intervention at sufficiently early stages (Green et al., 2005) and it takes on average 10 years for YP to receive appropriate treatment (Centre of Mental Health, 2016). Policy (DoH, 2015a; 2015b) placing YP and families at the centre of MHS is seen to be integral in transforming support for YP in MHS. Despite this a recent damning report by the Education and Health and Social Care Committee (House of Commons, 2018) describes government policy on mental health as failing a generation, increasing the urgency for YP's voices to be meaningfully heard in MHS.

This research finds participation as a key action towards transforming YP's voice and experiences in MHS and considers participation as prevention and early intervention. In considering the generalisability of this study, further

exploration of participation in relation to early intervention with effective service provision for YP could significantly impact on improving YP's mental health (MHTF, 2015).

4.3. Reflection, Dialogue and Action

Aligned with liberation approaches to wellbeing, Freire (1973) discusses that emancipation and empowerment cannot be given. Aims of emancipation and empowerment in PAR remain debated. I chose not to make this an explicit research aim as I felt concerned about the process of 'doing to' and maintaining a researcher-participant dynamic, contrary to the PAR project ethos. Castro Romero and Afuape (2016) consider; "liberation, resulting from the transformative process of *conscientização*, is dialectical, dialogical, relational and co-created; therefore no one person does the liberating" (pp.165). This highlights the interconnected role MHS and YP have in participating in transforming YP's voice in MHS.

'Action' is debated among PAR theorists however it is noted that PAR should be action-oriented to avoid becoming tokenistic (Beresford, 2002). PAR is advocated as a form of action through the process of changing power dynamics to explore and make meaning towards creating knowledge (Atweh, Kemmis & Weeks, 2002). Other theorists suggest that collective action develops throughout the process with explicit planning (Greenwood & Lewin, 1998). Collective action and individual acts emerged through reflection, raising awareness and uncovering inequalities. Through dialogue by deconstructing and constructing new narratives about YP and MHS also acted towards defined problem by YP in MHS, and further opened new possibilities for action.

Liberation dialogue developed through YP discussing and sharing experiences of inequality due to mental health, gender, culture, ethnicity and age. Raising awareness of social inequalities was a form of *conscientização* for both YP and myself, towards investigating and sharing our realities and then acting towards transforming these. YP demonstrated action through their

collective voice in constructing individual and mutual understandings of their positions and power within MHS, making action feel more real and possible on different levels. This liberating process evolved organically within the group through continued reflexivity, dialogue and actions through an 'unforced consensus' (Kemmis, 2011). I believe that through positions of transparency, and not maintaining neutrality when YP expressed dissatisfaction with oppressive systems and practices, I moved towards demonstrating 'accompaniment' (Watkins, 2015) in witnessing, listening and supporting YP towards 'solidarity'. I witnessed solidarity when YP constructed new knowledge and meaning-making together in the group through verbal and non-verbal connections of validation relating to and understanding their voice on collective and individual levels. I also witnessed displays of kindness, compassion and humour among YP when facilitating this solidarity. Another explicit personal act included one co-researcher studying psychology at university applying for and being granted research funding to investigate participation in inpatient settings during the period of this project.

This project was also transformative and emancipatory for me. I noticed being increasingly aware of the importance of YP's voice and being driven to make change, more than usual, with small acts of challenging other professionals to larger acts of developing organisation-wide policy, training and strategy for YP participation in statutory MHS across a national organisation when on placement, towards creating new possibilities about YP's voice in MHS. Throughout my career, at times I have felt alone when pushing for YP's participation, however YP's voice and action did and will sustain me in this cause, thus highlighting bi-directional learning and action throughout this project. Positioning and valuing YP as equally knowledgeable, emphasised the importance of critical thinking and highlighted the limitations of my and professional knowledge. Templar (2017) reflects that researchers should hope to be taught by co-researchers as much as they may teach co-researchers, which I felt was most definitely the case.

4.4. Reflexivity

Daralaston-Jones (2007) highlights that considering and theorising the influences on research process is vital to ensure ethical research practice. Therefore, I discuss reflexivity through epistemological, critical language awareness (Willig, 2008), personal and relational reflexivity in evaluating the processes and outcomes of this research.

4.4.1. Epistemological

Epistemological reflexivity evaluates the qualitative research process through considering the quality of this research and how knowledge has been generated. The critical realist approach within a social constructionist framework is advocated as necessary by many (Parker, 1992; Willig; 1999; Sims-Schouten, Riley & Willig, 2007). This position aids increasing clarity, coherence and plausibility in connections between voice and social entities that shape these (Elder-Vass, 2012). I felt this best suited this research in attending to the critical approach of this study while highlighting language and discourse in the construction of meaning-making and knowledge within historical, cultural and social contexts. Through developed epistemological-specific criteria, Madill et al (2000) suggest in contextual constructionist approaches (similar to the philosophical positions utilised in this research) quality is determined by the researcher's ability to situate analysis within the contexts that created them. I have recognised this for both the group accounts and my interpretations throughout.

By locating dialogue and action within historical and political contexts alongside discursive elements, my evaluation is therefore based in aspects of the world I consider 'real' (e.g. inequality, discrimination and stigma) and relativist aspects I question (such as 'self'). The epistemological position supports this reflection and critical examination of YP's contexts in raising critical consciousness moving to action. These reflections are shaped by both my own and YP's personal histories including our cultural, moral and political positions as opposed to epistemology and/or ontology (Nightingale & Cromby, 1999). I therefore acknowledge that through this we may have unintentionally committed 'ontological gerrymandering' (Woolgar & Pawluch, 1985), although

it is argued that political stances are entwined with both epistemological and ontological positions (Glesne, 1992).

As outlined in Chapter 2, YP supported the analysis of their own words thus enhancing credibility of interpreting dialogue they were actively part of. All co-researchers were also offered the opportunity to construct the themes, three were able to do so. My supervisor, with knowledge and experience of conducting research and TA checked analysis, providing comments and feedback. Transcript examples, extract coding and development of themes are available to provide an audit trail of the process (Appendices J-L). Ongoing feedback and reflexivity also meant closer alignment with meanings and understandings of the dialogue. Co-researchers reviewed findings with opportunities to feedback, correct or challenge my interpretations which increased the trustworthiness of the research (Willig, 2008). The pluralist and diverse approach to this research through PAR also attempted to decrease bias and increase credibility and trustworthiness of the research. Qualitative data interpretation is intimately connected to biases of the researcher, and therefore we minimised this as a group. YP reviewed the dialogue throughout by reading transcripts of focus groups and contributing to analysis. In adding the extra-discursive element to analysis, I became concerned that YP may have not expected this level of analysis of their voice and when sharing this write-up, I hope to discuss this with the group in a transparent way to build upon established trust and safety.

The dynamic nature of constructing dialogue and action through nuanced contexts, participants and experiences cannot be replicable, making individual PAR projects unique. Qualitative research does not claim to make generalised claims (Willig, 2008), therefore our analysis and my interpretation will not result in a unitary understanding of all YP's experiences within MHS. PAR is recognised as more relevant and robust when working closely with communities it seeks to understand (Staley, 2009). Thus, experiences captured by this group of YP may also be present in the wider group of YP within MHS. It is therefore hoped the core themes and results which highlight

personal and collective action towards this problem are also useful in understanding and changing YP's voice and participation in MHS.

4.4.2. Critical Language Awareness

Working with YP requires understandable language without jargon as a way to connect to YP's ways of being (Afonu, Kovacova & Unwin, 2016). I was aware of linguistic constructions, both my own and YP's, and the impact of this in constructing this research. Linguistic terms were often not 'defined' which I felt appropriate due to constructing meaning together in determining the direction of the research. However, when introducing the concept of power, I did so through discussing intersectionality, therefore YP may have conceptualised 'power' in this way or held different understandings of this construction of the dialogue together. The term 'voice' could also have held a range of constructions to YP. YP being involved in the analysis provided further understanding about dialogue and meanings and it is hoped the open and reflective space supported this co-construction.

4.4.3. Personal

I aimed to maintain self-reflexivity throughout in supporting this write-up, the rationale, reviewing my role and decisions in this research process. Acknowledging my experiences and values, being a supervisee and 'outsider' NHS professional also shapes this research.

My supervisor is strongly aligned to values and action of social justice and equality. As my mentor, I am inspired by her illuminating insights and critical lens challenging me to think outside the 'mainstream', which my course is partly aligned with. Through this, I felt empowered towards endless possibilities outside the 'norm', and further motivated to opening possibilities of YP's creativity and ideas in this research.

Through my 'outsider' position during this research, as a professional employed by the NHS which YP were critical of, I felt it important to make the group as open and transparent as possible. I see the non-neutral stance shaping this research as a strength by providing YP with an encouraging open and uncensored space to discuss their experiences in the system. Although

an initial discussion schedule was used in the first discussion group only, using my intuition, I chose not to raise particular lines of discussion due to my ethical responsibility towards YP's wellbeing. An example of this was through not directly challenging conceptualisations of psychiatric diagnosis in considering many YP's perceived zone of proximal development (Vygotsky, 1987) in relation to this issue. I became concerned about safety in this regard, not wishing to cause harm through overwhelming or undermining YP's current understanding of their experiences. I did not want to collude with any harm YP talked about and therefore presented my ideas tentatively encouraging difference, in addition to a non-neutral stance.

4.4.4. Relational

Relational reflexivity expands reflexivity beyond individual experiences into the relational context (Burnham, 1993). I therefore considered aspects shaping the research in terms of the research group and wider organisational contexts. In maintaining a safe space, I saw value in creating an environment of participation led by YP as much as possible, where uncertainty and unpredictability became part of the project. This felt challenging at times with time limitations, however recognising the ethical importance of avoiding coercion and manipulation, a reflective diary, supervision and open dialogue with YP attended to this. Adapting my expectations from an early stage helped balance this with my thesis requirements. Further, attempting to provide participatory and inclusive space through rolling recruitment undoubtedly impacted on the construction of the research. Different YP attended the research at different times, resulting in some voice being more present than others at times. In maintaining transparency throughout, I let YP know about the process from the beginning including the thesis completion timeline and potential ideas beyond the thesis scope. Knowledge of open-ended possibilities may have also shaped engagement and determined the ideas and action discussed. Co-researchers were already introduced to action through the YoungMinds young activist programme which may have shaped the research. Co-researchers who were also acting as 'Young Activists' were potentially further engaged and socialised into more opportunities, possibilities and motivation for action and change in MHS (in comparison to YP in MHS

who were not part of this programme). It may have also been that many co-researchers in this forum had more of a desire to act against MHS linked to difficult and extensive experiences in oppressive MHS. In recognising this, the group raised questions for future research towards YP not actively participating in MHS and for YP outside of MHS.

YP engaged with the social GRRAACCEESS (Burnham, 2012) exercises to consider intersectionality and power that we might hold in the group. Bringing these conceptualisations of power to YP's critical consciousness (which YP reported they had not considered before and requested this to be repeated in future sessions), undoubtedly shaped the dialogue in raising critical awareness, opening up possibilities for discussing and positioning the 'problem' in part through this lens. With the diversity of YP all identifying with different marginalised positions of race, ethnicity, culture, sexuality, gender and age, it did not surprise me that discussions around intersectionality and societal inequalities, resonated and became central to dialogue and action YP engaged with. I see this as a strength of this project, being aligned with YP's genuine experiences and desire for social change (Rodriguez & Brown, 2009).

YoungMinds' safeguarding procedures meant that a consistent staff member was present in all communication and correspondence with YP. This relational impact was a strength in providing continuity and safety for YP (Coates & Howe, 2016) and constructing a safe space for this research which undoubtedly contributed to the richness of dialogue and discussion. Although trust was clearly evident between the organisation, the staff member and YP, this extra layer of the organisational gaze may have impacted research, dialogue and action, connected to ideas of surveillance (Foucault, 1977) as a possible barrier towards connecting with aspects of dialogue and action.

Not all members were on 'Slack' and I felt it important to share the same information by email with YP not on this group. At times the Slack group became quiet, for some YP the group chat may have felt overwhelming and others may have signed on at different times or had other commitments. To safeguard against manipulation, which Chen, Poland and Skinner (2007)

discuss as a risk with PAR, I took care not to push or overwhelm YP when for example no responses were posted on Slack.

Time became one of the biggest contextual issues in this project. Although reflecting value in 'well begun, half done' (Lang & McAdam, 1996) approach, this reduced time for 'data collection' of recorded dialogue and action. A data collection option which was considered by the group to collect data from outside the PAR group through a secure online platform became difficult to achieve and plan, especially with cancelled sessions due to severe weather within the time restrictions. This has been discussed as a future option for the group to consider in research this further. Time was also challenging in having about an hour and a half for each session. Although a directive approach is required throughout PAR projects within time limits (Templar, 2017), at times I struggled with this balance when conversations became energetic and passionate with YP discussing issues they may have not had space to explore in this way previously. I did not want to shut down this dialogue and found it difficult to wind this down in a 'facilitator' role. The online group, access to YoungMinds staff members and time at the end allowed for debriefs and check-ins after groups. This engagement reinforced the importance of YP being able to talk about issues openly with limited 'professional' gaze. At the beginning of sessions, some YP requested more direction seeking questions at the start of dialogue sessions. In considering the space, where professionals usually ask YP for specific consultation, I wanted to construct this space differently. I offered some initial direction, linking it to expectations discussed in the 'banking system' (Freire, 1973). The 'banking system' refers to traditional education systems, conceptualised through a metaphor of students as 'containers' into which 'educators' instil their 'knowledge' (Freire, 1973). Freire (1973) argued that this model reinforces a lack of critical thinking and ownership of YP's knowledge which reinforces oppression by limiting humanity and creativity. It fascinated me that when I promoted dialogue becoming more open after this initial direction, I witnessed YP's voice filling up the space, with me often struggling to interject, which I saw as another strength of this project with dialogue becoming YP led.

4.4.5 What Could be Done Better Next Time?

When reviewing the project with YP, including about what we could do differently, there was not a lot of critical feedback. I wondered about YP feeling open enough to let me know, relating this to potential power dynamics and expectations such as through the 'banking system' (Freire, 1973). I therefore provided a private and anonymous online space for this however despite this there remained only a small number of ideas about improvements. This may be explained by many elements of the PAR process (such as YP being actively involved from the beginning in constructing and directing the research through ongoing reflexivity and flexibility) which is likely to have organically and iteratively improved the research processes, in line with YP's preferences and views. YP discussed feeling more open and able to speak 'freely' throughout this research which may have also impacted on the level of critical feedback at this stage.

YP discussed that more time would have been helpful, especially to analyse the group discussions together and use the data in further meaningful ways. In response, I have offered to revisit analysis with the group, discussed below, to inform further dissemination. Gathering qualitative data from other YP was raised as another point that could have been improved upon throughout the process. This was an option which was not decided upon by the group, mainly due to time limitations. In recognising this, an option to collect more data such as through an online platform for YP may be revisited by the group. YP also reflected their voice would not have been expressed the way that was without the space being set up to feel relaxed, open and equal. This reinforced value in engagement and attending to the environment through a 'well begun, half done' approach.

4.4.6. PAR Group Beyond this Thesis

As discussed, I felt it important to offer the sustainability of this group, beyond the scope of the thesis to honour YP and their acts of resistance towards change. Many co-researchers confirmed they would like this space to remain, with me involved to the degree the group choose. We have decided to set initial goals together towards sustaining the group towards further action. In

addition to any ideas the group have, this research highlights options for the group to consider such as; campaigning, writing policy, training inside and outside of MHS and other research YP may want to lead, stemming from this project. Two co-researchers have noted interest in constructing an article together to disseminate this research. There will also be presentation opportunities, such as through YoungMinds, to present our meaning of this project to others. This dissemination can also be considered as 'outsider witnessing' with potential to thicken our narratives and meanings made in this research towards further transformative action in YP's MHS.

4.5. Summary of Implications and Recommendations

The generalisability of the research lends itself to informing local contexts of YP's MHS with potential to extend to other levels through future research. As an 'alternative' to conventional and traditional research, this research demonstrates PAR as an approach to conducting research in a more relevant manner for YP in MHS through attending to power and inequality. Accepting PAR as a legitimate research methodology requires institutional change in how research performance is judged (Baun, MacDougall & Smith, 2006). I have been inspired by other YP's PAR examples (Taggart, 2008, Afonu, 2016, Templar, 2017) and hope this project continues to challenge inequalities in YP's realities, MHS and research forums. Actions towards change, found by YP and recommended throughout this chapter, towards breaking the defined problems of YP's voice not being heard in MHS, is summarised in Figure 5 below.

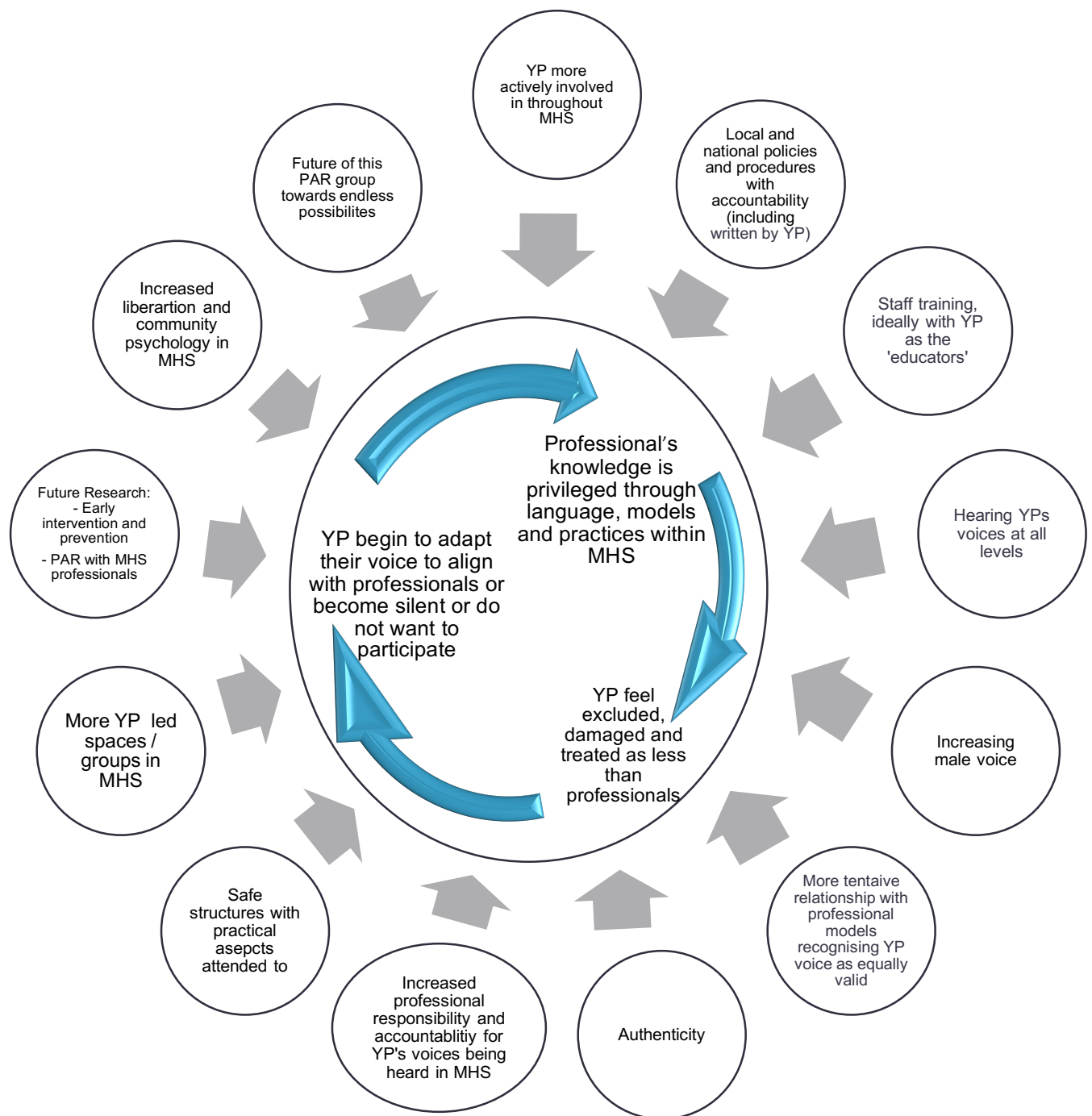


Figure 5. Breaking the Cycle of the Defined Problem Through Further Action

4.6. Concluding Reflections

I found the direction this project took enlightening which I view came from the flexibility PAR provided in allowing me to work alongside and experience YP's skills and brilliance. The journey we embarked on together truly highlighted the incredible power of 'psychology' coming from 'the people' in learning through dialogue and action. This has compelled me, and I hope others, to grow and act further through re-examining assumptions, power and practices.

Through this project I experienced emotions ranging from frustration to sadness, anger and guilt however the humour, inspiration, hope and ambition towards future change will be lasting. YP have and will continue to empower me with sustained strength towards resisting oppressive systems towards YP inside and outside of MHS through the future of this group and beyond. I felt incredibly inspired and honoured to witness YP's voice and actions towards considering our wildest dreams as a group and hope we can move closer towards solving YP's limited voice in MHS, on personal and collective levels. The group and I hope this research can move towards further action towards the inequality YP face. I would like to end on a quote that I hope captures the essence of the project and the possibilities beyond:

"Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has" (Mead, 1964, pp.158).

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APPENDICES

APPENDIX A: Table of Identified Risks

Identified Risk	Description of Risk	Proposed Approach / Considerations
<i>Informed consent</i>	As the project will evolve as the research progresses, it is not easy to specify explicitly what involvement in the research will exactly mean for the participants	<ul style="list-style-type: none"> - Being explicit about the changing nature of the project in verbal and written form using 'co-researcher' agreement form/ terms of reference. - Being clear and checking in at all stages of research about the right for co-researchers to re-negotiate their terms of involvement. This may be especially important to do so at key-stages of the research (data collection, - Use supervision to consider this risk and approach further.
<i>Confidentiality/ Anonymity</i>	Co-researchers may exercise their right to waive aspects of privacy and anonymity where there is a decision to have their contribution to the project recognised (e.g. as a co-author in presenting the research).	<ul style="list-style-type: none"> - Discuss in planning stages what confidentiality and anonymity means for this project and how it will be navigated. - Support 'co-researchers' to engage in a risk/benefit analysis of waiving anonymity (not in write up of thesis but for any further dissemination) versus any risks of their involvement being known publicly. Including a discussion of how and when public details of involvement may later be retracted, and cases where this is unlikely to be possible, E.g. with publications YP can still remain anonymous however their names cannot be retracted once it is on the paper. - Use supervision to consider this risk and approach further
<i>Inducement and Seduction</i>	Young people may be attracted to becoming 'co-researchers' because of access and development of skills and resources.	<ul style="list-style-type: none"> - Being clear and realistic about this experience being an opportunity to develop skills and resources and not making any 'promises'. - If young people want to develop particular skills to consider this with them and how this might be achieved within the project, in line with ToR and agreement form. - Being aware and careful not to 'sell' or pressure involvement. - Use supervision to consider this risk and approach further

<i>Coercion</i>	People who may not wish to participate in the process/aspects of the process can feel group pressure to do so.	<ul style="list-style-type: none"> - Offer an introductory information session with an open invitation to join but no expectations from this first session. - Discuss with the group in planning stages how to navigate individual and group consent. Use individualised 'co-researcher' agreement forms to capture any concerns and clinical skills and supervision to be aware of any 'co-researchers' whose voice is less heard in group meetings. - Making it clear at organisational and individual levels that there is no pressure to be involved. This is also included in information sheets
<i>Domination</i>	If methods have been decided without 'co-researchers' involvement or consent, such as ground rules being decided to impose a particular form of conduct.	<ul style="list-style-type: none"> - Openly discuss any tensions that may exist because of academic pressures, such as timelines and aim to negotiate with 'co-researchers'. - Be clear with co-researchers about non-negotiable conduct such as duty of care, breaking confidentiality for safety re: risk to self or others. - During engagement and in meetings to construct as much as possible with 'co-researchers'. - Use supervision and reflexivity to consider this at all stages of research. - Check in with co-researchers as a group and individually to elicit and discuss any concerns in relation to being influenced.
<i>Manipulation</i>	This could occur if researcher or co-researchers have strong views and uses this to circumvent objective or view.	<ul style="list-style-type: none"> - Being aware and careful to take an open stance, not forcing opinions or experiences on 'co-researchers'. - Facilitating open discussion, cultivating multiple perspectives and using <i>negotiation</i> to reach joint decisions.

<p><i>Authority leading to Disempowerment</i></p>	<p>If co-researchers concede an expert status of researchers. This may occur due to the inherent power imbalance (myself as an adult, professional) there is the risk that this power imbalance will be maintained throughout the process and unilaterally shape the research design, methods and discussion processes, rendering the process tokenistic and potentially disempowering or harmful.</p> <p>The dissolution of the project according to the thesis timeline could also leave co-researchers feeling abandoned and exploited.</p>	<ul style="list-style-type: none"> - Discuss and acknowledge with the group the inevitable influence of my thesis requirements and how to minimise the consequences and safeguard against unilateral agenda setting. - Discuss and commit to methods of power sharing, such as varying who chairs meetings and decides actions. - Use supervision to challenge and question my role in shaping the research agenda and process. - Use acknowledgements and provide opportunities at all stages of the research to co-author, where possible and desired. - Support 'co-researchers' to plan their own independent activities in relation to this project post-completion and review with group such as withdraw formal involvement gradually.
<p><i>Right to withdraw</i></p>	<p>The long-term nature of the project can make withdrawing from the project seem difficult due to group expectations or concerns about loss of influence/acknowledgement.</p>	<ul style="list-style-type: none"> - Make clear through verbally and written information that it is expected that individuals may change their minds and can withdraw at any time with no consequences to non- involvement. - Be clear about the right for 'co-researchers' to re-negotiate their terms of involvement at any stage (such as anonymity), as well as explicitly revisiting involvement at key stages of the project (e.g. data collection, analysis, post-completion).

<p><i>Distress</i></p>	<p>YP may have historical or current mental health difficulties and may feel distressed at times throughout the project.</p> <p>This research may remind or bring up difficult issues (such as power/subjugation) and YP may feel distressed by this.</p>	<ul style="list-style-type: none"> - Create environment of understanding that young people may feel distressed and currently or previously may have been connected to mental health services. - Check in throughout group meetings and on individual basis. - Feeling distressed/upset is proposed to be discussed and procedures negotiated when constructing ground rules and individual meetings. - If a YP becomes distressed encourage them to speak to me/ YM staff individually negotiate who to notify with YP. - To also provide all YP with signposting list in the case they may feel distressed at any time. - If there are any concerns about YP or others safety confidentiality will be broken in conjunction with supervisors with the aim to discuss with YP first.
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APPENDIX B: Ethics approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorate

REVIEWER: Max Eames

SUPERVISOR: Claire Higgins

COURSE: Professional Doctorate in Clinical Psychology

STUDENT: Lucy McGregor

TITLE OF PROPOSED STUDY: A Participatory Action Research Approach to Participation with Young people Within Mental Health Settings.

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

Approved, but minor amendments are required before the research commences.

Minor amendments required (for reviewer):

It is requested that the student reviews the comments for consideration in the actual proposal. Consideration is solely what is required before the research commences. If there is a sense that the comments made would enhance the informed consent of participants, then if the student wishes she may wish to incorporate what is suggested.

Major amendments required (*for reviewer*):

N/A

ASSESSMENT OF RISK TO RESEARCHER (*for reviewer*)

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

HIGH

☐

MEDIUM

☒

LOW

Reviewer (*Typed name to act as signature*): Max Alexandre Eames

Date: 26 June 2017

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

Confirmation of making the above minor amendments (*for students*):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *Lucy McGregor*

Student number: u1525467

Date: 26/06/17

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL PSYCHOLOGY

ATTACHMENTS YOU MUST ATTACH TO THIS APPLICATION

1. A copy of the invitation letter that you intend giving to potential participants.
2. A copy of the consent form that you intend giving to participants.
3. A copy of the debrief letter you intend to give participants (see 23 below)

OTHER ATTACHMENTS (AS APPROPRIATE)

- A copy of original and/or pre-existing questionnaire(s) and test(s) you intend to use.
- Example of the kinds of interview questions you intend to ask participants.
- Copies of the visual material(s) you intend showing participants.
- A copy of ethical clearance or permission from an external organisation if you need it (e.g. a charity or school or employer etc.). Permissions must be attached to this application but your ethics application can be submitted to the School of Psychology before ethical approval is obtained from another organisation if separate ethical clearance from another organisation is required (see Section 4).

Disclosure and Barring Service (DBS) certificates:

Your details

1. **Your name:** Lucy McGregor
2. **Your supervisor's name:** Dr. Claire Higgins
3. **Title of your programme:** Professional Doctorate in Clinical Psychology
4. **Title of your proposed research:** A Participatory Action Research Approach to Participation Young People Within Mental Health Settings.
5. **Submission date for your DClinPsych research:** April 2018
6. **Please tick if your application includes a copy of a DBS certificate** ☒
7. **Please tick if you need to submit a DBS certificate with this application but have emailed a copy to Dr Mark Finn for confidentiality reasons (Chair of the School Research Ethics Committee) (m.finn@uel.ac.uk)** ☐
8. **Please tick to confirm that you have read and understood the British Psychological Society's Code of Human Research Ethics (2014) and the UEL Code of Practice for Research Ethics (See links on page 1)** ☒

2. About the research

9. The aim(s) of your research:

This study aims to investigate young people's (YP's) experiences of 'user participation' within mental health settings, through a Participation Action Research (PAR) framework.

The aims of this proposed study are to actively establish experiences of 'user-participation' in mental health settings with YP as 'co-researchers' and through developing a 'co-researcher' group.

This is proposed to be initially explored through a series of focus groups with 'co-researchers'. This will include asking research questions, such as below, to investigate participation within young people's mental health settings:

What are the benefits identified by young people of user participation?

What encourages young people to become involved in user participation?

What are the barriers identified by young people of user participation?

If this project is to stay as true to the PAR process as possible, the above research questions may evolve. These proposed research questions will be used to guide the research.

After qualitative data has been generated from the focus groups, 'co-researchers' will have the opportunity to analyse this data. If the group decide it will be helpful then a decision will be made with the group to open this research to wider participants, such as through developing a short questionnaire.

10. The sample/participants:

Recruitment will take place from a 3rd sector youth organisation (Youngminds). Discussions and agreements for this recruitment have been initiated.

Existing YP in this organisation aged 13-19 will potentially be recruited to become participants and if interested 'co-researchers'. Existing groups within this organisation will be approached for recruitment. YP under 13 are excluded from this study as I am interested in capturing the adolescent voice in this research. This also fits with the age-range of the existing groups in Youngminds.

At the recruitment stage, it will be made clear that being part of this research would be purely voluntary. This would include if any of the participants are paid youth advisors, it will be made clear that participating is not part of the

role and purely voluntary. This would aim to remove the potential for any power imbalances within the group.

Recruitment to this project is planned to be promoted through monthly youth advisor meetings, posters, my presence in these services and through the organisation sending round information emails or posting on their closed Facebook account to reach other YP within the organisation.

If YP are interested in participating, this role will be collaboratively established through an initial meeting with myself, YP and parent/guardian, if appropriate, ensuring informed consent is carefully considered through information sheets, Terms of Reference (ToR) and 'co-researcher' agreements, which will be regularly reviewed (Appendices B-G).

Participant Meetings

Once participants are identified, following discussions with myself and parent/guardian with relevant consents in place (discussed further in 6.5) and the framework of engagement established through 'co-researcher' agreements (Appendix H), a 'co-researcher' group will be established with around 4-10 YP.

Through on-going discussions YP will have the opportunity to decide to be actively involved in various levels of the research, with support from myself, depending on their own preferences such as:

- Involved in data generation (being part of focus groups)
- Involved in analysis (of focus groups and analysis of research if widened out)
- Involved in data collection method (if research is widened out)
- Involved in dissemination

Once the group is established it is hoped that some or all of the YP will be interested in developing the questions, in analysing and/or commenting on the data. From recent PAR research with this population (Templar, personal correspondence) it is noted that use of closed and secure online groups, such

as Facebook and WhatsApp, have been flexible and enabling ways for 'co-researchers' to partake in data analysis. This option will also be offered to 'co-researchers' as part of being involved in analysis.

After qualitative data is generated from focus groups, if the group decide more data would be helpful then opportunities for other YP within the organization to be less actively involved as 'research participants' will also be offered after this stage. This may be through completing a questionnaire.

Research activities will be developed through regular meetings with 'co-researchers', including establishing:

the 'co-researcher' group and negotiating ToR and practices within the group

methods of data collection (if research is widened out)

the multiple options of being involved, as discussed above

Ethics and risk assessments (please see Appendix J for table of identified risks and proposed approaches) would be carefully considered by myself and in consultation with my DoS, throughout this research and especially after the consultation process. It is my responsibility for consenting individuals and discussing with parents/guardians. This will include informed consent, parental consent and confidentiality. As lead researcher I will also have responsibility for facilitating research meetings, data gathering and co-ordination of participants.

I will offer a training workshop to ensure 'co-researchers' are fully briefed with regard to ethical aspects including informed consent and confidentiality.

Supervision and guidance from my DoS will be important areas of support to consider any identified training needs of the group

11. Measures, materials or equipment:

As the method will be shaped through working with 'co-researchers', resources cannot fully be known at this stage but may include audio-

recording, transcribing equipment and a password-protected computer. These will be encrypted, stored confidentially and destroyed two years after the research.

12. If you are using copyrighted/pre-validated questionnaires, tests or other stimuli that you have not written or made yourself, are these questionnaires and tests suitable for the age group of your participants?

Non Applicable

13. Outline the data collection procedure involved in your research:

Participatory Action Research (PAR) is the selected research methodology which challenges the distinction between the 'researcher' and the 'researched', giving people the opportunity to take an active role in the research by considering issues that affect them and their communities (Gaventa, 2003). PAR is a non-linear process, therefore methods will emerge through the process and cannot be fully known at the outset (Greenwood et al, 1993).

In this proposed study YP would have the opportunity to be involved through many processes of this research (as discussed in 10.) to the degree they choose through being 'co-researchers' (agreed through Appendix G). This study proposes to provide opportunities of a 'medium-high' level of PAR (Bakazar et al., 2004) and 'collaborative' level (Kirby, 2003) reflecting the degrees of control, commitment and collaboration. This would include generating the data, selecting methods of data collection, being part analysis process and disseminating the research (further discussed in 5.0). This involvement would be supported through consulting with guidelines to involve YP with research such as INVOLVE (Appendix K).

All 'co-researchers' will sign a confidentiality agreement (within Appendix H). They will meet as a group; agree ground rules and be made fully aware of the opportunities to be involved in. It is hoped all members (approximately 6) will be interested in all levels of participation.

At this stage data will be collected from the 'co-researcher' group, through focus groups, to document the emerging process. Due to the dynamic nature of PAR, if research is decided to be opened out to 'research participants', methods employed will be decided with 'co-researchers' and anticipated options include:

- Questionnaires (mixed methodology or qualitative data)
- Focus groups (qualitative data)
- Individual Interviews (qualitative data)
- Online collection through online surveys (one of which is secure and does not store data elsewhere/outside of the UK) or forum (mixed methodology or qualitative data).

3.Ethical Considerations

Please describe how each of the ethical considerations below will be addressed:

A full table of identified risk and proposed approaches to address these risks are listed in Appendix J. This includes risk of distress and if this occurs negotiating with YP who to notify of this distress, for example their parent/guardian or GP and also signposting to relevant services. The limits of confidentiality will be made clear and breach will be discussed, if appropriate, with the YP before contact to parent/guardian or GP. YP are a vulnerable group and it is my responsibility and duty of care to protect them. For full protocol of involving YP in research please see Appendix K.

Consent, Confidentiality and Anonymity

Consent from parents/guardians for YP aged 13-15 years, deemed competent in line with Mental Capacity Act (2005), will be required, before the role of 'co-researcher' is established, to ensure they are fully informed and given the opportunity to withdraw their child from the study at any time. YP aged 15-19 years do not need parent/guardian consent however will be encouraged to discuss with parents/guardians. This consent is proposed to be established

through a parental/guardian information letter and consent form (Appendices B-F) and also during the proposed initial meeting with myself, YP and parent/guardian. Or via a telephone conversation with the parent / guardian.

'Co-researchers'

PAR brings issues of anonymity with 'co-researchers' as they have the right to waive public anonymity and gain recognition for their roles. This will be discussed through agreement forms (Appendix G) and with parents/guardians, acknowledging this decision can be revisited at any time before February 2018 (when the write up will commence). For example, if YP want to have their names on any publications. While it is recognized that any withdrawal will change the dynamics of the group, it is hoped that the YP will be engaged enough in the process.

After data is collected within the initial focus groups with 'co-researchers' it is hoped it will be analysed with members of the focus group, therefore the data will not be anonymous as YP will already be knowledgeable about what has been said at the focus group they were a part of. When written up YP will be anonymous and when publishing the option to relinquish anonymity will be revisited. This therefore reduces power dynamics and hopes to ensure a transparent process.

Research Participants

Consent from parents/guardians for YP aged 13-15 years, deemed competent in line with Mental Capacity Act (2005), will be required, before any YP consents to participate, to ensure they are fully informed and given the opportunity to withdraw their child from the study at any time before thesis submission date.

If research participants are recruited, information about participants and content of data will be kept confidential and anonymous. It will be made clear that as the final research will be shared and published, names and identifying

features will be altered in any data, thesis extracts and resulting publications, to protect anonymity.

For both 'co-researchers' and participants limits of confidentiality will be made clear before beginning, and broken in consultation with supervisors if the researcher has serious concerns about any person's safety, with the aim to discuss with the person first. YP are considered a vulnerable group and it is important to remain ethical at all times to make sure no harm is done, this is further considered in section 20, Appendix I and J. Consent forms and data will be kept in a secure environment. Only the research team (who will sign confidentiality agreements, Appendix H), supervisors and examiners will have access to data. This will be made clear to participants before they consent.

Online Safety

If online forums are created YP will have their anonymity and confidentiality protected including secure websites, usernames, coded passwords and report buttons will be clear. An information and debrief sheet (Appendix I) will be displayed online including any rules, contact details for the research team and signposting to support. For a fuller risk assessment please see Appendix J.

Ethical approval

Ethical approval will be initially sought from the UEL in line with their policies and is agreed as sufficient by Youngminds. As PAR is an emerging process, it is anticipated that data may include:

- Questionnaires (mixed methodology or qualitative data)
- Focus groups (qualitative data)
- Individual Interviews (qualitative data)
- Online collection through online surveys or forum (one of which is secure and does not store data elsewhere/outside of the UK) (mixed methodology or qualitative data).

14. Fully informing participants about the research (and

parents/guardians if necessary): Would the participant information letter be written in a style appropriate for children and young people, if necessary?

Consent from parents/guardians for YP aged 13-15 years, deemed competent in line with Mental Capacity Act (2005), will be required to ensure they are fully informed and given the opportunity to withdraw their child from the study at any time before thesis submission date. This will be discussed during the proposed initial meeting with myself, YP and parent/guardian. YP between 15 and 19 years will not require parental/guardian consent but will be actively encouraged to inform their parents/guardians about participating.

15. Obtaining fully informed consent from participants (and from

parents/guardians if necessary): Would the consent form be written in a style appropriate for children and young people, if necessary? Do you need a consent form for both young people and their parents/guardians?

Informed consent is particularly important considering working with YP who are considered a vulnerable group, ensuring YP are not being coerced or recruited by rewards, please see Appendix H and J for further information.

This will include the consultation phases for co-researchers and involving parents and/or guardians in this process and thinking carefully with YP about what being involved in this research would involve through information. This information will include Terms of Reference (ToR) form (Appendix H) and individualised 'co-researcher' agreement forms (Appendix G). This risk is further considered in Appendix I.

16. Engaging in deception, if relevant

There will be no deception involved in this research.

17. Right of withdrawal:

In the participant invitation and information, it is clearly stated that participants do not have to take part in this study and should not feel under any pressure

to do so. They will be made fully aware that they are free to change their mind (before thesis submission date) and withdraw from the study throughout the process. If they choose to withdraw from the study they may do so without disadvantage to themselves and they do not need to give a reason.

18. Anonymity & confidentiality: (Please answer the following questions)

18.1. Will the data be gathered anonymously?

For 'co-researchers' anonymity will be decided with YP on an individual basis and with parent/guardian if appropriate.

If research participants are recruited this data will be gathered anonymously.

Co-researchers

PAR brings issues of anonymity with 'co-researchers' as they have the right to waive public anonymity and gain recognition for their roles. This will be discussed through agreement forms (Appendix F) and with parents/guardians, acknowledging this decision can be renegotiated throughout the research process.

Research Participants

Names and identifying features will be altered in any data, thesis extracts and any resulting publications, to protect anonymity. This will be made clear as the final research will be shared and published.

For both 'co-researchers' and participants limits of confidentiality will be made clear before beginning and will be broken, in consultation with supervisors, if the researcher has serious concerns about any person's safety, with the aim to discuss with person first. Consent forms and data will be kept in a secure environment. Only the research team, supervisors and examiners will have access to data. This will be made clear to participants before they consent.

19. If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

Please refer to 18.1

20. Protection of participants:

For both 'co-researchers' and participants limits of confidentiality will be made clear before beginning and will be broken in consultation with supervisors if the researcher has serious concerns about any person's safety, with the aim to discuss with person first.

Involving young people in research can fundamentally help redress power imbalances between researchers and the researched, and between adults and younger people. For their involvement to be a positive experience there needs to be an enabling environment and culture in which they are in a power-sharing role. This is about building and creating new relationships in which everyone's input is welcomed, respected and considered valid (Kirby, 2003).

The following issues need to be considered when planning for the health, safety and wellbeing of young people to be actively involved in research (further considered in Appendix J):

- It is important to ensure all participating young people's safety, including those doing research and those being researched.
- Safety precautions include: training young people in child protection issues, police checks, ensuring safe locations and using mobile phones.
- Recognise research may impact on emotional well-being, assess this risk and offer appropriate support where necessary.

Please see Appendix I for table of identified risks and proposed approaches to address these risks. Supervision and guidance (Appendix K) will be essential in helping to protect participants.

Online Safety

If online methods are employed YP will be protected within different levels to protect anonymity and confidentiality. This includes having secure websites, usernames, coded passwords and report buttons. An information and debrief sheet (Appendix H) will be displayed online including any rules, contact details for the research team and signposting to support.

21. Protection of the researcher:

As this research will take place on in group forms and potentially on a 1:1 basis, a third party such as my DoS will be informed of a time and a place where data collection will occur and when it is due to be completed as per an agreed safety protocol. Youngminds will also be informed of the details of any meetings arranged. Please see Appendix J, the INVOLVE protocol (Appendix K) and debrief form in Appendix I for further consideration.

22. Debriefing participants:

A sample debrief form is displayed in Appendix I, this will be developed further in consultation with co-researchers which will ensure that information will be included such as:

- Being thanked for their time
- Time will be given at the end of the data collection task to ask researchers questions or raise concerns
- They will be reassured about what will happen to their data
- They will be given information such as name and contact details for appropriate support organisations for participants to contact should they experience any distress as a result of participating the research.

23. Will participants be paid?

NO

24. Other:

(Is there anything else the reviewer of this application needs to know to make a properly informed assessment?)

N/A

Other permissions and ethical clearances

25. Is permission required from an external institution/organisation (e.g. a school, charity, local authority)?

YES

If participants who are accessed through a charity or another organisation, you must obtain, and attach, the written permission of that institution or charity or organisation.

If YES please give the name and address of the institution/organisation:

Youngminds, Suite 11, Baden Place, Crosby Row, London, SE1 1YW.

Please attach a copy of the permission. A copy of an email from the institution/organisation is acceptable. Please see Appendix A.

In some cases you may be required to have formal ethical clearance from another institution or organisation.

26. Is ethical clearance required from any other ethics committee?

NO

If YES please give the name and address of the organisation:

Has such ethical clearance been obtained yet?

NO

If NO why not?

If YES, please attach a scanned copy of the ethical approval letter. A copy of an email from the organisation is acceptable.

PLEASE NOTE: Ethical approval from the School of Psychology can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committees as may be necessary.

27. Will your research involve working with children or vulnerable adults?*

YES

If YES have you obtained and attached a DBS certificate?

YES

If your research involves young people under 16 years of age and young people of limited competence will parental/guardian consent be obtained.

YES

If NO please give reasons. (Note that parental consent is always required for participants who are 16 years of age and younger)

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children see www.uel.ac.uk/gradschool/ethics/involving-children/

28. Will you be collecting data overseas?

NO

This includes collecting data/conducting fieldwork while you are away from the UK on holiday or visiting your home country.

* If YES in what country or countries will you be collecting data?

<http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

29. Signatures:

TYPED NAMES ARE ACCEPTED AS SIGNATURES

Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name: Lucy McGregor

Student's number: U1525467

Date: 12/06/2017

Declaration by supervisor: Claire Higgins

I confirm that, in my opinion, the proposed study constitutes a suitable test of the research question and is both feasible and ethical.

Supervisor's name: Claire Higgins
12/06/2017

Date:

APPENDIX C: Ground Rules

Agreed PAR Group Ground Rules

- Confidentiality and information about disclosure & safeguarding
- Agreed use of phones within individual group (e.g. taking a call or texting is ok just let the rest of the group know so we are aware)
- Respect others' opinions - attack points not people
- Try to not speak over each other – try to give everyone a chance to have their say
- Being non-judgemental and accepting of others and their different experiences
- Please feel free to let Lucy or Alice know if you have any concerns, questions or issues about any aspect of the project.

Please feel free to discuss and add any more suggestions at any point

APPENDIX D: 'Co-Researcher' Terms of Reference (ToR) Sheet

Please note that this is a draft document which aims to set out information and the objectives of this research project at this stage. It is hoped that as a research team that we can edit this document to reflect our discussions and agreed objectives.

THE CONTEXT

As part of a training programme and doctoral thesis the University of East London, Lucy McGregor Trainee Clinical Psychologist at the University of East London hopes to conduct Participatory Action Research (PAR) with young people about the area of young people being involved in mental health settings or 'user participation'. PAR is an approach aimed at actively working together with members of a community to shape and develop research to the degree they choose. This would include options of being involved with methods of data collection, the analysis of the data and presenting this research together. It would also be agreed and decided how much young people would like to be involved in this project as 'co-researchers' (or their own preferred term) and what young people would hope to get out of being involved as part of this research.

PURPOSE

The purpose is to actively involve young people as 'co-researchers' (or preferred title). Ensuring involvement of young people throughout research aims to recognise barriers of young people's having a voice in society and within mental health settings. Involving young people in research can help redress power imbalances between younger and older people and build new, more positive, relationships to produce meaningful insights into developing high-quality participation practices.

OBJECTIVES

- To develop research in collaboration with young people as 'co-researchers' (or other title preferred).

- To establish individually what 'co-researchers' would like to achieve from the process, how much they would like to be involved and establish levels of preferred anonymity.
- Regular contact to conduct this research through stages of planning and action.
- 'Co-researchers' will have opportunities at all stages of research to be involved in this research.
- 'Co-researchers' will also have opportunities to be recognized for their input (and dependent on chosen public anonymity) such as co-authoring research and disseminating research.

OPERATIONAL

- To meet regularly together as research team.
- To work together until May 2018 when project is completed.
- To encourage and work with 'co-researchers' and the organisation to continue this work and develop action plans or further research after the project is completed.

APPENDIX E: Consent and Confidentiality Agreement Forms

For 13-15 years with parent/guardian

A Participatory Action Research Approach to Participation with Young People Within Mental Health Settings.

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me. ☐

I understand that my involvement in this study and the participating group that I am a member of, (including that particular data from this research) will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. ☐

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent, I understand that I have the right to withdraw from the study at any time (at any time (before the submission, approximately March 2018) without disadvantage to myself and without being obliged to give any reason. ☐

I also understand that should I withdraw (after the write up), the academic researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher. ☐

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature:

.....

Parent / Guardian's Signature:

.....

Researcher's Name (BLOCK CAPITALS)

.....Date:.....

For 16+ years

A Participatory Action Research Approach to Participation Young People Within Mental Health Settings.

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me. ☐

I understand that my involvement in this study and the participating group that I am a member of, (including that particular data from this research) will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. ☐

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent, I understand that I have the right to withdraw from the study at any time (at any time (before the submission, approximately March 2018) without disadvantage to myself and without being obliged to give any reason. ☐

I also understand that should I withdraw (after the write-up), the academic researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher. ☐

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Date:

Co-researcher agreement form

**A Participatory Action Research Approach to
Participation Young People Within Mental Health
Settings.**

Name:

Date:

I have read the information sheet

YES/NO

I have read the draft Terms of Reference sheet

YES/NO

I have signed the consent form

YES/NO

By doing so I understand that I have agree to take part in the
research study as a 'co-researcher' (or other preferred title)

YES/NO

How much would I like to be involved?

What do I hope to get out of being a 'co-researcher'?

Other:

Confidentiality

I agree to: - Keep all the research information shared with me
confidential by not discussing or sharing research information in

any form or format with anyone other than the research team

YES/NO

Keep all research information in any form or format secure while it is in my possession **YES/NO**

Return all research information in any form or format to the research team when completing research tasks.

YES/NO

I understand that this decision can be changed throughout conducting this research by speaking to Lucy McGregor, Trainee Clinical Psychologist or others listed below.

YES/NO

If I have any questions or do not agree with anything I will try discuss the below people or get another adult to advocate any concerns as soon as I can by speaking to either:

- Lucy McGregor, Trainee Clinical Psychologist
- Alice Victor or staff members at Youngminds
- Dr. Deanne Bell, University of East London

Signed:.....

Co-researcher:.....

Parent / Guardian:.....

Trainee Clinical Psychologist:

APPENDIX F: Information Sheets

(For young people ages 13-15 years, 16+ and parents/guardians)

Information Sheet for Young People aged 13-15

University of East London. School of Psychology Stratford Campus Water Lane London E15 4LZ

Invitation and Consent to Participate in a Research Study

The information sheet is to give you information that you need to consider in deciding whether to take part in a research study. If you think you might like to take part, a copy will also be given to your mum, dad, or legal guardian. This is because they will also need to decide whether they agree to you taking part.

The study is the Project described in this information sheet which is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London.

Project Title

“A Participatory Action Research Approach to Participation with Young People within Mental Health Settings”.

Project Description

You are invited to become a ‘co-researcher’ to develop and shape research within the area of young people participating in mental health settings or ‘user participation’. The aim is that we would work together to develop the research. This would include what the aims are, how we would collect data, the analysis and presenting this research together. We would also agree and decide how much you would like to be involved in this project and what you would hope to get out of being involved as a ‘co-researcher’.

This research would be separate to any treatment you may be receiving and may be an opportunity for you to develop your own personal skills and experiences.

Confidentiality of the Data

As a 'co-researcher' you will be actively involved in shaping this research and you may wish to be recognised for this. You can exercise your right to waive your public anonymity for this reason or if you prefer, you can decide to keep your anonymity. You can change your decision about this too throughout the process. This will be discussed with you and your parent/guardian to help you reach a decision about this as part of the process.

After we have discussed this and when the level of anonymity is established we will meet regularly and decide how the co-researcher team would like to record our meetings as we develop the research. Before beginning limits of confidentiality will be made clear (such as concerns about your or others safety) and will be broken in consultation with supervisors if I have serious concerns about your or others safety. When possible I will discuss this with the individual concerned before breaking confidentiality.

What if I don't want my parents/guardians to know?

When young people are asked to be part of research their parent or guardian must be informed and agree to this. There is a good reason for this as they are responsible for keeping you safe and helping you to make important decisions. Informing and getting agreement to be part of this project from your parents will be required.

Location

The research will take place at Youngminds, Suite 11, Baden Place, Crosby Row, London, SE1 1YW.

Will I get anything for taking part?

In keeping with university research codes, you will not be paid for being part of this study. However, I hope that you will find taking part in this research interesting and that being involved in this project may be an opportunity to help you to develop your skills and experiences.

Do I have to take part?

You do not have to take part in this study and should not feel under any pressure to do so. You are free to change your mind at any time (before the

submission, approximately March 2018) and withdraw from the study. If you choose to withdraw from the study you may do so without disadvantage to yourself and you do not need to give a reason.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form before you can take part. You mum, dad, or legal guardian, will also be asked to sign a consent form. Please hold on to this invitation letter in case you want to look at it again in the future.

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

The study's supervisor is Dr. Deanne Bell, School of Psychology, University of East London, Water Lane, London E15 4LZ.

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Lucy McGregor

Trainee Clinical Psychologist

Information Sheet for Parents/Guardians

UNIVERSITY OF EAST LONDON

School of Psychology

Stratford Campus Water Lane

London E15 4LZ

Name: Lucy McGregor, Trainee Clinical Psychologist

Consent for My Child to Participate in a Research Study

This is to give you information that you need to consider in deciding whether you agree to your child taking part in a research study. Your child has also been giving a copy of this information and you need to agree for him or her to take part.

The study is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London.

Project Title

“A Participatory Action Research Approach to Participation with Young People Within Mental Health Settings”.

What will the project involve?

Your child is invited to become a ‘co-researcher’ to develop and shape research within the area of young people being involved in mental health settings or ‘user participation’. The aim is that we would work together to develop the aims of the research, how we would collect data, analyse it together and present this research. We would also agree and decide how much your child would like to be involved and consider what your child would hope to get out of being involved in this research.

This research would be separate to any treatment your child may be receiving and may benefit them by developing their skills and experiences.

Why am I being asked about this?

When young people (under 16 years) are asked to take part in research, a parent or legal guardian must also agree to this before taking part and we will seek your consent. There is a good reason for this as a parent or legal guardian is responsible for keeping their child safe and helping them to make important decisions.

For young people aged 16 years and over, parental or guardian's consent is not required however we encourage people involved to discuss and inform their parents about taking part.

Do both parents have to agree?

Only one parent or legal guardian has to agree to a young person under 16 years of age taking part, though if possible it would be good for everyone to agree together. The important point is that an adult who has parental responsibility agrees to the young person under 16 years of age taking part, whether this is their mum, dad or another adult who has parental responsibility for them.

Where will the project take place?

This project will take place at YoungMinds, Suite 11, Baden Place, Crosby Row, London, SE1 1YW.

What happens to the things my child shares? Will they be kept private?

As your child will be involved in this research as a 'co-researcher' and as the aim is that they will be actively involved in shaping this research they may wish to be recognised for this. You can both think together, for this reason, whether to waive the right to public anonymity, or if you prefer to exercise your right to keep public anonymity. This decision about anonymity can be changed throughout the process. It is hoped that this issue can be discussed with you and your child to support you in reaching this decision.

A copy of the content of meetings will be kept on the researcher's computer in a password-protected folder. This is so the content can be analysed and be accessed if necessary for writing up the research for publication. This copy as well as any personal information will also be deleted when it is no longer needed for the research.

Will they get anything for taking part?

Your child will not be paid for taking part in this study. However, I hope that they will find the discussions and participating in this research interesting and a helpful opportunity to develop their skills and experiences.

Do they have to take part?

Your child does not have to take part in this study and should not feel under any pressure to do so. You are also under no obligation to agree to them taking part. Both you and your child are free to change your mind at any time and withdraw them from the study (before March 2018). If your child withdraws from the study they may do so without disadvantage to either of you and there is no need to give a reason.

If your child withdraws, things that they have already shared or written may be used in the write-up of the study and any further analysis that may take place. This is because some discussions that other young people have also been involved in may only make sense when what they have contributed is included. However, where possible this will be avoided and any information that is used will be summarised.

Please feel free to ask me any questions. If you are happy to continue your child will be asked to sign a consent form. You will also be asked to sign a consent form before he or she can take part. Please hold on to this invitation letter in case you want to look at it again in the future.

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

The study's supervisor is: Dr Deanne Bell, Professional Doctorate in Clinical Psychology, School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4475.

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you for considering whether to agree for your child to take part in this project.

Yours sincerely,

Lucy McGregor

Trainee Clinical Psychologist

Information Sheet for Young People (Aged 16+)

UNIVERSITY OF EAST LONDON

School of Psychology,

Stratford Campus Water Lane,

London E15 4LZ

Name: Lucy McGregor

Invitation and Consent to Participate in a Research Study

This information sheet is to give you information that you need to consider in deciding whether to take part in a research study. If you think you might like to take part, a copy will normally also be given to your mum, dad, or legal guardian.

The study or Project is being conducted as part of my Professional Doctorate in Clinical Psychology at the University of East London

Project Title

“A Participatory Action Research Approach to Participation with Young people within Mental Health Settings”.

Project Description

You are invited to become a ‘co-researcher’ to develop and shape research within the area of young people participating in mental health settings or ‘user participation’. The aim is that we would work together to develop the research. This would include what the aims are, how we would collect data, the analysis and presenting this research together. We would also agree and decide how much you would like to be involved in this project and what you would hope to get out of being involved as a ‘co-researcher’.

Confidentiality of the Data

As a co-researcher you will be actively involved in shaping this research and you may wish to be recognised for this. You can exercise your right to waive your public anonymity for this reason or keep your anonymity if you would rather. You can change your decision about this too throughout the process. This will be discussed with you and your parents to help you reach a decision about this as part of the process.

After these discussions, and the level of anonymity is established we will meet regularly and decide how the co-researcher team would like to record our meetings as we develop the research. Before beginning, limits of confidentiality will be made clear (such as concerns about your or others safety) and will be broken in consultation with supervisors if I have serious concerns about your or others safety. When possible I will discuss this with the individual before breaking confidentiality.

Consent and agreement forms will be kept in a secure environment. Only the research team, supervisors and examiners will have access to data.

Do my parents have to agree?

If you are aged 16 or over, your parents or legal guardians do not need to consent to you taking part. However, I would actively encourage you to discuss taking part in this project with them first as it is an important decision.

Location

The research will take place at Youngminds, Suite 11, Baden Place, Crosby Row, London, SE1 1YW.

Will I get anything for taking part?

In keeping with usual practice for academic research projects, you will not be paid for being part in this study. However, I hope that you will find taking part in this research interesting and that this may be an opportunity to develop your skills and experiences.

Do I have to take part?

You do not have to take part in this study and should not feel under any

pressure to do so. You are free to change your mind at any time and withdraw from the study (before March 2018). If you choose to withdraw from the study you may do so without disadvantage to yourself and you do not need to give a reason.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form before you can take part. Your mum, dad, or guardian, will also be encouraged to sign a consent form. Please hold on to this invitation letter in case you want to look at it again in the future.

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

The study's supervisor: Dr. Deanne Bell , School of Psychology, University of East London, Water Lane, London E15 4LZ tel: 0208 223 4408

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Lucy McGregor

Trainee Clinical Psychologist

APPENDIX G: Research Workshop Slides



HISTORY OF PAR

Based on four central groups of aims:

- Active Research**
 - Participatory research: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
- Consultation & Participation**
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data

HISTORY OF PAR

- Participatory research**
 - Participatory research: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
- Consultation & Participation**
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data
 - Young people as co-researchers: young people work with adults to generate research questions and collect data

THEREFORE, PARS AIMS TO...

- Develop voice
- Develop ability to articulate social realities
- Develop social insights
- Develop psychological insights
- Recognise the effects of power dynamics
- Take action against social inequalities & systems of power
- Continuity members generate research questions
- Community members participate in social transformation

FURTHER AIMS OF YOUNG PEOPLE PARTICIPATING IN RESEARCH

Young people can benefit from research questions that professional researchers might not ask or prioritise. Young people can benefit from research questions that professional researchers might not ask or prioritise. Young people can benefit from research questions that professional researchers might not ask or prioritise.

Young people can benefit from research questions that professional researchers might not ask or prioritise. Young people can benefit from research questions that professional researchers might not ask or prioritise. Young people can benefit from research questions that professional researchers might not ask or prioritise.

APPROACHES TO RESEARCH... EPISTEMOLOGICAL POSITIONS

Epistemological positions are the ways in which we understand the world and how we know what we know. They are the foundations of our research and the ways in which we interpret the data we collect.

Epistemological positions are the ways in which we understand the world and how we know what we know. They are the foundations of our research and the ways in which we interpret the data we collect.

WHERE ARE WE COMING FROM?

Our research is a journey, not a destination. We are constantly learning and growing, and we are always open to new ideas and perspectives. We are always open to new ideas and perspectives. We are always open to new ideas and perspectives.

Our research is a journey, not a destination. We are constantly learning and growing, and we are always open to new ideas and perspectives. We are always open to new ideas and perspectives. We are always open to new ideas and perspectives.

ETHICAL CONSIDERATIONS

- ETHICAL APPROVAL
- CONSENT
- RIGHT TO WITHDRAW
- RISK
- CONFIDENTIALITY
- ANONYMITY (and right to be forgotten)
- DATA SAFETY

Information ethics, consent forms, to ensure that participants are fully informed, and that their data is safe and secure.

GENERAL PROCESSES / THE JOURNEY OF RESEARCH

- Question
- Formulation
- Plan
- Method
- Results
- Discussion
- Conclusion

ABSTRACT:

Concept: Inquiry and policy drive participatory research, often of justice. Inquiry: Inquiry is a process of asking questions and seeking answers. Inquiry is a process of asking questions and seeking answers. Inquiry is a process of asking questions and seeking answers.

Concept: Inquiry and policy drive participatory research, often of justice. Inquiry: Inquiry is a process of asking questions and seeking answers. Inquiry is a process of asking questions and seeking answers. Inquiry is a process of asking questions and seeking answers.

INTRODUCTION:



- An Introduction to the topic, general background to establish the context for the research
- Literature Review in relation to the topic to appraise existing research and gaps
- Clear about what gaps/problems and what your study would aim to investigate in relation to this

AIM:

It's given an overview of the specific aims of the research



- They/It's to include specific research questions
- This study aims to explore and investigate Young People's experiences of 'peer participation' within mental health settings through a full framework with Young People as 'co-researchers'. This is proposed to be firstly explored through a series of focus groups with 'co-researchers'.
- Although this project aims to also look to the PhD process, the following research questions are provided to guide the basis of research:
- What are the benefits identified by Young People of 'peer participation'?
 - What advantages/losses participants in services and with Young People?
 - What are the barriers identified by Young People of 'peer participation'?

METHOD:

What are you going to collect, where, support the aims and questions?

(If you don't already know what you will be measuring e.g. needs, awareness), (Qualitative) (Quantitative) (Mixed methods) (Both qualitative and quantitative)

If you are going to explore this research, the author should provide a way for someone to do it



Are they going to:

1. Have a general discussion (qualitative) and
2. Try to find some groups to explore if we need to collect more and how we might do this (quantitative)
3. Otherwise you would be to discuss after this

DATA ANALYSIS:

To get to results, we have to ANALYSE the data

Depending on the type of data, there are different techniques available for the research and those groups

Thematic Analysis...

Thematic analysis requires researchers to identify groups of patterns in the data that connect to significant themes in relation to the research question.

- Identifying themes (by applying codes) by listening to the group and reading text
- Thinking about what these themes might mean, be related and connect to

RESEARCH QUESTIONS AND AIMS

This research actually aims to establish and investigate Young People's experiences of 'peer participation' within mental health settings through a PhD framework with Young People as 'co-researchers'.

Although this study aims to also look to the PhD process, this is not what we will be within the current process and expectations of both research (PhD and Research). Therefore, the following research questions are provided to guide the basis of research:

- What are the benefits identified by Young People of 'peer participation'?
- What advantages/losses and Young People to become involved in 'peer participation'?
- What are the barriers identified by Young People of 'peer participation'?

A further aim is for this project to lay the foundations for Young People's and mental health with the possibility for it to continue the project with an aim to the degree above up the group beyond the period of this specific research.

WHY THEMATIC ANALYSIS?

CONSIDERATIONS TO UNDERSTAND AND INTERPRET THE DATA

LEADS THEM WELL TO COLLABORATIVE PROCESSES (WORKING TOGETHER)

AUTHORITY IS TO ALLOW OUR OWN IDEAS, REFERENCE TO ANALYSE AND BRING THEM TOGETHER

REMOVES/DECREASES ASSUMPTIONS

- It's about what groups (own words) and how to make connections to both in the data and analysis (own words)

Thematic Analysis Process

Stage 1: Reading through the data / transcription



Stage 2: Highlight / write down initial codes (could be a word / phrase) from any patterns that you spot as you are reading through.

- Put these lines on post-it notes and place on the wall.



Stage 3: Grouping, regrouping and re-organising of these codes together to give us CLEAR THEMES and sub-themes.

Stage 4: Naming these themes together

Stage 5: Any ideas about what might be going on in each theme, related to / connects to

AN EXAMPLE OF WHAT IT MIGHT LOOK LIKE



Table 1: Summary of Themes

Topic	Young People
Experiences	Experiences, Relationships in Healthy Young People, Learning, Learning from Others
Participation	Learning from Others, Learning from Others, Learning from Others
Knowledge and Learning	Knowledge to Improve, Knowledge that Improves the World, Learning from Others, Learning from Others, Learning from Others
The Impact of the Project	Learning from Others, Learning from Others, Learning from Others

RESULTS:

WHAT WAS FOUND?

HOW WILL THIS BE PRESENTED?

DISCUSSION:

- Should link to the introduction
- Discuss about the research process and findings
- There should be an awareness of weaknesses in the research
- Discuss about how the problems could have been resolved differently
- Recommendations for future investigations of a similar nature



DISSEMINATING:

Sharing the research and working together...

- Presentation
- Writing a journal paper
- Blogging
- Why other ideas?



WILDEST DREAMS

What are your wildest dreams for this project?

- When did you wake up at all this project in the first?
- When did you think you could not?
- How might you have constructed this project differently?



REFERENCES

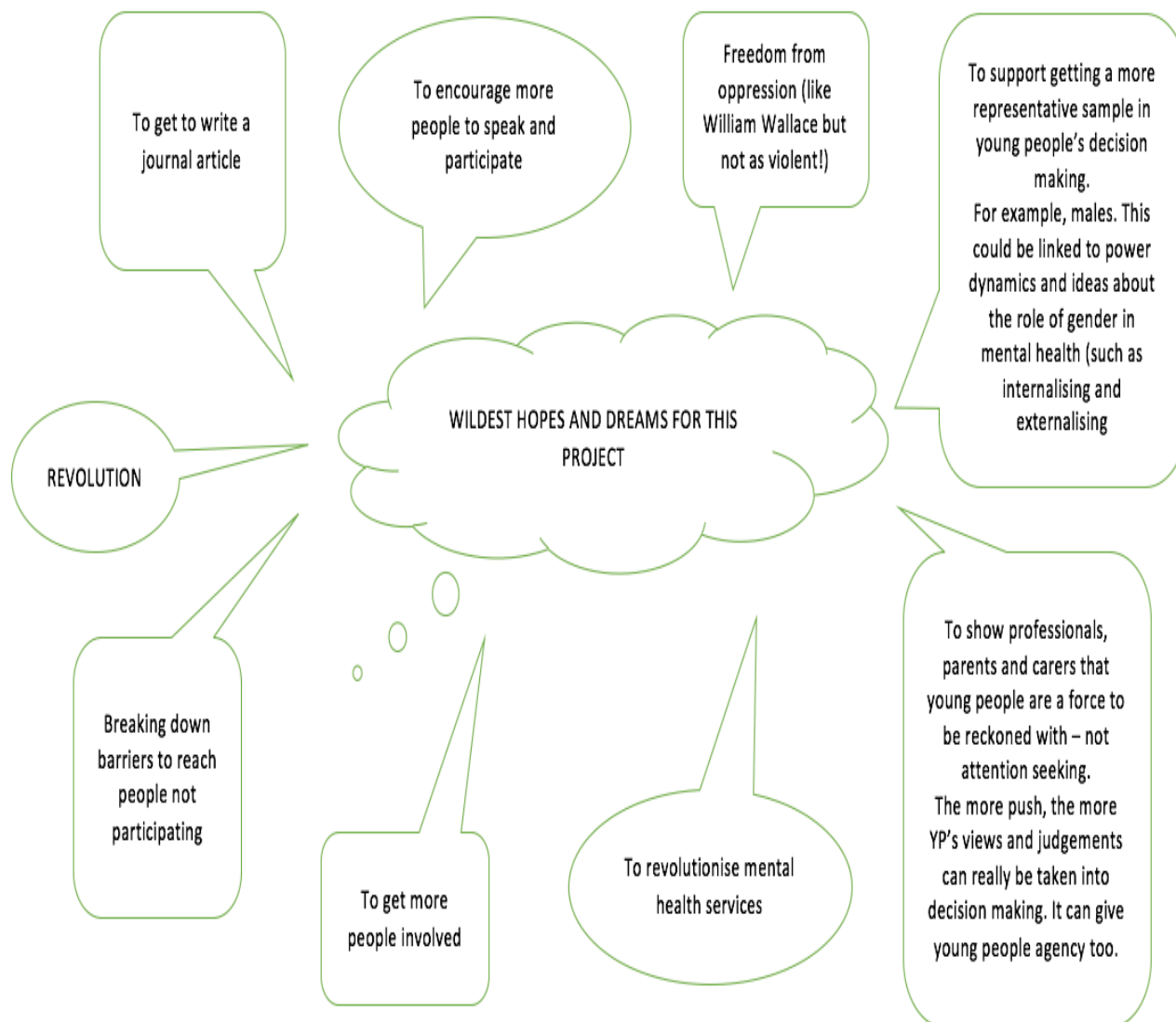
PLEASE LET US KNOW IF YOU NEED ACCESS TO ANY PAPERS!

- Anderson, J. (2012). Development in South Africa (2000-2010) under scrutiny: what's next? In J. Anderson (Ed.), *Global Development Review*.
- Kohn, P. (2010). *Waking Up: A Guide to Waking Up to the World's Most Important Issues*. New York: HarperCollins.
- <https://www.researchgate.net/publication/311111111>

Online version (also see reference list in first proposal document)

- Day, E. (2010). *Waking Up: A Guide to Waking Up to the World's Most Important Issues*. New York: HarperCollins.
- Kohn, P. (2010). *Waking Up: A Guide to Waking Up to the World's Most Important Issues*. New York: HarperCollins.
- Kohn, P. (2010). *Waking Up: A Guide to Waking Up to the World's Most Important Issues*. New York: HarperCollins.
- Kohn, P. (2010). *Waking Up: A Guide to Waking Up to the World's Most Important Issues*. New York: HarperCollins.

APPENDIX H: Wildest Hopes and Dreams



APPENDIX I: Discussion Schedule for Focus Group 1

Introduction to the session

Thank you all for coming to do and sparing your time to come and talk about young people's 'participation' within mental health settings tonight. As many of you know, this study aims to understand and explore Young People's (YP) experiences of 'user participation' within mental health settings through a Participation Action Research framework with YP as 'co-researchers'

My doctoral study is about the work we're doing in this group and how we're doing it is a part of the research. As a 'co-researcher' I have burning questions which I'd like us to consider but also want to include burning questions you have.

Would it be possible for us to work on my 3 questions for today and make sure we name yours so that if we run out of time this evening (and we agree to come back on work on them) we work on yours as well?

- Time at the end to think of areas that not covered.

This group is one of the first ways of us exploring this area together. The purpose of this focus group is to begin to understand the topic together. This group discussion will form the basis for and inform the rest of our project. Last time we all thought about our wildest dreams for this project and hopefully these discussions are an initial step towards us getting there.

There are no right or wrong opinions, I would like you to feel comfortable and encourage you to say what you really think and how you really feel (ground rules). As you have consented, would it be ok to record this session? This will remain anonymous and confidential within the group. Remind of signed consent and sharing agreements.

- Is there anything you need from me to support you feeling free to contribute to this project as a co-researcher?"

Broad Questions:

- What benefits do YP identify by being 'service-user participants'?
- What encourages increased YP participation practices in MHS?
- What barriers do YP identify in their role as 'service-user participants'?

Discussion 1: Benefits

An area of interest is experiences and thoughts about 'user participation, involvement, co-production' (being involved in mental health settings at different levels). Thinking specifically about 'user participation, involvement, co-production', I would like to firstly discuss with you all any benefits you think being involved or 'user participation' brings?

Discussion 2: Encouragement

Benefits of being involved are likely to have an impact on how much YP get involved within mental health setting before we think about the barriers and challenges of user participation. I would like to spend some time thinking about thinking about what encourages participation practice in mental health settings?

Discussion 3: Barriers

Challenges and barriers to 'user participation' within young people's mental health settings are also likely linked to benefits and engagement. What are the barriers to YP's participation in mental health settings?

Other Questions

- What have we not discussed here that is relevant?
- What areas would we like to research and think about for next group meeting?
- Any other comments or questions?

Ending the session prompts

Summarise the discussions and thank YP for their time.

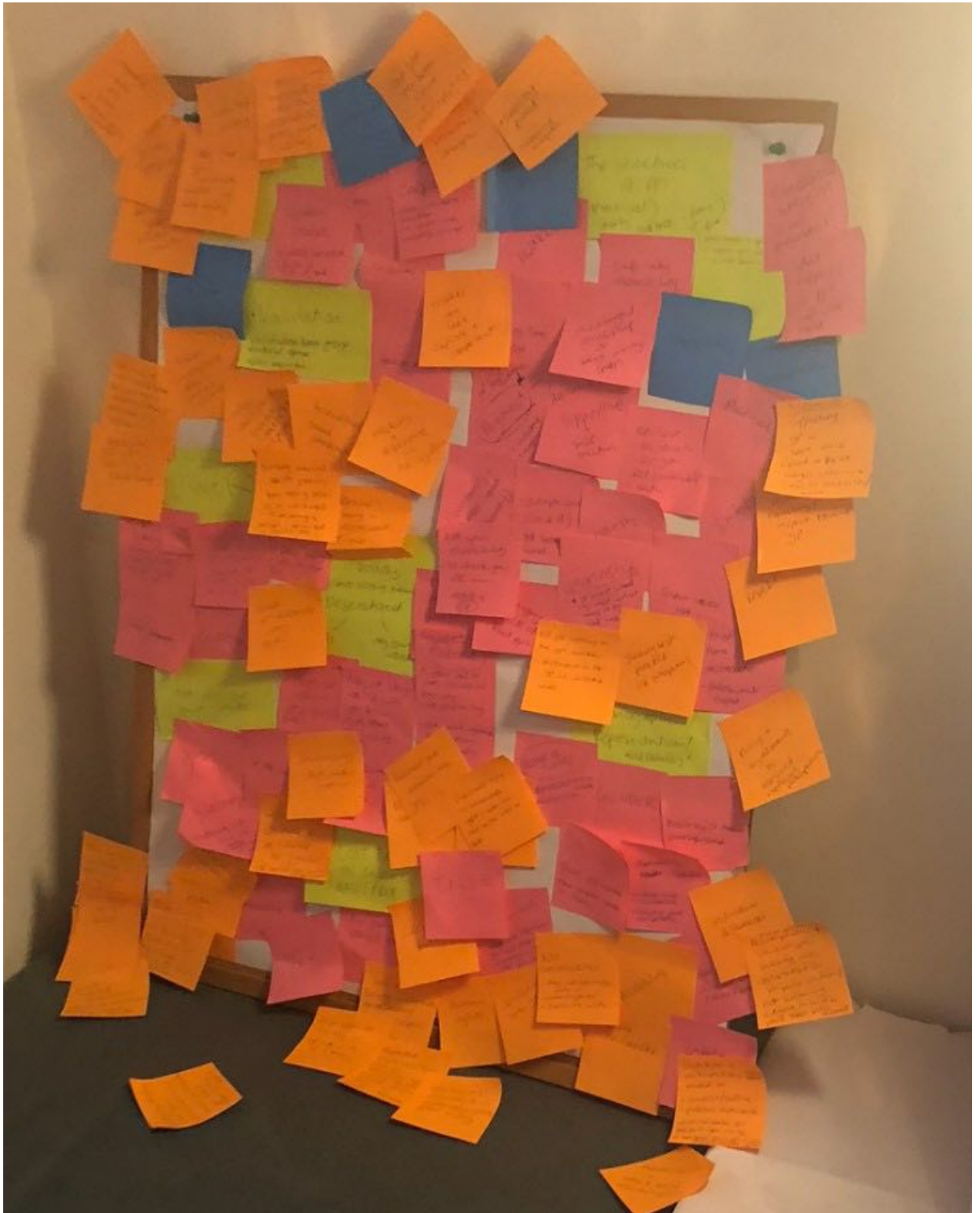
Remember to collect the consent forms and promote being a part of the research group, if any young people who have not been present in the 'engagement phase'.

Re-emphasis that this is the first stage in supporting us to think about the research. I will transcribe and type up the transcript and make available (anonymous) on online forum if everyone is ok with that.

As a team, we can think about if we think we would like to hold another focus group or collect data in another way that the group think of (remind of option to be involved in analysing the data after 'data collection' stage)

The image shows a whiteboard with a large number of sticky notes. The notes are organized into several distinct groups, each with a central theme or title written on a larger, often yellow, sticky note. The themes include 'Positives of VP', 'The Structure of PST', 'POWER', 'TRUST', 'LOST TRUST IN SERVICES/ NUS / PRC', and 'Demographic Representation'. The individual sticky notes contain handwritten text in various colors (pink, blue, yellow) and some include small diagrams or sketches. The notes are densely packed, especially in the lower half of the board, and cover most of the white surface.

APPENDIX J2: Supplementary Codes and Thematic Analysis



Professionals vs JP
Adults in charge
JP overheard ignored
Systemic not just professional power JP
JP shared ignored
Policy
It's responsibility
Shared experience
Professional challenge of JP solidarity
Systemic issue
negotiated
normalised ways in
'interaction'
JP shared ignored

solidarity JP-JP
Validation
engagement
humanised
seen as different by professionals
JP overheard ignored
systemic issues
JP's
Pot voice being heard
JP shared ignored
Policy
change / action
successful
solidarity JP
structure to safeguard
JP
change / action
Power
professionals vs JP
sense of difference
JP as whole
solidarity
change

P1: I guess like, out of what you guys raised it's like good points and it like even helps build rapport like there's people who are, they, we kind of like have a rapport in a way because I interviewed them or whatever and they kind of like remember me in that sort of way but I guess that even though it's good to have young people involved it's, there is still like that power difference, sort of thing like the adults are still in charge and sort of thing. I have done like young people focussed interview panels and I've also done some that were like professionals as well. I can find the young people one is kind of like it's always done first, it's been a free for all when we can ask whatever we want sometimes like the interviewees they still look down on us because we are young people, even sometimes the adults they don't really pay attention to young people. You guys have given great examples of where like young people have been listened to but sometimes like young people aren't listened. Sometimes things like CAMHS is overstretched or we can't afford to do another recruitment drive or we really like this sort, kind like over of thing over power, over the young people's panel even though it's a good thing and also stuff like availability as obviously it's a 9-5 like service and sometimes young people can't make it because of school and what not

Practical aspect / structure for participation
F: So, it's interesting that you have talked about power there and age being (remember like when we did the GGRRAACCCESS) somewhere where power and the adults might hold more of that and it was interesting when you were saying that even though everyone was like "what"? That person still got picked for the job and interesting like you were saying, X it was a bit different in X and things were listened to a bit more. So, I wonder if there's quite a lot of differences in services as well?

P5: What you were saying about young people not being listened to, because X has been going around for about 12 years and that's what actually happened it's like they would be interviews or group meeting with consultations with professionals and there would be young people sat in the room and the professional would just look at the participation worker and not the young people. X actually came up with this agreement where any visitors / adults had to sign it and if they didn't agree to it then they just wouldn't be accepted because obviously one of the things at the X is like I say it's young person holistic, it's all about the young person. You can't expect the young people who come into that service then they are not going to be willing to help because their whole persona, not persona, their ethos is all about young people and empowering young people. What you are saying it just reminded me of, it actually did happen in X and now it's changed because we / X put something in place (this was before I joined it) but they put something in place and actually it works really, really well now, so I agree 100% with what you are saying but I just wanted to like to say something was put in place to stop that, do you know what I mean? To like balance it out

Validation, Solidarity JP-JP
P1: Yeah, it's a good idea that kind of thing to be put in place like makes people be more aware of that whilst working with young people and I'm glad that has kind of like made a difference.

P6: They don't even know they are doing it. As a general rule, if you are an adult or professional working with teenagers you work with them in a very linear I am a Doctor you are the patient kind of way and like mental health treatment isn't usually super, super collaborative like obviously there's a bit of collaboration but it's not really usually something, like, the professional is very much the professional and it can be very difficult for professionals to kind of step out of that, that idea of like I know what to do and you don't because if you knew what to do then you wouldn't be in treatment but in terms of terms of participation and youth participation I know what to do and they don't because like they don't have no experience of the service from the other side

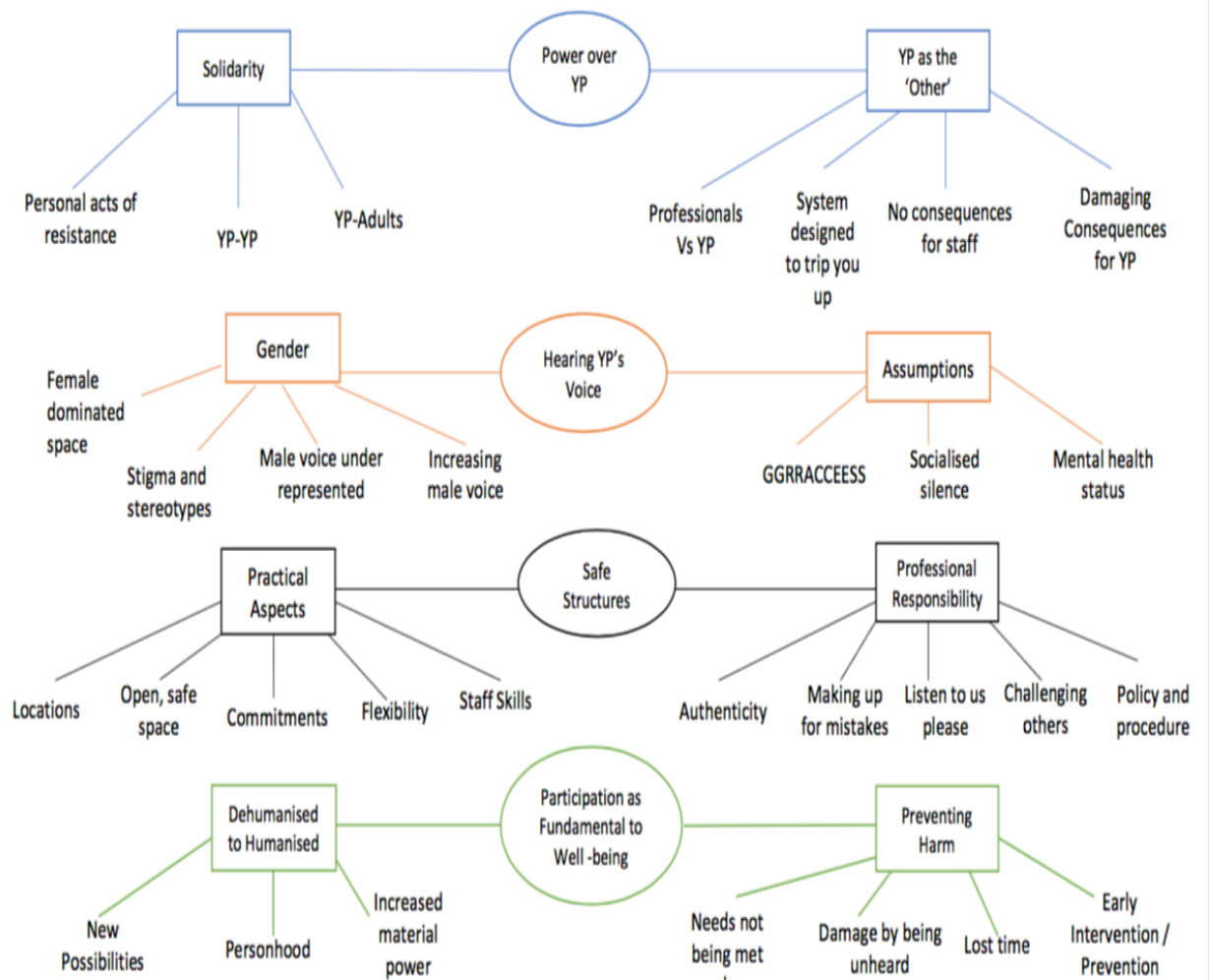
P2: I think it could promote more, I know what you're saying more individualised care rather than generic care which often operates within inpatient like there are rules and there is procedures and I guess a journey of care that they expect all the young people to go through and when that doesn't really work out for that particular young person then they don't know what to do, so user involvement and things like that they've had in the hospitals I have been in, I mean we don't always get listened to but that kind of shared individual experiences so that the professionals know to like tailor to different people rather than just a general kind of broad treatment plan.

Better services
interaction
personhood recognised

APPENDIX L1: Mindmap for Organising Codes



APPENDIX L2: Intermediate Thematic Map



APPENDIX L3: Final Thematic Map

