EXPLORING THE BENEFITS AND CHALLENGES OF VOLUNTEERING: PARTICIPATORY ACTION RESEARCH WITH PEOPLE WITH LIVED EXPERIENCE OF MENTAL ILLNESS

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ABSTRACT

Volunteering is associated with a range of health and employability benefits. However, there is limited evidence of the collective experience of volunteering for people recovering from mental illness. This thesis presents a participatory action research project in collaboration with a group of ten working age adults comprising four men and six women of white British ethnicity, predominantly Scottish and all living in the same Scottish city. All had lived experience of mental illness; many had significant experience of volunteering and all were actively engaged at the time of the research in unpaid volunteering in the community through personal choice as part of their recovery journey. The aim of the project was to hear about the benefits and challenges of volunteering including the positives and negatives of socio-political and welfare systems that support people with lived experience of mental illness to volunteer, with a view to producing something through action that would be of benefit to the group and/or the wider community.

Participants took part in a preliminary interview and attended a series of five participatory action research groups. Thematic data analysis of the interviews was carried out by the researcher. Data generation and analysis of the PAR groups was combined and followed Freire's (1970, p. 80; p. 104) process of "problem posing" and "conscientization" or critical consciousness raising where participants by asking critical questions about their situation recognised the potential for transformation. Data analysis of the PAR groups was collaborative, iterative, cumulative and co-constructed with themes revisited and revised by participants. Findings revealed factors that supported and hindered a positive volunteering experience including challenges from the socio-political impact of welfare reform. Participants produced a briefing paper to inform newly devolved powers supporting the Social Security (Scotland) Bill to support change at policy level and resolve the problem of mandatory volunteering in Scotland.

This project has generated a new understanding of the experience of volunteering for people with lived experience of mental illness proposing an original theory of five conditions for successful volunteering that are necessary to support recovery namely: readiness and support to volunteer; synergy between volunteer and experience to ensure volunteering is meaningful; flexibility to stay well; opportunity to meet needs for identity and connectedness; and opportunity for influence and activism. Findings have also highlighted the negative effects of neoliberal welfare policies on the experience of volunteering for out-of-work disabled welfare recipients; demonstrated how PAR contributes to positive socio-political change with findings supporting Scottish Government policy development; and exposed how at a practice level the hegemony of paid work dominating occupational therapy vocational services limits an understanding of volunteering to one viewed solely through a work lens, with limited critique.

Keywords: volunteering, welfare reform, neoliberalism, participatory action research, lived experience, mental illness, recovery, occupation, occupational therapy, vocational rehabilitation

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> …..if I have seen further than others, it is by standing upon the shoulders of giants. (Isaac Newton 1675)

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CHAPTER 1: INTRODUCTION

> …..volunteering? It's been very good for me, I'm telling you. It's been a lifesaver. (Doug, interview)

As an occupational therapist working for many years in acute and rehabilitation mental health services in Scotland, I have witnessed the therapeutic potential of volunteering as a meaningful occupation for people with lived experience of mental illness in supporting their recovery journey. Occupational therapy is based on the premise that engaging in meaningful occupation through personal choice promotes wellbeing and supports recovery (Reilly 1962; Wilcock 1998b; 1999; 2007; Reed et al. 2010; WFOT 2010; Wilcock and Hocking 2015; Hammell 2017). Indeed, occupational therapy research evidence suggests that meaningful occupation including volunteering provides purpose and daily structure; offers possibilities for developing social connections and a sense of belonging; and fosters roles that reaffirm identity (Rebeiro and Allen 1998; Farrell and Bryant 2009a; 2009b; Aldrich et al. 2014; Fegan and Cook 2014). Although this explanation is helpful in understanding the therapeutic potential of volunteering, it could be argued that volunteering in and of itself and more specifically the type of volunteering experience selected by people with lived experience of mental illness, may offer additional benefits through altruistic acts of helping others, which has been less explored.

In the 1980's, while working in a local mental health hospital, I became a founding member of a multi-agency group supporting voluntary work as therapy, working alongside mental health pioneers from the voluntary sector to support the transition of people from hospital into the community through volunteering in what was at that time viewed as an original and innovative project. No empirical evaluation of this work was ever undertaken despite anecdotal evidence suggesting that it was highly valued by all who participated and was a useful first step in tackling the stigma and social exclusion of people with lived experience of mental illness at a local community level and more significantly, enabled people to transition from their role as patients to become providers of services. In 2012, a serendipitous conversation with a former colleague now employed by Volunteer Edinburgh, one of the third sector organisations at the forefront of the original project still supporting people with lived experience of mental illness into volunteering, led to us reflecting that despite the substantial service developments that have taken place over the last thirty years, there remains a distinct lack of research in this area. The seeds were sown for this project.

This thesis tells the story of this project based on participatory action research with people with lived experience of mental illness who are volunteering in the community through personal choice to support their journey of recovery. In this chapter I introduce the context, rationale and aims of the study and provide an overview of how this thesis is organised.

1.1. The context and rationale for this study

> …..volunteering brings enormous benefits and enjoyment, not only to beneficiaries, but to communities, and to volunteers themselves... volunteering increases social and civil participation, empowers communities, and reduces loneliness and isolation. (Scottish Government 2019b, p.6)

Arguably, volunteering is a powerful, societal commodity. In the UK it is rooted in a history of philanthropy, providing charity for those less fortunate through a non-profit paradigm; and mutual aid*,* identifying common concerns and working collaboratively to bring about change through a civil society paradigm embracing self-help and activism (Baines and Hardill 2008; Ellis Paine et al. 2010). There are more than 140 million people volunteering across the world representing the equivalent of 20.8 million full time jobs, all making a significant contribution to the global economy, who if they congregated as one population, would form the ninth largest country in the world (Johns Hopkins centre for civil society studies, in Wu 2011, p. 5). In Scotland, volunteering contributes over two billion pounds to the economy (Cross Party Group on Volunteering 2016; Scottish Government 2019b). However, there is significant variation in participation rates across the UK, with differences in definitions of volunteering including what constitutes formal and informal volunteering and differing research methodologies, making comparisons unreliable (Harper 2015; Volunteer Scotland 2017). For example, formal volunteering is defined as:

> *…..*the giving of time and energy through a third party, which can bring measurable benefits to the volunteer, individual beneficiaries, groups, communities, the environment and society at large. It is a choice undertaken of one's own free will and is not motivated primarily for financial gain or for a wage or salary*.* (Scottish Executive 2004, p.6)

By "third party*"* this definition clarifies this is formal volunteering, undertaken with a charity or public body, which is outwith the individual's family and is not informal good neighbourliness. Although there is general agreement that volunteering is given of free will, without pay, for the benefit of others, debate remains as to what counts as volunteering with informal volunteering outwith a charitable organisation, often carried out in low income and marginalised communities, going "under the radar" and frequently excluded from volunteering evaluations in Scotland suggesting a limitation not only in definition but also in comparing research data UK wide (Ellis Paine et al. 2010; Woolvin and Harper 2015; Benenson and Stagg 2016, p.133; Volunteer Canada 2017). Informal volunteering is defined as giving individual help to people who are not relatives such as being a member of a local grassroots community group or resident association; and informal mutual aid such as looking after children or participating in a community clean up (Harper 2015; Scottish Government 2019a).

In Edinburgh 35% of the adult population formally volunteer (Volunteer Edinburgh 2017) which is higher than the national average of 28% in Scotland, and lower than the 41% of adults in England (Volunteer Scotland 2017; Scottish Government 2019b). Although the Scottish figure has declined from 31% in 2010, it rises to 48% when informal volunteering is included (Maltman et al. 2019). According to the Scottish Government (2019a) levels of formal volunteering increase as the area deprivation decreases. Edinburgh's formal volunteering figure is therefore likely attributed to Edinburgh being an affluent city with average household incomes estimated at above the Scottish average and the city having high employment rates and high average wages in comparison to the rest of Scotland (Edinburgh Poverty Commission 2018). However, alongside this apparent affluence sits a degree of poverty with 16% of the city's population recognised as living in relative poverty with the relative income poverty line defined as 60% of the median UK household income once housing costs are removed; whilst an estimated 22% of all children in Edinburgh live in poverty (Edinburgh Poverty Commission 2018).

Perhaps unsurprisingly, an analysis of the results from the Scottish Household Survey 2007-2017 (Maltman et al. 2019) suggests that within the formal volunteer population there appears to be a distinct lack of diversity, with people with higher levels of socio-economic status and education more likely to volunteer, forming a "civic core" who tend to be women, of white ethnicity, aged between 35-44 years, in higher paid employment, living rurally, healthy and non-disabled, and with a

Christian affiliation (NCVO 2017, p. 25; Maltman et al. 2019; Scottish Government 2019a; 2019b). This civic core account for 19% of volunteers providing 65% of volunteering hours (Scottish Government 2019b). Participation rates are lowest for those with a long-term health condition (13%) and for those who are unemployed (Maltman et al. 2019; Scottish Government 2019b). Indeed, despite evidence suggesting that the health and wellbeing benefits from volunteering are stronger for those most excluded in society who face the greatest level of disadvantage (Linning and Jackson 2018), people who could most benefit from volunteering are least likely to participate due to such factors as inequity of access opportunities; fear of social exclusion; negative perceptions of volunteering due to a lack of identification with other volunteers; and distrust of neighbours (Lim and Lawrence 2015; Scottish Volunteering Forum 2015; James et al. 2017). This project is therefore well placed to shed light on the experience of volunteering for people beyond the civic core, exploring the benefits and challenges of volunteering with lived experience of mental illness.

Furthermore, definitions of volunteering become problematic when considering the giving of free will, without pay, and for the benefit of others criteria, with for example, a range of incentives, payments and rewards being offered to volunteers and a degree of coercion into volunteering taking place through legal, social and institutional obligations (Ellis Paine et al. 2010). For example, there has been an increasing requirement for people including young people and recent immigrants to demonstrate their suitability for employment through voluntary work experience, which has resulted in the use of the term “coerced volunteerism” (Schugurensky 2013, p.2) to illustrate the growing trend for unpaid internships in the for-profit sector. Additionally, volunteering has traditionally been viewed as a helpful stepping-stone to paid employment for disabled people, building skills for employability. Indeed, there is a strong association between volunteering and paid work in vocational rehabilitation services where positive employment outcomes for disabled people are viewed as a measurement of success and a means of meeting government targets through supported employment programmes. However, viewing volunteering solely through a vocational lens is potentially problematic and leads to a perception that volunteering is “second best” to paid work and that out-of-work disabled people who are volunteering are either incapable of paid work or potentially capable but deliberately avoiding work and therefore cheating the system in some way. Further, it views volunteering as a means to an end rather than an end in itself.

This view is reinforced by neo-liberal politics underpinning welfare reform in the UK, which has had and continues to have, a significant impact on the lives of disabled people (Equality and Human Rights Commission 2017). Welfare reform is based on the government's view that out-of-work claimants including disabled people are becoming too dependent on benefits rather than obtaining paid employment; and that this promotes a culture of dependency and irresponsibility, in marked contrast to responsible citizens who are in work; thus, defining from the outset the difference between the "deserving" and the "undeserving" (Patrick 2017, p.2). Indeed, the changing narrative of disabled benefit claimants as scroungers, reported in the popular media, has also attracted a range of media criticism and academic research interest, arguably in light of the threat of furthering the oppression already experienced by disabled people (Briant et al. 2013; Baumberg 2016; Gedalof 2018). Welfare reform reinforces a neo-liberal rhetoric of individual responsibility positioning paid work as central to defining the "dutiful citizen" in a contractual form of citizenship where people are expected to work for their benefit payments or face financial sanctions (Patrick 2017; Gedalof 2018). This contractual relationship is not only to the state but also to the taxpayer thus adding further risk of marginalisation through negative public attitudes (Patrick 2017). Many disabled claimants receiving welfare benefits have been required by workfare programmes to undertake mandatory unpaid community work within charities or voluntary organisations in order to receive Job Seekers Allowance (or Universal Credit) or risk significant financial sanctions including loss of benefits. In carrying out what has become viewed by disabled people as "oxymoronic mandatory volunteering", claimants have been offered no choice in their volunteering placement and may have been forced to give up a meaningful volunteering role for one deemed by the UK Government's Help to Work programme as more appropriate to gaining employment, despite no evidence to support this (Keep Volunteering Voluntary, 2014). This contradicts the definition of volunteering as an "…activity undertaken freely that involves spending time, unpaid, doing something that aims to benefit the environment or individual or groups" (Department of Health 2011, p.9-10). Indeed, disabled people could be viewed as being punished through welfare benefit sanctions for not being in paid employment. Furthermore, Improving Lives: the future of work, health and disability

(DWP 2017b) document outlines the UK Government's aim to increase the number of disabled people, including those with lived experience of mental illness, into paid employment thus reinforcing a preoccupation with paid work for all.

Arguably, this focus on work reinforces an able-ist agenda where everyone is viewed as capable of employment given the right support. Although the attraction of support into paid work for some disabled people cannot be disputed, experience suggests that many disabled people face further exclusion, marginalisation and poverty (Newman 2011; Grover 2017). Furthermore, "paid work" is viewed as "unproblematic" and endowed with "transformative properties" as the only way to beat poverty (Patrick 2017, p.28) despite the reality that paid work is often poorly paid, precarious and potentially demeaning, often exemplified by zero-hour contracts where workers have no control, or access to annual leave or sick pay (Standing 2011; Bloodworth 2018; Gedalof 2018). Indeed, whilst being out-of-work significantly increases the risk of poverty, being in employment does not guarantee a way out of poverty (Newman 2011). Employment figures suggest that the gap between disabled people and non-disabled people in employment is widening (Equality and Human Rights Commission 2017). Furthermore, according to Low et al. (2015) only 10% of those with lived experience of mental illness are in paid employment and disabled people are more likely to be in low paid, part-time work, with a third of families with a disabled person living in poverty.

The controversies and complexities surrounding volunteering including the impact of UK welfare reform on the experience of people living with mental illness and volunteering through personal choice warrant further investigation. More specifically, any understanding of the impact, opportunities and challenges from a Scottish perspective is lacking in the literature. This project offers a means to address these gaps.

In terms of volunteering outcomes, evidence suggests that volunteering matters to communities, who thrive through the engagement of active volunteers, whose willingness to contribute and influence is key to developing community spirit and social capital and is essential to the delivery of good services (Scottish Volunteering Forum 2015). Volunteering also matters to individuals. Volunteering is recognised as playing an important role in supporting positive mental health and wellbeing (Tabassum et al. 2016; Scottish Government 2019b). It enhances a sense of belonging and offers an opportunity to contribute (Ellis Paine et al. 2010; Paylor 2011; Wu 2011; Harper 2015; Scottish Government 2019b). Historically, this was an opportunity denied to people with lived experience of mental illness who were perceived as the recipients of help rather than people who could be contributors or influencers. There is now growing recognition that people with lived experience of mental illness can be providers as well as recipients of support in health and social care settings through peer support services, user-led self-help groups, activism, advocacy, mentoring, befriending, and time-banking schemes (Mental Health Strategy 2011; Mental Health Foundation 2013; Rethink Mental Illness 2018). Social prescribing of volunteering is recognised as a powerful means to reconnect people living with mental illness to their communities (Volunteer Scotland 2015). Indeed, volunteering could be considered as a “population intervention” with the potential to increase health and wellbeing, address social exclusion and public health inequalities and support marginalised groups out of poverty, such as people with long term mental illness, through skills development, confidence building, social connection and integration (James et al. 2017, p.4). However, there is general consensus that further research is required to more fully understand the benefits and challenges from the perspective of people with lived experience of mental illness.

Negative effects of volunteering are rarely considered yet cross-national differences in regular volunteering indicate a detrimental effect on mental health, lower than for non-volunteers, in countries with less generous employment benefits, highlighting the impact of poverty, loss of control in cultures that value paid work over volunteering and the importance of financial support in sustaining mental health and wellbeing (Kamerade and Bennett 2015; 2017a; 2017b). Furthermore, whilst there is a range of research evidence on the health benefits of volunteering and the motivation to volunteer (Schugurensky 2013), there is less emphasis on the experience of volunteering itself (Wilson 2012) with limited published evidence of the experience of volunteering, including the benefits of volunteering for improving social inclusion for people with lived experience of mental illness who volunteer as part of their journey of recovery (Farrell and Bryant 2009a; Jenkinson et al. 2013). Further, volunteer organisations are recognised as reflecting experiences of stigma and social exclusion as prevalent in wider society (Farrell and Bryant 2009b, Mental Health Foundation 2013). There is therefore a need to investigate the complexity surrounding volunteering to promote mental health and wellbeing, social inclusion and social justice from a range of perspectives. This project has the potential to address these gaps.

The concepts of mental illness, mental health and recovery also require some scrutiny. In western society, mental illness is used to refer to a range of diagnostic classifications associated with a medical model where individuals fit the criteria for DSM/ICD mental disorders (Friedli 2009). It is generally recognised that one in four people will experience a mental health problem in their lifetime, with 19% of adults in Scotland in 2018 reporting having a potential mental health problem (Scottish Public Health Observatory 2019). In contrast, good mental health and wellbeing is associated with positive outcomes for individual and communities including better physical health; improved social relationships; greater productivity; resilience in coping with illness and adversity; and a better quality of life associated with human flourishing (Friedli 2009). Interestingly, although wellbeing is often considered on a continuum from positive mental health to mental disorder, Friedli (2009) posits that mental illness and mental health are independent of each other with the presence of one not necessarily related to the absence of the other, therefore making it possible to live with a mental illness whilst also experiencing a degree of positive wellbeing. Furthermore, whilst the classification of mental disorders continues to emphasise individual deficits and pathology (Bracken et al. 2012; Harper and Speed 2012; Kinderman et al. 2013; Timimi 2013; Wright 2014) it fails to acknowledge that people will also experience social exclusion, barriers to employment and housing and feel devalued and stigmatised by mental health identities and diagnostic labels which further impacts on their mental health (Harper and Speed 2012). Indeed, evidence confirming the relationship between inequalities and poorer health and other outcomes calls for consideration of mental illness and psychosocial stress less as individual pathology and more in relation to social injustice and deprivation where individual psychological resources are embedded within social structures (Friedli 2009). Unsurprisingly, this has coincided with a rise in user/survivor and recovery movements' critique of psychiatric services to expose the abuse and dominance of biological approaches to psychiatry that over-rely on diagnostic labelling, medication, involuntary detention and restraint and ignore evidence of wider psycho-social and socio-political causes (Chamberlin 1978; Lewis 2013). Indeed, debate continues between individual versus societal origins of mental illness with the critical psychiatry and survivor movements campaigning for a radical rethink of what forms of knowledge are privileged, how mental health is conceptualised and how services are delivered (Bracken et al. 2012; Kinderman et al 2013; Timimi 2013; Wright 2014; Russo and Beresford 2015).

Although recovery is recognised as deeply personal, there has been a lack of conceptual clarity of the nature of recovery (Harper and Speed 2012). For example, in emphasising self-management of the mental illness experience as a personal tool for change, the onus of responsibility for managing the impact on wellbeing from conditions such as poor housing, unemployment, poverty and other social determinants of mental health problems is transferred to the individual rather than society (Harper and Speed 2012). Indeed, critics argue that empowering disabled people through self-management and self-determinism risks individualising social problems and prevents them from being explored politically and collectively (Onken et al. 2007; Harper and Speed 2012). Adopting an emancipatory approach, survivor movements advocate for alternative possibilities for recovery including peer support and full participation in decision-making and organisational governance as “consumer/survivors” (Lewis 2013, p.121; Timimi 2013). Recovery from mental illness is complex and involves both personal and collective challenges. Arguably, this project has the potential to bring to light some of these challenges by exploring the benefits and challenges of volunteering for people with lived experience of mental illness during their recovery journey.

Finally, in supporting the voice of disabled activists resisting disability powerlessness and oppression, beautifully captured by the phrase “nothing about us without us” (Charlton 1998, p.3), there is a drive within policy and practice to engage service users in co-producing, co-designing and co-creating future health and social care services. Co-production advocates equal reciprocal partnerships between service deliverers and service participants (Boyle and Harris 2009) and contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else (Needham and Carr 2009). This requires an element of control from the service deliverer to be relinquished (Carey and Burke 2013). Within critical social research there is growing recognition that traditional research methodologies can remove information from their contexts involving participants as “subjects” and “respondents” rather than active participants in the research process (Baum et al. 2006). Personal recovery narratives become “disability tourism” rather than tools for socio-political change (Costa et al. 2012, p. 85). In rejecting research methodologies that privilege the researcher position over that of the participants, this study adopted a participatory action research (PAR) approach. Interestingly, no PAR study was identified that explores volunteering in Scotland from the perspective of people with lived experience of mental illness.

1.2. Research Aims

This project set out to explore the experience of volunteering in collaboration with a group of adults with lived experience of mental illness, who were engaged in unpaid voluntary work in the community through personal choice as part of their journey of recovery. Preliminary questions were phrased to give scope to the participants to shape the focus of the study, namely:

1. What are the strengths and weaknesses of socio-political and welfare systems that support volunteering from the perspective of the volunteers?

2. What changes might people with lived experience of mental illness be empowered to make through the participatory action research process?

These questions led to the formulation of the primary aim for this doctoral research as follows:

> To hear about the benefits and challenges of volunteering, as well as to explore the positives and negatives of socio-political and welfare systems that support people with lived experience of mental illness to volunteer, with a view to producing something through “action” that would be of benefit to the group and/or the wider community.

In considering research objectives, I recognised that these could change as a result of the participatory action research process. Initial objectives were:

1. To explore the experience of engaging in voluntary work for people with lived experience of mental illness.

2. To explore the benefits and challenges from the volunteer perspective.

3. To explore the benefits and challenges from the volunteer involving organisation (VIO) perspective.
4. To engage and empower participants through the participatory action research process to collaboratively identify strengths and weaknesses of socio-political and welfare systems that support volunteering and explore the potential for change based on the experience of volunteering.

5. To generate knowledge through a process of reflection and action by formulating an action plan to consider how best to address, present and disseminate the data gathered for example, through the production of something of benefit to the group and/or wider community. The "product" could be a written guide or arts-based film, exhibition etc. for volunteer organisations; prospective volunteers with lived experience of mental illness; local government; health and social care professionals; community organisations; friends, families and carers. Findings would also be published in a journal and/or presented at a conference.

6. To reflect on how change had been brought about at an individual, group and wider community level through generating the "product" and by participating in the research project. This could result in further action where action plans are generated in a continuing cycle, which could be sustained independently by the group if they so choose.

It was anticipated that change would occur through engagement in the project with benefits for participants in voicing their experiences with others, feeling understood and not alone, recognising their expert status and having the opportunity to gain insight into the challenges and benefits of volunteering with a lived experience of mental illness from the perspective of others. Through the participatory action research process participants would have the opportunity to positively influence their own experience of volunteering and the lives of current and future volunteers through creating a resource or product to be shared with the wider community. It was also anticipated that there was potential to develop a peer support network that could be self-sustaining if participants were interested. Additional positive outcomes were anticipated through generation of knowledge that could be shared with a wider audience including the voluntary sector and the professional and academic community.

1.3. Thesis structure

Following this introductory chapter, I review selected literature relating to volunteering and mental illness in Chapter 2. There are four sections to the literature review. Firstly, I explore theoretical underpinning from an occupational therapy perspective specifically the link between meaningful occupation and wellbeing before considering empirical work on volunteering and mental health highlighting problems of definition, tensions and challenges, and the place of altruism. I then explore the importance of the context of welfare reform on the experience of people with mental illness as out-of-work benefits claimants highlighting challenges and perceptions of deservingness; before finally examining mental illness and recovery.

Chapter 3 outlines the methodology and research strategy and provides a rationale for participatory action research (PAR) within a critical emancipatory paradigm.

Chapter 4 explores the research process, choice of methods and how the participatory process shaped the original research intention. It includes a description of participant recruitment, the collaborative partner and ethical considerations.

Chapter 5 presents the data analysis process ensuring transparency.

Chapter 6 provides an introduction to the findings with chapters 7, 8 and 9 presenting findings according to three overarching themes from the data analysis process. Chapter 7 is concerned with “Selfish Altruism: Journeys of Recovery Through Volunteering”; Chapter 8 with “The Darker Side of Volunteering”; and Chapter 9 with “Reflection and Action: Keeping Volunteering Voluntary”.

Chapter 10 offers a discussion of the key findings from the previous three chapters including reflections on the experience of PAR and the research process.

Chapter 11 concludes this thesis, summarising the research intention and key themes and outcomes from the findings to make recommendations and highlight the potential of this study to contribute to theory, policy, practice and future research.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction to Literature Review

A literature review is a creative process that involves joining discipline specific conversations to critically analyse and reveal what is already known about a topic, identifying controversies, flaws and gaps to comment and advance the dialogue (Silverman 2000, p.295; Bloomberg and Volpe 2018). This requires decisions about the type, scope and extent of the review; whether it should be written before or after the other chapters; and how literature is selected (Aveyard et al. 2016; Hart 2018). The review requires transparency in reporting key elements including questions to be explored; search strategy with key terms, inclusion and exclusion criteria to screen the literature; acknowledgement of sources of evidence; and critique, analysis and synthesis of findings in relation to the research question and the quality of evidence to draw conclusions (Aveyard et al. 2016; Garrard 2017; Hart 2018). Choice of different types of review and approaches are available. A categorical review categorises the literature according to a set of topics or concerns, whilst a generative review draws on the available literature to generate a case and argument for the proposed research project that will extend the literature (Hart 2018). These are not mutually exclusive (Hart 2018) and this review will attempt to do both.

Given that a key aim of the study was to hear about the benefits and challenges of volunteering, as well as the socio-political and welfare systems that support people with lived experience of mental illness to volunteer this was a good starting point in considering the scope of the literature review and highlighted questions to be explored in the literature, for example:

1. What is the evidence for the benefits and challenges of volunteering for people with lived experience of mental illness?
2. What is the evidence of the experience of people living with mental illness and volunteering in the current socio-economic climate in the UK?
3. Is occupational therapy literature useful in conceptualising volunteering for people with lived experience of mental illness?
4. To what extent does the proposed study fill a gap and extend the literature?

These questions signalled an approach encompassing research evidence from a range of disciplines including occupational therapy. Specific details of the search strategy are provided in Appendix 1 including a map of the literature review themes (Figure 1), search terms, and decisions on inclusion and exclusion criteria.

2.1.1. Literature Review Themes

Four themes generated areas for conversation from the search strategy and serve to structure this review:

1. Meaningful Occupation and Mental Health:

This first, takes an occupational therapy and occupational science discipline specific perspective to frame my study within a discipline specific backdrop. It explores seminal theory underpinning meaningful occupation and how this supports the lives of people with lived experience of mental illness.

2. Volunteering and Mental Illness:

This theme investigates the conversations beyond occupational therapy advocating and evaluating volunteering in supporting mental health and wellbeing. It reveals the scope of volunteering, evidence of outcomes and the place of altruism and motivation to volunteer and positions the study in a wider context.

3. “Work always pays”: Welfare Reform and Perceptions of Deservingness:

This theme became necessary given the dominance of welfare reform issues emerging in my findings and was added following data analysis. It considers political conversations surrounding welfare reform in the UK and exposes the position of disabled out-of-work claimants including people with lived experience of mental illness currently volunteering. These conversations are important in framing my study within the current socio-political context in Scotland and the UK.

4. Mental Illness and Recovery:

This final theme explores influences on the conceptualisation of mental illness, highlighting debates surrounding recovery, which are implicit in my study and warrant investigation.

2.1.2. Terminology

Before discussing each theme, key terms require clarification.

The term “disabled people” will be used in line with the social model of disability that argues that it is society that disables people who have impairments (any functional or physical limitation) regardless of whether these are physical or psychological (Shakespeare 2013). This includes people living with mental illness unless otherwise stated. The social model attends to the collective experience of disablement in summoning a call to action to “identify and remove the barriers which have excluded people with impairments from participation as equals in everyday life” (Cameron 2105, p. 109). This aligns well with my PAR study looking at the benefits and challenges of volunteering for people with lived experience of mental illness. However, the social model has flaws in its argument that disadvantage has nothing to do with individual impairment (Shakespeare and Watson 2010). This study therefore aligns with Shakespeare and Watson’s (2002; 2010) and Shakespeare’s (2012; 2013) revisioning of the UK’s strong position on the social model of disability to embrace an embodied ontology that acknowledges the complexity of disabled people’s lives and understands “disability as the dynamic interrelationship of an individual with a health condition and the environment in which they find themselves” agreeing that disability “cannot be reduced simply to barriers and oppression” (Shakespeare 2012, pp. 129-130). Furthermore, this study also aligns with the affirmation model definition of impairment and disability proposed by Cameron (2015, p. 118) where impairment is identified as difference rather than deficit and recognised as an “ordinary” rather than “extraordinary” element of the human experience and defined as:

> …physical, sensory, emotional and cognitive difference divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society.

Disability, within this model is proposed as:

> …a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal. (Cameron 2015, p.118)

This study adopts Cameron’s (2015) position that disability is a role which forms a productive as well as restrictive relationship in terms of what people are excluded from in their lives and more significantly includes the roles that people are required to adopt in relation to their impairment whether passively accepting being a victim of personal tragedy or denying the significance of difference thus negating impairment in response to the dominant societal discourse of what is considered normal.

The term "volunteering" will be used rather than "voluntary work" unless otherwise stated in the literature under review. This is to distinguish volunteering as an entity in itself rather than one that is viewed primarily through a vocational or work lens.

The term "occupation" will be used in line with the occupational therapy and occupational science literature, defining occupation as "the things that people do in their everyday lives" (WFOT 2010, p. 1); or "all the things that people need, want, or have to do" (Wilcock 2006, p. xiv); with occupational therapy recognised as "promoting health and wellbeing through occupation" (WFOT 2010, p. 1). Occupation is therefore a broad range and means of everyday purposeful and meaningful, time filling activities traditionally divided into work, self-care and leisure, which may include sport, creativity, social, cultural and educational activities or hobbies and may be carried out individually and as communities and societies (Townsend 1997; Wilcock and Hocking 2015). As such, volunteering fits within this traditional definition of occupation. However, in challenging traditional categories of occupation as simplistic and ethnocentric, Hammell (2017) calls for a more inclusive understanding of occupation recommending that occupation is conceptualised according to the meaning or qualities of experience described by the people engaged in the occupation and the extent to which it is valued and meets their wellbeing needs. This study aligns with Hammell's (2017) conception of occupation in considering what qualities of meaningful living have value for the wellbeing of people with lived experience of mental illness and to what extent volunteering as an occupation fulfils these dimensions of value.

2.2. MEANINGFUL OCCUPATION and MENTAL HEALTH.

> …..unless you have some kind of occupation you don't really exist at all, do you, in society or as an individual? You're just nobody in a sense, aren't you? (Blank et al. 2015, p.201).

The above quote from a person with lived experience of mental illness highlights the importance of occupation in supporting a sense of identity and the notion of doing as necessary in contributing to an experience of being (Blank et al. 2015). The quote also invites us to consider being as existing as an individual but also being as connected to society. Although not explicit within the quote, it calls to mind the African philosophy of Ubuntu, "I am; because of you" which embodies notions of connection and community with existence and humanity bound together through "human kindness and mutual caring" (Torgovnick May 2013, online).

Indeed, occupational therapy theory emphasises meaningful occupation or doing as a mechanism for health and wellbeing as highlighted in Mary Reilly's seminal quote: "That man, through the use of his hands as energized by mind and will, can influence the state of his own health" (Reilly 1962, p88). The dynamic relationship between occupation, personal choice, motivation, wellbeing and empowerment is implicit in this quote, which underpins occupational therapy. It has roots in humanistic psychology emphasising human flourishing, through purpose and meaning, and self-determinism, through creativity and thoughtful action, to realise aspirations (Rogers 1977; Maslow 1998; Vanderweele 2017). Further, these ideas have resonance with the principles of recovery from mental illness including empowerment and self-management (Leamy et al. 2011). Interestingly, Aristotle's notion of an impoverished life, which is recognised as one "without the freedom to undertake important activities that a person has reason to choose" (Aristotle in Sen 2000, p.4), is helpful in highlighting a potential problem in Reilly's thinking. For example, whilst Reilly's quote is inspiring, it could be argued that it emphasises individual responsibility and ignores wider socio-cultural, environmental, economic and political forces including social determinants of health beyond the control of the individual that impact on communities and populations, which perhaps Aristotle makes implicit in his reference to freedom and choice. This theme will be revisited.

According to occupational theorists, meaningful occupation can be regarded as simple and everyday but also complex due to the range of internal and external values that are placed on what constitutes meaning (Reed et al. 2010). Meaningful occupational engagement enables possibilities through its transformative potential and can be linked to identity and tradition, motivated by passion and human connectedness (Reed et al. 2010). Hammell (2017, p.211) in recognising the importance of meaningful occupational engagement as central to meeting wellbeing needs draws on cross-disciplinary research to identify these as: taking care of oneself through sourcing shelter, sanitation and food; meeting needs for hygiene and for emotional self-care through routines, rituals, rest and restoration with or without the help of others; having the need for belonging and social connectedness to family, friends and communities; contributing to the wellbeing of others alongside feeling valued and having a positive sense of self-worth and identity; being able to experience and express pleasure and having purpose and meaning through roles that are individually and/ or collectively valued; having the ability and opportunity to express and experience hope, choice, control and empowerment. Indeed, Hammell (2017) recognises these needs as having resonance with those necessary for recovery for people with lived experience of mental illness.

Further, meaningful occupation can be understood as a central mechanism for health and survival through a process of "doing, being, becoming and belonging" (Wilcock 1998b; 1999; 2007; Wilcock and Hocking 2015). These dimensions, now well-used terms within occupational therapy literature, may be useful in considering the lived experience of people with mental illness who are volunteering in a process of recovery and are therefore worthy of further consideration.

Doing, is engagement in meaningful and purposeful occupation including work that provides structure, pleasure, social interaction and societal development, which may or may not be health giving (Wilcock 1998b; 1999, p.1). However, it should be noted that meaningful occupation is not always purposeful or structured (Hitch et al. 2014a) and occupations that people participate in are not always meaningful, purposeful or pleasurable and may, for example, be carried out on the basis of cultural expectations (Hitch et al. 2013). Indeed, some individuals may be coerced or forced into doing or they may choose to do occupations that have arguably negative consequences for them, a concept now described as the "dark side" of occupation (Twinley 2013, p.301). Engaging in meaningful occupation that has personal significance in a "self-directed process of healing and transformation" resonates with the concept of recovery from mental illness (Deegan 2002). Further, it aligns with Csikszentmihalyi's (1975) concept of flow where people become absorbed in their doing, an intrinsically rewarding experience, which arguably leads to being.

Being, is investing meaning in life, drawing on personal characteristics and abilities to fulfil creative endeavours or occupational roles and involves self-reflection (Hitch et al. 2014a). It is about being true to ourselves as individual human beings recognising our values and worldview and how these influence what we do (Wilcock 1999). Choice and agency are usually expressed through being, but this may not always be achievable (Hitch et al. 2014a). Arendt's (1958 in Dant 2003, p.43) thinking is useful when reflecting on choice and meaning in distinguishing between labour and work, where labour is described as the necessary, ongoing, grind of everyday life involving pain and "must be accepted as part of the human condition" thus indicating a lack of choice. Arendt considered labour and more specifically "alienated" labour, drawing on Marx's view of loss of freedom and self-control in productivity through capitalism, as never ending (Arendt 1958, in Dant 2003, p.44); whereas work, a more creative process involves as an end point, the production of something that has permanence and utility beyond the labour process thus indicating creative fulfilment and being (Arendt 1958, in Dant 2003). Arendt's position primarily relates to the industrial revolution where the shift from reliance on tools to machines also impacted on worker autonomy who, no longer in control of the work process, lose the ability to realise their own creativity and imagination through work (Dant 2003). It could be argued that work in this regard represents being from an occupational perspective where personal creativity is invested in the process of doing, compared to labour which is a viewed as a type of endless drudgery, perhaps exemplified by current demeaning forms of paid employment or zero hour contracts where workers have no control, or access to annual leave or sick pay (Bloodworth 2018; Gedalof 2018). It will be interesting to consider where volunteering sits in relation to the occupational therapy notion of being and Arendt's view on work and labour in this project.

Becoming, considers how our actions influence the future with the potential for growth and transformation (Wilcock 1998b, 1999). Becoming is an on-going process of personal development through hopes and ambitions freely chosen or imposed by and grounded in, historical and cultural influences (Wilcock 1999; Hitch et al. 2014a). It has a temporal quality that can be motivating in terms of recovery and re-framing our identity and future self (Hitch et al. 2014a) and closely aligns with human flourishing. This raises an interesting question regarding the potential that volunteering may have to promote recovery, growth and transformation.

Belonging, reinforces the importance of social relationships in sustaining positive health and wellbeing (Wilcock 2007) and reinforces “a sense of connectedness to other people, places, cultures, communities and times” where occupations can arise and where “a sense of reciprocity, mutuality, and sharing characterise belonging relationships, whether they are positive or negative” (Hitch et al. 2014a, p.242; Hitch et al. 2014b). Belonging therefore involves reciprocity and interdependence and in order to belong one must also be accepted by others (May 2013). This raises important questions regarding the experience of stigma and social exclusion for people with lived experience of mental illness and will be revisited later in the section on welfare reform. Indeed, belonging recognises “the interdependent, collective, collaborative and co-occupations” nature of occupation, shifting focus from a solely individual concern to recognising “that doing occupations with others strengthens relationships, enhances well-being, and can help mitigate the negative health effects of stressful life events” (Hammell 2017, pp. 210-211). As such it will be interesting to explore to what extent volunteering fits this notion of a collective occupation, one that is done with others and which fosters a sense of belonging and social connectedness.

Although intended as interdependent, the inter-relationships between these four dimensions have received little exploration (Hitch et al. 2014a; 2014b). In considering the inter-relationship between being and belonging Hitch et al. (2014b, p.252) draw on Sutton (2010) to illustrate how someone excluded because their being is not in the mainstream will be stigmatised regardless of how they may be contributing to their community. Further, they suggest that connections between becoming and belonging i.e. occupations that enable people to meet their personal goals along with feeling connected require further exploration (Hitch et al. 2014b). This highlights a gap in the literature that this project may be able to address in exploring whether volunteering enables participants to feel more connected to other people, places, cultures, communities and/ or times.

2.2.1. Occupational justice

> …..I make a living you see. That’s the difference between me and the people who are mad. They don’t call you mad, if you’re making a living. (Mantel, 2005, p. 259)

This quote reinforces the stigma of mental illness and societal expectations of productivity through work as a means of fitting in. Not fitting in or being excluded from occupations on the basis of mental illness is an occupational justice issue, a form of social justice concerned with equality of opportunity and means to choose and take part in meaningful occupations including paid work (Townsend and Wilcock 2004; Farrell and Bryant 2009b; Whiteford and Townsend 2011; Hitch et al. 2014a; Wilcock and Hocking 2015). Occupational justice is based on the premise that our occupations affect our health and wellbeing in an interrelationship; and that what we do regardless of whether it is good for us or not, influences all aspects of our health both positively and negatively (Wilcock 2006). Having restricted opportunity to participate in meaningful occupation or being forced to take part in occupations that are not meaningful or harmful can be damaging to our individual wellbeing and to the wellbeing of our communities and is therefore deemed a matter of occupational injustice which is defined as “socially structured, socially formed conditions that give rise to stressful occupational experiences” (Townsend and Wilcock 2004, p. 251). Given that “what one does shapes one’s identity” and values associated with occupations and occupational identities are additionally influenced by socio-economic, political and cultural determinants; occupations become affected both positively and negatively by context specific opportunities including availability, socio-cultural values and expectations as well as individual factors such as interests, strengths and choices (Durocher 2017, p. 9). Furthermore, people who engage in occupations that are valued in particular contexts may be perceived more positively and receive more social recognition benefits than those who engage in occupations that are not valued (Durocher 2017). This raises an important question for this study as to what extent volunteering is valued within the current socio-political context in the UK. Indeed, the World Health Organisation recognises the availability of “healthy occupational and environmental conditions” alongside basic life necessities of food, water, shelter and healthcare resources as a fundamental human right (WHO 2013 in Durocher 2017, p. 10). Thus, opportunities to engage in healthy occupations that support people to use their abilities, develop positive identities, contribute to society whilst maintaining good health and wellbeing is a fundamental human right and a matter of occupational justice (Durocher 2017). According to Hammell (2017, p. 210) since engaging in meaningful occupation is viewed as integral to wellbeing and since wellbeing is viewed as integral to human rights, then occupational therapists should be concerned with enhancing everyone’s “right to equitable occupational opportunities and choices” to engage in occupations that have positive outcomes for their mental wellbeing and the wellbeing of their communities.

Being unable to participate in society and in the communities where people live has a negative impact on mental health and people with lived experience of mental illness may be more vulnerable to such stress (Fieldhouse and Onyett 2012). There are several risk factors for occupational injustice that threaten health and wellbeing causing anxiety, boredom, depression and burnout, if meaningful occupational cannot be realised namely: occupational imbalance; occupational deprivation; occupational marginalisation; occupational alienation; and occupational apartheid (Wilcock 1998a; Wilcock et al.1997; Townsend and Wilcock 2004; Kronenberg and Pollard 2005; Wilcock and Hocking 2015; Durocher 2017). Occupational imbalance is a lack of equilibrium between work, rest and play and between those occupations that we want to do versus those that we have to do (Wilcock et al.1997; Townsend and Wilcock 2004; Wilcock and Hocking 2015). This is reminiscent of the distinction raised earlier in Arendt’s (1958, in Dant 2003, p. 43) definition of work and labour. Occupational deprivation is the marginalisation and denial of opportunity to participate fully in society due to a range of socio-cultural, economic and political factors including policies and regulations, poverty, lack of access or availability, and stigma and discrimination that are outwith the immediate control of the individual (Whiteford 2000; 2011; Whiteford and Townsend 2011; Wilcock and Hocking 2015). Occupational deprivation is therefore a by-product of social exclusion and impedes the potential for personal growth and human flourishing (Whiteford 2000; 2011; Whiteford and Townsend 2011; Wilcock and Hocking 2015). Occupational marginalisation is an invisible form of occupational deprivation where people are not offered opportunities to participate in specific occupations and are thus excluded due to unseen societal norms and expectations for example individual, societal and institutional perceptions of impairment or ability (Townsend and Wilcock 2004; Durocher 2017). Occupational alienation is where there is a loss of purpose through an imposition to engage in occupations that are neither meaningful nor health promoting, and which may be manifest through obligation or force and institutional structures causing potential detriment to the person’s identity and development (Townsend and Wilcock 2004; Durocher 2017). Occupational alienation is therefore characterised by estrangement from self and society with an experience of disempowerment due to institutional forces that prevent individual occupational potential being realised (Wilcock and Hocking 2015). For people with mental health problems, this impingement on doing and becoming can also occur as a result of dependence on services that remove individual decision-making (Bryant et al. 2004). Occupational apartheid is when people are denied the opportunity to participate in occupations due to personal characteristics such as age, race, gender, nationality, disability or socio-economic status (Kronenberg and Pollard 2005). According to Kronenberg and Pollard (2005) this may be due to political, institutional, religious or social structures that afford privilege to some individuals based on a set of values and discourses whilst denying, exploiting or removing opportunities and resources for others. Paying attention to issues of occupational justice and to the risk factors identified above reinforces the need to engage in the co-construction of knowledge with people who are experiencing marginalisation, deprivation, alienation, imbalance and apartheid (Gerlach 2015) and strengthens the participatory approach for this study.

2.2.2. Meaningful occupation, mental illness and recovery

> …..the tragedy of life is not that it ends so soon, but that we wait so long to begin it. (Anonymous in Gould et al. 2005, p.467)

For many people living with mental illness, participation in meaningful occupations is often conditional or denied and there can be significant life disruption with deterioration in participation in occupation over time (Roy et al. 2013; Hamer et al. 2017) leading to restricted opportunities for social relationships, self-expression and access to community resources (Gould et al. 2005; Fieldhouse 2012a). Internal factors such as experiencing positive symptoms associated with a specific mental illness diagnosis for example distressing thoughts or paranoid ideas; and negative symptoms such as lack of motivation and interest reflecting gradual social and cognitive withdrawal; sit alongside negative self-competence and poor self-esteem; which may be further compounded by resource issues associated with poverty and homelessness including limited access to transport reinforced by negative societal attitudes of stigma and exclusion (Hitch et al. 2013). For women this may be intensified by complex personal circumstances, parenting roles and gendered assumptions through societal and staff attitudes (McKay 2010). For the young men in Gould et al.'s (2005) study the onset of mental illness signified lost dreams and a sense of anguish akin to losing their lives where simple everyday occupations became onerous or impossible. Following a period of “coasting” which could last for several years, they began to re-engage in a period of “renegotiating themselves” taking control and recognising negative triggers and positive supports to maintain their mental wellbeing as a means to “envisioning a better life” (Gould et al. 2005, pp.470-471). Similarly, Fieldhouse’s (2012a; 2012b) action research project revealed disengaged individuals feeling stuck due to limited opportunities yet wanting things to be different. Through a co-constructed process of scaffolding where support was initiated then gradually reduced, the individuals began to adapt to their environment, utilising naturally occurring non-stigmatised community resources and peer supports as a means to reduce social exclusion and feel connected (Fieldhouse 2012a; 2012b). These periods of coasting and feeling stuck highlight the importance of taking time to reconfigure experience as a pre-cursor to doing, moving on in rebuilding an occupational life in a process of recovery (Gould et al. 2005; Fieldhouse 2012a; 2012b). Gould et al.’s (2005) study also highlights the temporal aspect of recovery and how meaningful occupation is often linked with past experiences (Reed et al, 2010; Eklund et al. 2012).

In considering the value of occupation for people living with mental illness, there is a high degree of concordance that engagement in meaningful occupation is fundamental to the lives of people with mental illness (Hitch et al. 2013). Positive engagement promotes enjoyment, relaxation and respite from the difficulties of lived experience of mental illness and generates a positive sense of self, compared to negative experiences which are associated with loss of hope and feeling stuck (Fieldhouse 2012a; Hitch et al. 2013). Meaningful occupation supports emotion and identity and enables people to take care of their own health and wellbeing along with establishing or maintaining relationships and community involvement (Leufstadius et al. 2008; Fieldhouse 2012a; Hitch et al. 2013). Indeed, relationships with family, friends and the broader community including mental health professionals who valued the person as an individual, although often challenging to maintain, are crucial in providing a sense of connectedness and facilitating engagement in meaningful occupations (Eklund et al. 2012; Fieldhouse 2012a; Hitch et al. 2013, p.82). Meaningful occupations support a desire to take control and monitor health and wellbeing when “coming to terms” with mental illness is a difficult but necessary step towards recovery (Hitch et al. 2013, p. 81).

Having the right degree of challenge is important in maintaining mental health in being neither over-stimulated nor under-stimulated (Hitch et al. 2013). Occupations that are valued are those that are familiar or those that offer structure, routine, accessibility, acceptance and meaning in life (Eklund et al. 2012; Hitch et al. 2013). However, Aldrich and Dickie (2013) argue that being out-of-work creates conditions that limit occupational possibilities such as lack of money and unpredictable waiting times at welfare agencies, that "prevent the establishment of functional routines, which then prevents engagement in the sorts of productive occupations that society values", for example volunteering, because people are "too busy making ends meet" (Aldrich and Dickie 2013, p. 13). Proposing volunteering as an occupational possibility without fully understanding the daily challenges of living with long-term unemployment and mental illness may inadvertently perpetuate inappropriate societal expectations and occupational injustice (Aldrich and Dickie 2013).

2.2.3. Vocational rehabilitation and paid work

There is consensus amongst findings that paid employment is an important means for many people to moderate the impact of their illness, giving a sense of worth and constructing a positive worker identity within a valued social context (Van Niekerk 2009; Hitch et al. 2013; Fegan and Cook 2014). Indeed, the dominance of vocational rehabilitation programmes within the occupational therapy literature, supporting people with mental illness to access meaningful paid employment, is unsurprising given the emphasis on work and the worker identity in Western culture (Aldrich and Dickie 2013). The UK government's drive to decrease the number of disabled people receiving out-of-work welfare benefits, including those recovering from mental illness is an additional push in the growth of this area for occupational therapists. Historically, people recovering from mental illness attended vocational rehabilitation programmes that advocated work training through industrial therapy using simulated work experience including volunteering in gardening, laundry and other supported projects in mental health hospital environments or were placed in sheltered employment schemes subsidised by the government (Hamer et al. 2017). Simulated work schemes have been replaced by individual placement and support (IPS) where people are placed in open employment and supported through for example, a job coach and/or reasonable adjustments, to succeed (Dominy and Hayward-Butcher 2012; Fegan and Cook 2014; Modini et al. 2016; Schneider et al. 2016). Having a tolerant and inclusive environment with collaborative partnerships supports engagement and better outcomes (Rebeiro Gruhl et al. 2012; Hitch et al. 2013). Indeed, evidence suggests that the IPS model is highly successful in supporting people with lived experience of mental illness into paid employment who might otherwise be out-of-work (Fegan and Cook 2014; Modini et al. 2016; Schneider et al. 2016) and being supported in paid work through IPS has positive effects on subjective quality of life (Dominy and Hayward-Butcher 2012). Volunteering, which offered meaningful worker roles for some people as a transition to paid work, is no longer considered a necessary first step for the success of IPS programmes (Fegan and Cook 2014).

Indeed, the role of worker is recognised as pivotal in understanding perceptions and revealing assumptions about an individual's socio-economic class, social and financial status and reveals the high social value attached to work in society (Blank et al. 2015). Paid work is therefore highly meaningful for many people recovering from mental illness in terms of self-perceived usefulness, social connectedness, income and structure (McKay 2010; Dominy and Hayward-Butcher 2012; Blank et al. 2015); with not working associated with feelings of not fitting in (Blank et al. 2015). However, relapses in mental health can significantly disrupt working lives over time (McKay 2010). In addition, people with severe mental illness make occupational choices based on socioeconomic realities as well as concern about relapse, often choosing occupations that maintain positive mental health (Nagle et al. 2002; Arbesman and Logsdon 2011). However, Van Niekerk (2009) argues that not supporting people into paid employment perpetuates occupational injustice whilst Fegan and Cook (2014) caution that if paid employment becomes the sole outcome, many people recovering from mental illness will be excluded. Indeed, despite many people wanting to work, the percentage of adults with lived experience of mental illness in employment is significantly low (Bonsaksen et al. 2016). People with lived experience of mental illness often have more difficulty securing employment than the general population, and those in mid-life are less likely to be employed or participate in education (Bonsaksen et al. 2016).

Paid work may hold ambivalence for people recovering from mental illness and having the identity of a mental health service user can be experienced as unhelpful (Blank et al. 2015). In a small phenomenological study, Blank et al. (2015) interviewed ten out-of-work participants attending a community mental health day centre to explore the meaning of work for people with severe and enduring mental illness. Findings suggest that when the onset of mental illness coincided with having to give up work, the experience of mental illness required construction of a new identity which included moving from patient status to becoming an expert through lived experience as a means of confirming existence to self and others (Blank et al. 2015). For some participants volunteering became important in achieving a sense of identity and belonging, and although Blank et al. (2015, p.205) do not explore volunteering in any depth, they suggest that supporting people to “craft an occupational identity” is an important recovery task. This also supports the inter-relationship between doing, being, becoming and belonging as discussed earlier in this review.

2.2.4. Volunteering as therapy

In contrast to the wide range of literature on vocational rehabilitation and employment outcomes for people with lived experience of mental illness, the occupational therapy literature on volunteering is surprisingly sparse and is mainly reported through a vocational lens with volunteering regarded as a stepping-stone to employment rather than a meaningful occupation in and of itself. Volunteering has regularly been advocated by occupational therapists as a therapeutic occupation to enable people living with mental illness to recover their mental health and reclaim a valued social identity by providing opportunities for meaningful participation including making a positive contribution to the wider community; giving a purpose and structure to the day; and developing a range of valuable and transferable skills (Rebeiro and Allen 1998; Farrell and Bryant 2009a; Farrell and Bryant 2009b; Fegan and Cook 2014).

Indeed, volunteering offers a range of personal, social and community benefits where people can find purpose in doing for others (Smith 2017). Volunteering has been noted to increase confidence and self-esteem, offer social support, replace lost roles and give a sense of inclusion and fulfilment in community life, but only when viewed as meaningful by the volunteer (Black and Living 2004; Fegan and Cook 2014). Further, there is growing evidence that supported volunteering, where additional support is offered to ensure the appropriate level of challenge, has the potential to enhance recovery, foster positive risk taking and provide a valued identity that can integrate mental health experience for people with fluctuating and severe and enduring mental illness as well as provide a pathway to employment if desired (Fegan and Cook 2012; Fegan and Cook 2014). However, just as in other occupations, providing the right level of challenge and support is crucial in ensuring a successful and meaningful volunteering experience; whilst matching the volunteer to the volunteering experience involves attention to level of skill, preference, influence, interest, monotony and pressure (Fegan and Cook 2014). Indeed, evidence suggests that any improvement in mental health and social inclusion is dependent on the right support and environment (Farrell and Bryant 2009a). Negative attitudes of volunteer recruiters resonant with wider societal stigma and discrimination pose a significant barrier to successful volunteering for people with mental health problems (Farrell and Bryant 2009b).

Rebeiro and Allen's (1998) single case study poignantly highlights the benefits of volunteering as a means to monitor illness, test ability, offer purpose through productivity and the opportunity to feel valued and "hang with the normals" in a socially accepted role which maintains a sense of self (Rebeiro and Allen 1998, p.283). Here, having choice in the type and place of volunteering was crucial to the decision to volunteer based on an existing connection with a meaningful organisation reinforcing the importance of the match between the person, the occupation and the environment. Interestingly the participant in this study became the second author indicating an innovative and unique collaborative approach to this research arguably ahead of its time (Rebeiro and Allen 1998); and although dated, findings generally concur with more recent research.

Recognising a gap in the literature surrounding the exclusion of people with enduring mental health problems from paid employment, Fegan (2014) taking a grounded theory approach investigated the dynamic relationship between volunteering and personal mental health recovery. Her findings uphold a theory that supported volunteering enhances mental health recovery by encouraging positive risk taking and endorsing a cherished identity that integrates and values mental illness experience (Fegan 2014). Whilst there are some similarities with Rebeiro and Allen's (1998) study, the two studies differ significantly in their attitude to paid work as the ultimate outcome. Volunteering according to Fegan (2014) provides a realistic, socially valued work experience that proves readiness and competence as a worker. Her key theory "emerging as a worker through volunteering" confirms her focus on vocational readiness and the importance of the construct of a worker identity for the volunteers in her study (Fegan 2014, p.174). Indeed, she states that the volunteers in having an “authentic experience of work” (Fegan 2014, p.174) were motivated to enhance their CVs in preparation for future employment. Although it is questionable as to what extent volunteering as a service user in a mental health service could be considered an authentic experience of work, her findings support the importance of having choice and finding meaning in volunteering alongside receiving support to negotiate the right degree of challenge whilst building confidence and self-efficacy in a process of “personal, social and vocational recovery” (Fegan 2014, p. 172). Volunteering enabled the participants to give something back to the mental health service that had supported them and to feel validated, find their voice and experience relationships with peers and professionals that enabled “crossing boundaries” as a person and volunteer rather than a user of services (Fegan 2014, p.). However, according to Fegan (2014, p.162) some volunteers got stuck in volunteering finding it difficult to move onto paid employment due to personal fears of readiness and lack of safety or due to their mental health condition and lack of self-belief. Fegan (2014, p.162) labelled them “career volunteers” because of the duration of time spent volunteering in supportive services and reflects that perhaps they were given less vocational goal orientated and structured support to progress further. However, the term has a somewhat pejorative feel in being used to signal a lack of vocational progression to paid work. This raises an earlier concern about volunteering in and of itself being viewed as of lesser value than paid employment and therefore the career volunteers potentially being viewed as less than those capable of paid work, leading Fegan (2014) to acknowledge that work may not be advantageous to wellbeing for all and that the value of non-work occupations including volunteering should not be misjudged.

Interestingly, Smith’s (2017) phenomenological study of asylum seekers in the UK unable to work due to government restrictions, explored their preference for engaging in altruistic activities where doing for the benefit of others through volunteering appeared to provide purpose and meaning in an environment otherwise bereft of any meaningful or self-respecting occupation. Motivation for these altruistic occupations was often embedded in cultural and personal needs and values as well as previous occupational choices thus enabling a re-connection or sense of continuity during transition with a previous sense of self, occupations, passion and interests in a form of what Smith (2017, p. 8) calls “occupational constancy”. Smith (2017, pp. 6-7) draws on four altruistic drivers namely, “kinship”, “empathy”, “learned behaviour” and “moral principles” to demonstrate how each of these significantly influenced occupational choice. For example, “kinship” prizes relationships, connectedness, commonality, community and a sense of belonging through being needed and feeling valued; “empathy” links with the desire to help through an emotional connection with the hardship of others and to give something back whilst also distracting from personal circumstances; “learned behaviour”, recognises altruistic desires as cultural norms associated with home and community, which contrasted with perceptions of the UK as a more individually orientated society; and finally, “moral principles”, were associated with having a strong moral compass and conscience where the needs of others were placed before oneself and where kindness and “being good and doing good” were valued (Smith 2017, pp.6-7).

Smith’s (2017) focus on motivation for volunteering provides an interesting perspective given that the asylum seekers in her study were denied the right to work. There are useful considerations here about the benefits of volunteering for asylum seekers that may have transferability to participants with lived experience of mental illness including: having purpose, meaning and structure to their day; feeling productive, valued and having worth; helping rather than being helped; having opportunities to learn new skills and use existing ones; and the perception that these benefits along with being more physically active contribute to improved physical and mental wellbeing (Smith 2017). However, Smith (2017) cautions that the benefits associated with altruistic occupational choice do not counteract the suffering experienced by forced migration, nor atone for the occupational injustices experienced during the asylum-seeking process. Smith (2017) therefore reminds us of the importance of restraint in making positive occupational claims in light of the wider context of people’s marginalised lives.

Finally, in considering recovery, there is general agreement amongst occupational therapists that valuing people as individuals whilst working collaboratively to generate a sense of hope for the future is crucial in providing “authentic, respectful and effective” support to people in their recovery from mental illness that recognises their role as the agents of change (McKay 2010; Hitch et al. 2013, p. 85). The importance of hope is highlighted as a key component within the recovery literature as is feeling heard and being supported to flourish and to take charge of one's own life through friendships and mental health activism (McKay 2010). Recovery will be further explored later in this review.

2.2.5. Summary

Discipline specific evidence from occupational therapy highlights the value of meaningful occupation in promoting positive mental health and wellbeing with the dimensions of doing, being, becoming and belonging having value in conceptualising recovery from mental illness. However, the interrelationship between these dimensions requires further exploration. Furthermore, this section introduces a conversation about personal responsibility for maintaining positive mental health and wellbeing versus societal responsibility, recognising that poor mental health in communities and populations emanates from wider socio-cultural influences including social determinants of health, and is beyond the control of the individual. Whilst paid employment is recognised as important for people recovering from mental illness, volunteering is also recognised as having the potential to contribute to recovery. However, the literature on volunteering is limited and has a tendency to view volunteering through a vocational lens, as a stepping-stone to paid employment. Aside from Smith (2017), no recent studies were identified that explored volunteering as an occupation in and of itself and while Smith's (2017) study is useful, the asylum-seeking context where paid work is not an option, is significantly different from participant experience in my study. This highlights a gap in the literature. Further, no recent occupational therapy studies were identified that consider volunteering from the perspective of participatory action research, actively involving people living with and recovering from mental illness in the research process. Thus, supporting this study's contribution to occupational therapy literature. The next theme explores volunteering more broadly.

2.3. VOLUNTEERING AND MENTAL ILLNESS

This review now turns to investigate conversations beyond occupational therapy advocating and evaluating volunteering to provide context to the experience of volunteering for people living with mental illness. It begins by considering the scope of volunteering before exploring volunteering outcomes for individuals and communities and the challenges and tensions surrounding volunteering. It ends with a brief investigation of the place of altruism in understanding motivation to volunteer.

2.3.1. The Scope of Volunteering

Volunteering has a broad scope and in addition to activities involving philanthropy and mutual aid, can include “governance” i.e. in decision making and political processes; “advocacy” and “campaigning” for improved services; and “expressive volunteering” i.e. fulfilling personal passion and interest in sport, culture or the arts (Ellis Paine et al. 2010, p.22). Furthermore, volunteering can be classified as formal or informal, and according to the type of activity and the intensity of involvement from sporadic to episodic and short to longer term (Ellis Paine et al. 2010). Interestingly, the Department of Health’s (2011, pp. 9-10) definition is more encompassing than the Scottish Executive’s (2004) definition referred to in my introduction in chapter one, suggesting that volunteering can be formal, informal and reciprocal including “peer support networks or time banks, and informal activity undertaken independently, such as visiting an older or vulnerable neighbour or providing transport for someone to access local services.” This raises an interesting question about class differences with informal volunteering potentially being a more prevalent form of moral economy in working class communities.

With regard to the formal or informal debate, how volunteering is organised should be viewed as an element of volunteering rather than a defining standard for example, individual volunteering i.e. “taking someone to hospital to keep an appointment” which may be similar to other forms of pro-social behaviour i.e. “offering a lift to a neighbour when passing them in the street” should serve to distinguish volunteering which could be described as a more spontaneous reflex activity (Ellis Paine et al. 2010, pp. 19-20). Interestingly, people often prefer the term “helping out” or “something you just do” to describe informal volunteering (Woolvin and Harper 2015, p.4; Volunteer Canada 2017). However, according to Ellis Paine et al. (2010) activities that only benefit the self, immediate and extended family and close friends do not constitute volunteering.

Indeed volunteering, rarely conceptualised as a subject in its own right, requires a “multi-lens approach” which according to Ellis Paine et al. (2010, pp.25-31) include: “work” - where it is viewed in terms of productivity as an unpaid job to benefit others, requiring formal management; “philanthropy” – where volunteers gift their time as a resource to organisations to benefit end users of the service through formal activities i.e. social welfare provision, as a charitable act rather than any political challenge to current structures; “activism” – as a challenge to the state, locating volunteering as a socio-political activity in the local community through mutual aid and advocacy, where benefits are reciprocal based on principles of solidarity, collaboration and altruism and volunteers become the organisation; “leisure” – where people volunteer because of the intrinsic rewards of pleasure, satisfaction and enjoyment although this perspective may trivialise volunteering; “care” – particularly for strangers, however caring where there is an obligation is not considered volunteering; “participation” – focusing on engaging people in their communities through pro-social and political activities although caution is necessary in assuming that pro-social equates with inclusion; and “learning” as a form of training including experiential or life-long learning however the focus here becomes the volunteer rather than the benefit to others and volunteering becomes a means rather than an end (Ellis Paine et al. 2010, pp.25-31). Volunteering as conceptualised through a work lens is particularly pertinent to this review and warrants further discussion. However, regardless of differences in definition and conceptualisation, volunteering is recognised as providing significant community and individual benefits, which will now be explored.

2.3.2. Volunteering outcomes

As stated in the introductory chapter, a range of evidence suggests that volunteering matters to individuals and communities. At a community level, volunteering promotes cooperation, encourages participation and contributes to the wellbeing of individuals and societies whilst volunteers and voluntary organisations significantly contribute to the economy (United Nations 2011; Wu 2011). Volunteering is a crucial element of citizenship and a valuable means of tackling social exclusion, enhancing community resilience and trust and addressing preconceptions and prejudice (Department of Health 2011; Paylor 2011; Wu 2011; James et al. 2017). Indeed, volunteering strengthens communities, who thrive through the engagement of active volunteers, filling gaps in services that are either unavailable or are cost prohibitive (Wu 2011; United Health Group 2013; James et al. 2017). Volunteering contributes to social action for marginalised groups and underpins community building and renewal (Wu 2011). It contributes to sustainability building skills and knowledge through informal learning (Duguid et al. 2007). The willingness of volunteers to contribute and influence is key to developing community spirit & social capital and essential to the delivery of good services (Scottish Volunteering Forum 2015). It is therefore not surprising that the power of volunteering is now recognised by governments and policy makers worldwide as a means to engage people in local communities to improve social capital and decrease health inequalities (Jenkinson et al. 2013; James et al. 2017).

At an individual level, evidence suggests that volunteering brings both intrinsic and extrinsic personal benefits (Wu 2011). Volunteering has the potential to improve mood and develops confidence and self-worth through a sense of purpose, accomplishment and social connectedness (Musick and Wilson 2003; Baines and Hardill 2008; Wu 2011; Brown et al. 2012; Binder and Freytag 2013; Kamerade and Bennett 2015; 2018). It also has the potential to reduce reliance on prescribed medication and improve coping ability (Casiday et al. 2008). Volunteers are described as having better mental and physical health, are happier and live longer (Musick et al. 1999; Brown et al. 2003; Borgonovi 2008; Casiday et al. 2008; Wu 2011; United Health Group 2013; Tabassum et al. 2016; Kamerade and Bennett 2018) with protective factors for mortality being length of time volunteering, optimally 10-14 years, and type of volunteering, optimally independent from a formal organisation (Ayalon 2008). The latter is interesting given that volunteering for a formal organisation is privileged in definitions of volunteering and links with the earlier question about whether independent volunteering is more prevalent in working class communities. Volunteering can influence wellbeing by offering social recognition, providing a sense of belonging and an opportunity to contribute (Ellis Paine et al. 2010; Paylor 2011; Wu 2011; Harper 2015). Volunteering can also provide opportunities for people to remain occupied, active and independent whilst gaining new skills including problem solving and interpersonal skills (Department of Health 2011; Wu 2011; United Health Group 2013; Kamerade and Bennett 2018). Volunteering is deemed to improve employability, reinforce a worker identity, offer accreditation and training and introduce people to career options that they may not have previously considered (Baines and Hardill 2008; Department of Health 2011; Wu 2011; United Health Group 2013). However, although it may improve the likelihood of employability, there is no robust evidence that volunteering increases chances of securing and retaining paid employment or advances earning progression (Ellis Paine et al. 2013; Kamerade and Ellis Paine 2014).

Indeed, Jenkinson et al. (2013) caution that because volunteering is often described in heterogeneous terms, future research needs to understand the type, frequency and amount of volunteering required for optimal health benefits as well as the motivating and sustaining factors for individuals before determining volunteering as health promoting. Interestingly, volunteers whose motive is primarily to benefit themselves rather than helping others e.g. to enhance career prospects or distract self from personal issues, are less likely to experience positive wellbeing or good outcomes (Stukas et al. 2016). Whilst there is general agreement that engaging in volunteering has better mental health outcomes than doing nothing whilst unemployed, this depends on the type of volunteering, the ethos and culture in the volunteer organisation (Scottish Government 2009, p.33); and the generosity of out of work welfare benefits when volunteering (Kamerade and Bennett 2015; 2018).

However, as stated in the introduction negative effects of volunteering are rarely considered yet cross national differences in regular volunteering indicate a detrimental effect on mental health, lower than for non-volunteers, in countries with less generous employment benefits, highlighting the impact of poverty, loss of control in cultures that value paid work over volunteering and the importance of financial support in sustaining mental health and wellbeing (Kamerade and Bennett 2015; 2018). Whilst there is literature advocating the health and social benefits of volunteering and volunteering is recognised as playing an important role in supporting positive mental health and wellbeing (Tabassum et al. 2016), there is less emphasis on the experience of volunteering itself (Wilson 2012) and limited literature examining the experience, outcomes or social capital returns for volunteers with lived experience of mental illness; or the barriers to volunteering experienced by marginalised groups including stigma (James et al. 2017).

2.3.3. Volunteering Tensions and Challenges

Interestingly, the literature on volunteering raises a number of tensions and challenges. For example, as the job market becomes more competitive, so too do volunteering opportunities, which are viewed as valuable resources to improve employability. In the current neo-liberal climate resulting in financial cutbacks within the public sector, governments are relying more on the voluntary sector for service delivery. There is an increasing requirement for young people and recent immigrants to demonstrate their suitability for employment through volunteering experience, thus coining the term “coerced volunteerism” which is further illustrated in the growing trend for unpaid internships in the for-profit sector (Schugurensky 2013, p.2). The UK Government setting employment targets for volunteer organisations further reinforces the pressure to get people into paid employment through volunteering. This raises a question about choice and free will in volunteering and highlights a potential problem for people with lived experience of mental illness having to compete for volunteering opportunities. Indeed, the link between volunteering and paid work is contentious. People often refer to volunteering as work, and indeed, volunteering has many “work like characteristics” with similarities to paid work in the time and commitment required; similar challenges of juggling family and child-care as paid workers; and recognition that some of the tasks carried out may be the same as those given to paid workers (Baines and Hardill 2008, p.313). Baines and Hardill (2008, p.315; p.308) recognise that volunteering has become a means to reconnect those excluded from paid employment through labour market failure offering “spaces of hope”, but caution against volunteering becoming “rebranded in ways that privilege its association with employment and marginalize notions of altruism and caring.”

However, there is a conceptual risk in viewing volunteering solely through a work lens where work is positioned hierarchically and volunteering is perceived as a means to employment rather than an end in itself in a type of “investment model” (Ellis Paine et al. 2010; Ellis Paine et al. 2013, p.18). Indeed, given that many people who volunteer do so as an “alternative to employment”, this should become the focus, where volunteering viewed through an alternative lens emphasises more valuable outcomes (Ellis Paine et al. 2013, p.19).

A further challenge in the current economic climate is sensitivity around job substitution, real or perceived where volunteers may be inappropriately expected to complete work that should be paid and therefore face exploitation (Naylor et al. 2013). In seeking to empower communities and build a society where autonomy, responsibility and reciprocity are the norm, the Department of Health’s (2011, p.4) strategic vision for volunteering states that it “is not about replacing paid employees but finding new solutions to enable people to contribute to their community and the services that matter to them”.

However, in a socio-political climate where negative views of people receiving out of work benefits, as well as stigma for people living with mental illness sits alongside the promotion of an altruistic society, it is not difficult to become cynical about the motivation of the UK government and other public bodies for promoting volunteering as a guise for free labour (Naylor et al. 2013). Indeed, controversy when the private company Underbelly advertised for 300 volunteers for twelve-hour shifts at Edinburgh’s Hogmanay led to questions of exploitative use of volunteers to replace paid jobs (Martin 2017). Differences between paid employment and volunteering need to be more clearly distinguished (Naylor et al. 2013).

Finally, as stated in my introductory chapter, disabled claimants in the UK including those with lived experience of mental illness receiving welfare benefits are required through workfare programmes to undertake mandatory unpaid community work within charities or voluntary organisations in order to receive Job Seekers Allowance or they risk significant financial sanctions including loss of benefits. In carrying out this oxymoronic mandatory or involuntary volunteering, claimants are offered no choice in their volunteering placement and may be forced to give up a meaningful volunteering role for one deemed by the UK Government’s Help to Work programme as more appropriate to gaining employment, despite no evidence to support this (Coote 2014; Keep Volunteering Voluntary, 2014; Moore 2014). This contradicts the definition of volunteering as an “activity undertaken freely that involves spending time, unpaid, doing something that aims to benefit the environment or individual or groups” (Department of Health 2011, pp. 9-10). Indeed:

> …..forcing people into unpaid labour contradicts the spirit of volunteering. People usually volunteer because they hope to find themselves in a congenial setting, doing work that is meaningful and personally fulfilling. Otherwise it is just thankless drudgery – no less demoralising and demotivating than long-term unemployment. (Coote 2014, online)

Mandatory volunteering contradicts the essence of volunteering and potentially damages its reputation (Jones 2013). It can be perceived as punishment for unemployment and prevents people from having time to do things they find more meaningful including volunteering through personal choice, or to engage with family commitments and other important unpaid activities such as education and caring (Coote 2014; Moore 2014). Whilst charities have a strong history in supporting people back into employment through community connections and offering people valuable opportunities to develop skills and support causes about which people feel passionate, mandatory volunteering contradicts the ethos of volunteering as mutually beneficial and puts charitable organisations into the position of enforcers of DWP schemes that involve benefit sanctions for people who do not participate (Bubb 2013). Jones (2013) urges charitable organisations to protect the notion that volunteering is time given freely rather than allowing it to become conflated with a different type of engagement. Motivation to volunteer warrants further investigation and this review now turns to consider human altruism.

2.3.4. Understanding Human Altruism and Motivation to Volunteer

> …..we are a social species and mutual aid is required to accomplish together what cannot be accomplished alone…we are so dependent upon the actions of others that we could no more survive on our own than an ant separated from its colony. (Wilson 2015, p. 9)

There is general agreement that the fundamental principle of altruism is an act that is carried out voluntarily with the goal of benefitting another as recognised in the above quotation (Feigin et al. 2014; Wilson 2015). Indeed, altruism previously known as benevolence, was introduced by Auguste Comte, the scientist-philosopher and founder of positivism (1798-1857), to counter the notion that human behaviour was grounded in selfish motivation (Feigin et al. 2014, pp.1-3; Steiner 2015; Wilson 2015, p.89). According to Comte, altruistic instincts were located in the brain and consisted of “kindness, veneration and attachment” (Steiner 2015, p.7). For Comte, altruism described a secular moral system of commitment to the interests of others based in science and phrenology, which contrasted with religious doctrine that kindness to others came through “divine grace” and where having no religious faith was regarded as decadent and immoral (Wilson 2015, p.90). Altruism independent of religion became viewed as morally superior to altruism through Christianity where “doing good” to atone for original sin and to achieve eternal salvation became regarded as selfishly motivated (Dixon 2005, in Wilson 2015, p.91).

Indeed, the motivation behind altruistic action continues to be highly debated and the definition of acting to benefit the welfare of others (altruistic) rather than oneself (pseudo altruistic) is contrasted with a more sceptical notion that self-interest is part of the human condition and as such, underlies all human behaviour (Batson 2011; Robotham et al. 2012; Feigin et al. 2014; Wilson 2015). However, literature interrogating the motivation behind altruism appears more interested in discrediting the act as self-serving due to evidence of egoism, rather than appreciating the behaviour in itself (Feigin et al. 2014; Wilson 2015). The argument here being that pleasure is derived through benefitting another person, therefore egoism is at play whether consciously or unconsciously through a principle of “psychological hedonism” (Batson 2011, p.22). Nevertheless, caution is required in interpreting the motivation behind any action and it could be argued that even the most selfless behaviour can be re-interpreted as selfish in some form or other.

Definitions of altruism are therefore concerned with whether there is some expectation of reward (Feigin et al. 2014). Wilson (2015, p.3) however, focuses on the altruistic act itself with altruism described as “concern for the welfare of others as an end in itself” which “often requires a cost in terms of time, energy and risk.” According to Wilson (2015, p.17), “the greater the cost, the more altruistic the action appears”. Feigin et al. (2014, p.2) agree and distinguish between “normative” everyday acts of low risk and low-cost helpfulness; and “autonomous” daring and heroic deeds where individual risk and cost is high.

There are a number of popular theories of human altruism ranging from behaviour motivated by internal rewards and personal wellbeing; to learned pro-social behaviour with internalised values through parental models or societal norms including religious and cultural influences (Robotham et al. 2012); to relieving discomfort from witnessing another’s distress; or helping others when feeling positive about oneself and having higher levels of empathy, social justice and responsibility (Feigin et al. 2014, pp.3-4). Additionally, Robotham et al. (2012, p.13) recognise “reciprocal altruism” where gratitude for a good deed done to us results in a desire or duty to reciprocate. A common volunteering example being the Time Bank where one person offers a service and benefits in exchange from a different service provided to them by another (Robotham et al. 2012). The most common theory, the empathy-altruism hypothesis is based on perceiving someone in need which leads to empathic concern, which in turn evokes motivation to increase the other person’s welfare (Batson 2011; Feigin et al. 2013). However, altruism can become pathological when focusing on another’s needs becomes detrimental to one’s own needs leading to mental health consequences including burnout and depression (Robotham et al. 2012; Wilson 2015).

In terms of volunteering, given the range of benefits identified earlier, it could be argued that any motivation to volunteer will contain some selfish component in terms of social and/or personal reward. Indeed, co-occurring motives underpinning altruistic behaviour include “egoism: acting for one’s own benefit; altruism: acting for the benefit of another person; collectivism: acting for the benefit of a particular community; and principlism: acting in response to a moral principle” (Smith 2017, p.3). Motivation to volunteer is therefore wide ranging encompassing a range of factors including identifying with a shared experience; giving something back; adjusting following a significant life event; gaining skills towards employability; and enacting political attitudes and values with causes that have meaning and significance (Bekkers 2005; Baines and Hardill 2008; Brodie et al. 2011). However, regardless of individual variations in motivation, there are disparities in opportunity to volunteer with being asked to volunteer, for many low-income individuals, having a direct bearing on participation (Brodie et al. 2011; Benenson and Stagg 2016).

2.3.5. Summary

This theme has extended the conversation on volunteering and has considered the broad scope of volunteering, explored the benefits, tensions and challenges for individuals and communities and investigated differing views on human altruism and motivation to volunteer. Despite the range of available literature there is limited evidence of the collective experience of people who live with mental illness and who volunteer as part of their recovery and no study was discovered that considers a participatory action research methodology. This doctoral project is therefore well placed to address this gap. The next theme explores the current socio-political context of welfare reform for disabled people including those living with mental illness who are volunteering.

2.4. WORK ALWAYS PAYS: Welfare Reform and Perceptions of Deservingness

> …..let's start with how we simplify the system and make work pay…just one core income-related benefit - a universal credit and one message - that it will always pay to work. (Cameron 2011, online)

The above quote sets the scene in reinforcing the government's position that work always pays, highlighting the centrality of work in relation to welfare reform. This section begins with a brief overview of welfare reform in the context of the UK under the current Conservative government led by Boris Johnson (2019-present). It examines how the legacy of welfare reform stemming from David Cameron and Nick Clegg's Conservative and Liberal Democrat Coalition Government (2010-2015) and supported by David Cameron's (2015-2016) and Theresa May's (2016-2019) Conservative Government, was built on Gordon Brown's (2007-10) and Tony Blair's (1997-2007) New Labour governments setting the tone for a renewed focus on work and workability in reforming welfare provision. This review will then consider work conditionality, workfare and employability before concluding with an exploration of changing perceptions of deservingness and stigma. It is impossible to provide a comprehensive summary of welfare reform in the UK in this brief section, but rather an attempt has been made to provide a contemporary overview and critique of the impact of welfare reform on people with mental health conditions to illuminate the political and welfare context experienced by the participants in this study. As such, this section of the review is confined where possible to considering the impact on disabled people.

2.4.1. Welfare Reform

> …..in a neo-liberal market economy it is expected that individuals will fulfil their responsibilities to society before they can claim social rights. These rights are principally based on evidence of economic productivity. (Grover and Piggott 2010, pp.267-268)

In the UK over the last thirty-five years welfare reform has redefined the agreement between the state and the citizen as to what is provided in terms of welfare support and what is mandatory in return (Patrick 2017). The mandatory requirement to engage in government specified activities described as "welfare conditionality" with the goal of facilitating people from out-of-work benefits into work, with reduced levels of financial support and a narrowing of entitlement (Patrick 2017, p.4), has a number of ethical, financial and social wellbeing issues for disabled people (Grover and Piggott 2010). Neoliberalism is recognised as complex and contested and is adopted within this review to recognise the process whereby the state is active in encouraging a free market economy with market forces and competition becoming prioritised over the welfare state and the reallocation of resources (Newman 2011; Metcalf 2017).

The most significant period of welfare reform has been post 2010 with David Cameron's coalition government (2010-2015) and David Cameron's own conservative government (2015-2016) signalling a change in emphasis through austerity driven rhetoric following the financial crisis in 2007-2008 to end welfare as a "lifestyle choice" (Patrick 2017, p.4). For example, in 2011 the UK government launched the Welfare Reform Bill based on the argument that out of work claimants including disabled people, had become too dependent on benefits rather than obtaining paid employment; and that this was promoting a culture of dependency and irresponsibility which was in marked contrast to responsible citizens who were in work; thus, defining from the outset the difference between the "deserving" and the "undeserving" (Patrick 2017, p.2). Perceptions of deservingness will be returned to later in this review.

Noteworthy, is that this tone was set by New Labour with Gordon Brown's government arguing that Labour had inherited a welfare system that had rewarded people for not working (DWP 2008, p.5). Brown's intention to overhaul the welfare benefit system centred on achieving an 80% employment rate by reducing by one million the people claiming incapacity benefits by 2015 (DWP 2008). This paved the way for moving disabled claimants from incapacity benefit (IB) to employment and support allowance (ESA) and for introducing the work capability assessment (WCA), a tougher form of medical assessment than previous, no longer considering wider impacting socio-economic factors (Grover and Piggott 2010). ESA was viewed as temporary until disabled people either recovered from or adapted to their health condition. New Labour's message was clear that disabled people were expected to engage in back-to-work activities and if they did not meet the requirements of their "work related activities", they would have their benefit reduced (DWP 2008, p.15).

The Government's relentless focus on achieving independence from the welfare state is interesting as arguably in a society where inter-dependence exists, it is difficult to conceive of people being wholly independent from social and welfare support (Beresford 2016; Patrick 2017). According to Beresford (2016, p.2) the term welfare has become contentious yet “is essentially concerned with how we take care of each other as human beings”. Indeed, welfare has a broad reach with a complex interplay between dependence and inter-dependence, with social welfare recognised as the “most stigmatised and problematised form of welfare” (Patrick 2017, p. 8). Lister (2016, p.xi) agrees that although welfare in the UK in relation to the welfare state was a positive one with the state supporting its people “to fare well from cradle to grave”, adopting the phrase “welfare dependency” from the USA signifies a negative, limited and stigmatised view which denies dependency as part of being human. Lister (2016) argues for a system where social security relieves as well as prevents poverty and provides us all with genuine protection and support at difficult times in our lives. Indeed Lister’s (2016) position reminds us to identify as people who may be in need of support through our own unpredictable life circumstances rather than distancing ourselves from others dependent on welfare. Reinforcing this point, she quotes John Hills (2015, cited in Lister 2016, p. xii) stating: “there is no “them and us”- just us”. This theme has resonance with stigma and perceptions of deservingness, which will be discussed later.

Interestingly, Labour in establishing the Department for Work and Pensions (DWP) in 2001 to supersede the Department for Social Security (DSS), shifted the focus from the language of security to one where work is deemed the best way for people to secure their own personal welfare and where concerns about welfare dependency have continued to pre-occupy successive UK governments (Lister 2016). For example, the Welfare Reform Bill (DWP 2011) distinguished between responsible citizenship and those dependent on welfare reinforcing a them and us culture, which could only be remediated through significant and radical welfare reform (Patrick 2017). These far-reaching proposals have continued through successive legislation, paving the way for the Welfare Reform and Work Act, 2016 (DWP 2016). Certainly, austerity with reduced work opportunities in the public sector and successive legislation to constrain trade union leverage regarding depressed wages, terms and conditions has paved the way for dependency on low paid private sector employment as the only alternative to starvation for many people (Visentini 2018). Indeed, there appears to be cross party agreement that the solution to minimising poverty is through welfare reform, getting people into work more quickly and using conditionality and sanctions for those who don't manage, without any critical consideration of the experience of low pay and poor working conditions (Jensen 2014).

2.4.2. Work Conditionality, Citizenship and Benefit Sanction

> …..now you have to have to sign a contract that says: you do your bit and we'll do ours… you have to seek work and take work – or you will lose your benefit. (Cameron 2012, online)

One of the most controversial topics within the welfare reform legislation is the punitive regime of benefit sanctions for those who are viewed as not complying with conditions set around finding employment and carrying out work related activities.

Image 1: Conservative Party's (2010) general election campaign poster

This is exemplified in Image 1 above, one of five Conservative party 2010 election campaign posters to reform the welfare system and elaborated through subsequent government policy. It is interesting to note Cameron's stance in this 2010 poster with his fists clenched and pointing his finger, wearing no tie and with shirtsleeves rolled up as if ready for work and meaning business in both a readiness for work sense and an aggressive attitude. Cameron stands to our left of the picture looking to the political right to guide, reassure and appeal to the presumably working taxpayers behind him. Cameron (2011, online) justifies this by stating:

> …..when it comes to the sanctions, we're also going to clamp down on those who deliberately defraud the system. No more cautions… So, if you're unemployed and refuse to take either a reasonable job or to do some work in your community in return for your unemployment benefit you will lose your benefits for three months. Do it again, you'll lose it for 6 months. Refuse a third time and you'll lose your unemployment benefits for three years.

Disabled people are not exempt from benefit sanctions and in relation to help to work for disabled people, Cameron (2011, online) adds:

> …..we are going to do something for those who aren't yet ready for work but who are assessed to be capable of work in the future. They'll be offered training, help, support - and again if they refuse that, they too will lose some of their benefits… Sanctions for those who abuse the system; real help for those who need it.

There are several points here. Firstly, is a perception that people are cheating the system, claiming benefits fraudulently and in need of individual behaviour change to remedy bad choices (Wright 2016). Secondly, is an assumption that people are unable to find their own solutions and as such need the government to take control of their lives further undermining self-esteem (Coote 2014). More significantly, is the changing view of citizenship with paid work central to defining the dutiful citizen (Patrick 2017; Gedalof 2018). Paid work is described as "unproblematic" and endowed with "transformative properties" that extend beyond financial remuneration to promote health, self-esteem and as a means to beat poverty (Patrick 2017, p.28; Gedalof 2018). This neoliberal view shifts a liberal theoretical and egalitarian position of citizenship where people have the freedom from state control to pursue the life of their choosing, to one of a civic republican tradition where citizenship becomes the practice of the good and moral citizen and is achieved through participation in state responsibilities irrespective of rights (Patrick 2017; Gedalof 2018). Indeed, citizenship is viewed as fluid and evolving and is used as a powerful tool to justify political positions (Patrick 2017; Gedalof 2018). Furthermore, Patrick (2017, p.19) highlights a discrepancy between citizenship as it is conceptualised "from above" through political discourse and policy agendas such as welfare reform and how it is experienced "from below" in terms of actual lived experience of inclusion and exclusion. Patrick (2017, pp.21-22) calls for "participation rights" where individuals are considered with "respect and dignity" and have their voice and preferences acknowledged "through a politics of recognition". This notion of citizenship conceptualised from below emphasising participation rights, supports the value of participatory approaches in other domains.

Benefit sanctions are linked to the principal of conditionality introduced through the claimant commitment (DWP 2014). This contractual form of citizenship for out-of-work benefit claimants including disabled people between the state and the individual, links entitlement to contribution through the promotion of what seems to be a fair agreement based on getting “something for something” thus challenging the “something for nothing” culture and introducing a form of social control and coercion that justifies benefit sanctions (Patrick 2017, p.23). It is a way of re-educating benefits claimants how to become good and dutiful citizens (Gedalof 2018). The claimant commitment is an agreed, personalised contract with clear expectations of adhering to job seeking and training opportunities in order to secure paid employment (Gauke 2017). However, this contract not only refers to the contractual relationship between the out-of-work claimant and the state but also to the relationship between the out-of-work claimant and the taxpayer (Patrick 2017). According to Patrick (2017) this highly divisive ploy reinforced the government’s contract with taxpayers to ensure that money was not wasted on people who refused to work. Arguably, this has created a two tiered citizenship affording people who are working taxpayers status over those who are on out-of-work benefits, feeding into public perceptions of deservingness and highlighting the duty of benefit claimants to the government and the UK taxpayer but in doing so, neglecting their rights (Patrick 2017).

Finally, it should be noted that conditionality also affects people who are in work and receiving welfare support (Patrick 2017). Indeed, benefit sanctions are recognised as key drivers of food bank usage and appear to be rising with figures from March 2017 suggesting at least a 50% rise for jobseekers not complying with an element of conditionality such as not attending a job interview, refusing to take a job or leaving a work training programme, leading to suspension of benefits from anything between four weeks and three years regardless of any legitimate reasons to justify these factors (Newman 2011; Jayanetti 2017). Sanctions and compulsion to find work can have a negative impact on self-esteem and mental health and lead to further social exclusion including significant debt and hardship for an already marginalised and vulnerable population (Newman 2011). More significantly, the threat of benefit sanctions changes the power dynamic between the out-of-work claimant and employment support services from one of support, co-ownership and empowerment to one based on punitive measures of conditionality (Newman 2011).

2.4.3. Impact on Disabled People: fit for work

Welfare reform has been presented as a way to support disabled out-of-work claimants to make the transition from welfare into paid employment and thus enable them to become included, socially integrated and responsible citizens (Grover and Piggott 2010; Patrick 2017). Although the attraction of support into paid work for some disabled people cannot be disputed, individual experiences of the actual process suggest that many disabled people are facing further exclusion, marginalisation and poverty (Newman 2011; Grover 2017). Indeed, the Welfare Reform and Work Act 2016 (DWP 2016; 2017a) in a bid to save the government money, reduced welfare spending, capped benefits, abolished the work related activity component of employment and support allowance (ESA) for new claimants significantly reducing the amount of benefit paid, and introduced Universal Credit to be completed by 2022 (see Appendix 2). Despite receiving criticism from opposition parties and disability charities for unfairly targeting the UK's poorest families, all attempts were unsuccessful in overturning the government's decisions (Low et al. 2015; DWP 2017a).

Noteworthy is that disabled people undergoing a work capability assessment (WCA) assessing fitness for work and eligibility for employment and support allowance (ESA) have three potential outcomes. They may be:

1. Found fit-for-work and moved on to job seekers allowance (JSA) or universal credit (UC) and must be available for and actively seeking work but are unable to control the type of work or the pay they are willing to work for (Grover and Piggott 2010).
2. Placed in the work-related activity group (WRAG) and expected to undertake mandatory work-related activity and agree an action plan with a personal adviser, which may include volunteering to become fit-for-work.
3. Deemed unable to work due to the nature of their impairment and placed in the support group which entitles them to higher levels of income than those on JSA or in the WRAG.

However, WCA tests for physical and mental impairment are considered harder to pass with fewer points allocated to many measures of disability making it harder to be classified as unfit for work (Grover and Piggott 2010; Gentleman 2011b). Although, the WCA claims to consider capability rather than disability, following a social model of disability assets-based approach, generally welcomed by disability groups, it is significantly flawed in assessing work capability (Gentleman 2011b; Grover 2017). The tick box structure is unable to cope with the gradations of complex health problems and fails to recognise the fluctuating nature of chronic illness meaning that many people are classified as fit-for-work despite medical evidence to the contrary (Gentleman 2011b; Gillberg 2016). Indeed, there are numerous personal reports of unfair assessment outcomes in the media (Gentleman 2011b; Goodley et al. 2014; Gillberg 2016; Moore 2017; Petrie 2017). Further, the administration of the WCA has been criticised for being rushed, impersonal and lacking any empathy (Gentleman 2011b). Assessments are viewed as not making the savings previously predicted by the Government yet causing significant deterioration in claimants' mental health with increased suicidal thoughts (Gentleman 2011b; Ryan 2017). A number of reports claim higher mortality figures following being found fit-for-work, however these should be considered with caution as the circumstances around the deaths is not revealed (Butler 2015).

Indeed, Barr et al. (2015) found that the six-monthly re-assessment of disabled people was responsible for a significant increase in the number of suicides, self-reported mental health concerns and higher rates of anti-depressant prescribing.
The re-assessment component was subsequently reviewed in the publication of the DWP's (2017b) Improving Lives: the future of work, health and disability policy document, a 10 year plan to transform employment prospects for disabled people and those with long term health conditions previously assessed as unable to work (Grover 2017). However, people with mental health problems may be hit hardest as changes rarely take psychological issues into consideration and people who appear capable at the assessment may have hidden support needs (Watts 2017). Additionally, changes to personal independence payment (PIP) assessments, have resulted in a loss of financial support for adults with long-term mental health conditions to access quality of life activities including volunteering (Watts 2017).
Furthermore, the appeal process has been criticised by disabled activist groups as confusing and inefficient (Bloomer 2017). Evidence suggests that disabled people

are often discouraged by the DWP from taking the first step (Bloomer 2016). More worryingly, a freedom of information request revealed that the DWP routinely set targets for staff to reject 80% of the benefit decisions they are asked to re-assess at appeal, many of which relate to benefits for disabled people, and this target was exceeded between the period April 2016 and March 2017 at a rate of 87.5% (Bloomer 2017). More positively, there have been an increasing number of successful appeals, (68% for Employment Support Allowance for the period from October to December 2016), prompting Moore's (2017, online) strapline in The Independent "It's funny that there are so many successful appeals against disability assessments – it's as if there is something wrong with the system". Whilst the title is humorous the message is sobering in reminding us of the enormous stress endured by disabled people navigating the appeals process (Moore 2017).

2.4.4. Workfare: working-for-your-benefits

> …..three people start today on this "work experience". They are to help us for up to 30 hours a week for eight weeks over the Christmas period. I am terrified by the idea that head office think they don't need to pay their staff. I myself am on part-time minimum wage and if they can have workers for free now, what is to stop them making my position redundant and using job centre people to run the store. (Shoezone employee 2012, in Friedli and Stearn 2015, p.40)

This quote demonstrates the impact of workfare from an employee perspective. Workfare is the government's mandatory work activity process of working-for-your-benefits intended to support the transition from welfare into work and has come under significant scrutiny and criticism for undermining working conditions by replacing jobs and undercutting the minimum wage (Clark 2013; Friedli and Stearn 2015). Workfare programmes violate the right to choose work freely and confer either no employment law protection for participants or considerably less than that given to paid employees despite similarities of expectation (Paz-Fuchs and Eleveld 2016). Out-of-work benefit claimants are forced to work to remain eligible for their benefits and made to take part in employee skills building training to modify attitudes to become more employable (Friedli and Stearn 2015). This individualises the problem away from wider issues such as "market failure, precarity, the rise of in-work poverty, the cost of living crisis and the scale of income inequalities" (Friedli and Stearn 2015, p.45; Wright 2016).

There is a trend amongst several high street employers and public services in utilising workfare participants to fill seasonal vacancies or gaps in services caused by financial cutbacks and redundancies rather than employing additional staff or paying overtime to existing staff (Clark 2013); with the escalation of workfare placements having a significantly negative impact on the availability of paid employment (Clark 2013). Under the DWP mandatory work scheme, which is outsourced to and organised by large private for-profit companies (e.g. G4S, Serco), people referred by the Jobcentre are compelled to work for 30 hours per week for four weeks without pay or face benefit sanctions despite DWP research demonstrating that this has had no effect on future employability (Clark 2013; Coote 2014; Friedli and Stearn 2015). Indeed, some writers have compared this to community service, a form of punishment after having been found guilty of an offence (Moore 2014; Toynbee 2014). Successful campaigns against workfare, for example, Boycott Workfare a grassroots UK-wide group aiming to end forced unpaid work for people receiving benefits, have pressurised high street shops and charities to stop workfare placements; and some local authorities have rejected workfare, whilst many public and private sector organisations continue to profit from unpaid work (Clark 2013).

2.4.5. Employability of disabled people and welfare fraud

> …..nice work if you can get it. And you can get it – if you try. (George and Ira Gershwin 1937)

Underlying welfare reform is the government’s view that work is both available and good for you emphasising a position that paid work is unproblematic (Patrick 2017; Gedalof 2018). This position presupposes that disabled people are out-of-work because of default of character rather than acknowledging that there may be a problem with the availability of suitable work (Grover 2017). Despite many disabled people wishing to contribute as responsible citizens the problem appears to lie more with the lack of flexibility of paid employment, uncompromising employer attitudes and a lack of attention to the skillset of disabled people (Gillberg 2016; Grover 2017).

Interestingly, the belief that neoliberal flexibility in the labour market has created more employment, is countered by Newman (2011) in her systematic review of the assumptions underpinning return to work programmes in the UK and she suggests that despite the majority of out-of-work claimants wanting to work, the casualisation of the job market and associated risks through job insecurity due to low quality, part-time and temporary contracts, is negatively affecting mental health making the decision to remain unemployed, a rational one. This appears particularly so in areas of high unemployment and deprivation where low pay akin to poverty levels pushes people into working extensive hours affecting both individual and family quality of life (Newman 2011). Whilst recognising that being out-of-work significantly increases the risk of poverty, being in employment does not guarantee a way out of poverty (Newman 2011) thus challenging the government's mantra that work always pays. Indeed, many people move in and out of work and routes out of poverty often require a second household earner; full-time work; promotion; further education and training; improved health; or an increase in benefits payments (Newman 2011).

Attempts to support disabled people into work have tended to rely on separating and categorising disabled people into either a work related activity group (WRAG) or a support group creating further division and framing the problem in terms of work and perceived employability rather than health, thus risking further misperception by the public that some disabilities or illnesses are more or less deserving that others (Grover and Piggott 2010; Garthwaite 2011). This serves as a form of "social sorting" of sick and disabled people into hierarchies of claimants defined by a perception of their ability to engage in paid employment (Grover and Piggott 2010, p.266). More worryingly, social sorting is based on an individualised view of disability that fails to recognise the broader issues of the labour market; the wide-ranging socio-economic disadvantages faced by disabled people; and the subsequent outcome of impact on income (Grover and Piggott 2010). Within the WRAG social sorting is again applied on the basis of compliance or non-compliance with the mandatory work-related activities and income is further reduced for those who are deemed non-compliant (Grover and Piggott 2010). Although this type of social sorting is not new, it highlights the social exclusion of vulnerable and marginalised disabled people within society (Grover and Piggott 2010).

Whilst those in the WRAG are recognised as people found unfit for work but able to do some work related activity such as training or volunteering with the potential to move into work at some stage in the future; and many disability charities support the government's aspiration to facilitate more disabled people into work, there is recognition that this should not be at a financial cost to disabled people (Low et al. 2015). These points were highlighted in the parliamentary review document, Halving the Gap? (Low et al. 2015), which responded to the government's proposed reduction to employment and support allowance and its impact on halving the disability employment gap. It was supported by Members of the House of Lords in conjunction with disability charities to provide a helpful overview of the employment and economic situation of disabled people in the UK from the perspective of disabled peoples' charities (Low et al. 2015).

The employment figures for disabled people are striking, with only 10% of those living with mental illness in paid employment; disabled people more likely to be in low paid jobs and part-time work; and more likely to live in poverty with a third of families with a disabled person living in poverty (Low et al. 2015). Disabled people are clearly a vulnerable population and although it is difficult to argue that any help to work scheme that supports disabled people transition into paid employment does not have a potential benefit, it is problematic to defend a government that appears to conflate support with punitive measures (Patrick 2017). Indeed, this highlights the contrast between the transformative potential of welfare reform on the lives of disabled people with the actual reality of the lived experience as a result of welfare reform (Patrick 2017). Wright (2016), in her qualitative research of the lived experience of claiming benefits and receiving advice from employment services recognises two dominant models of the active welfare claimant. The first takes an individualised and deficit view of someone who is morally, solely and personally responsible for their wrong decisions and needing correction through sanctions and welfare reform to "become active" (Wright 2016, p.236); whilst the alternative narrative is of a more connected community of experience of people who are already active and who have the capacity for dynamic political engagement and action but are in need of empowerment (Wright 2016, p.239). Wright's (2016) evidence supports the latter position and challenges the dominant and individualised discourse as deeply flawed calling for policy makers to engage with evidence from lived experience of claiming benefits to more fully understand the links between motivation, behaviour and outcomes. More controversially, Berlant (2011, in Goodley et al. 2014, p.981) views work as "a practice of slow death" and the "physical wearing out of a population" particularly for those in low-income jobs.

Goodley et al. (2014, p.981) suggest that policies of “neoliberal-ableism” privilege conquering disablement and embracing ability in order to survive and call for alternatives beyond work and slow death for disabled people.

Turning to welfare fraud, there is continuing public perception that billions of pounds are lost each year due to benefit fraud despite figures published by the DWP indicating that the actual figures are significantly lower than media attention would suggest and are insignificant in comparison to estimates of money lost each year through tax evasion (Jensen 2014). Indeed, members of the public identifying fraudulent benefit claimants in a type of witch hunt, led to more than 280,000 tip-offs to the national benefit fraud investigation hotline during 2015-17 despite no evidence to support any fraudulent activity (Cowburn 2018). Further, during the financial periods 2015-16 and 2016-17 there was an 87% no result outcome meaning the government could find no or little evidence to substantiate fraudulent claims despite the recruitment of an additional 200 anti-fraud officers, involving lengthy surveillance (Gentleman 2011a; Cowburn 2018). The amount invested in anti-fraud investigations appears disproportionate; and critics have questioned the lack of attention to tax fraud and evasion, which constitutes a far greater loss of revenue for the government (Gentleman 2011a). The number of people making fraudulent claims is estimated as less than 1% of all claimants and is likely to be the poorest, most marginalised people in society with the actual amounts involved being very small and the motivation being less to do with greed and more to do with struggling (Gentleman 2011a; Cowburn 2016). Unsurprisingly, resulting sanctions and making people pay back over-claimed amounts pushes people further into poverty (Gentleman 2011a). Indeed, under claims are more common and many over-claims are from people failing to report changes in their circumstances or wrongly completing forms rather than having any fraudulent intent (Cowburn 2016). Despite the reality of the extent of benefits fraud, stigma of benefits claimants including disabled claimants along with a perception of benefit claimants as scroungers and undeserving appears to persist. This will now be explored.

2.4.6. Perceptions of Deservingness- Poverty Porn, the "Benefit Scrounger" Narrative and Stigma:

> …..if you are not careful, the newspapers will have you hating the people who are being oppressed, and loving the people who are doing the oppressing. (Malcolm X [no date])

The above quote from the human rights activist Malcolm X (1925-1965) has synergy with the UK where public support and a rise in stigmatising media coverage and reality television programmes provide limited and startling depictions of life on welfare benefits, giving way to derogatory judgemental attitudes that are then reinforced by politicians and sections of the media (Patrick 2017). The term "poverty porn" has been used to highlight both the obscenity of poverty where people are objectified for the gratification of others as well as the emotional arousal incited through repetitive viewing (Jensen 2014, p.1). Such media coverage provides "voyeuristic tourism" where moral judgements are made about deservingness and offers a view of a dysfunctional welfare state leading Jensen (2014, pp. 1-2) to conclude that:

> …..such programmes repeat imagined connections between welfare recipients and moral laxity, greed and even criminality…[which] functions to embed new forms of "commonsense" about welfare and worklessness.

In critiquing this position Jensen (2014, p.2) draws on Pierre Bourdieu's (1972) notion of "doxa" meaning "that which goes without saying because it comes without saying" thus reinforcing how critical analysis and debate become denied in a world of sound bites and media commentary and where the perceived social world becomes viewed as self-evident and legitimised. Jensen (2014, p.2) states:

> …..these new forms of commonsense themselves signal how far the social democratic model of social security has been corroded under neoliberalism and replaced with a more punitive and limited model of welfare, littered with sanctions and restrictions and characterized by conditions to be satisfied, rather than by universal entitlements.

Commonsense welfare discourses suggest that people claiming benefits don't want to work and are happy to be rewarded by the welfare system for not working; that paid employment is the only way to escape poverty; and that total employment is possible in neoliberal times of austerity (Jensen 2014). Indeed, these positions view out-of-work claimants as problematic and rely on media support and political action to redress the balance (Patrick 2016, p. 246). People become divided into polarised binary positions such as passive versus hard working; dependent on welfare versus independently working in paid employment; responsible versus irresponsible, none of which critically engages with the wider socio-political context including the serious challenge of paid employment in a neoliberal economy (Jensen 2014). Moreover, it individualises social issues thus blaming the individual for being unemployed, experiencing family breakdown, addicted to substances, having limited education, and being in arrears, thus denying any underlying and systemic causes of poverty (Patrick 2016, p.246). Lister (2016) agrees that the division of people into either workers or shirkers is simplistic which denies that many people are forced into a cycle of moving between low paid work and unemployment due to the insecurity of available work as well as the reliance on benefits for those already in paid work. Patrick (2017, p.6) notes that disabled people traditionally regarded as deserving are now being viewed as “undeserving claimants” and “workshy” needing continuous medical assessment to prove their eligibility for welfare support. Thus, the term skiver as a person of social loathing has been roused by wilful and premeditated media attention to denote welfare trickery and fraud; and by inventing anxieties about the fraudulent activities of people entitled to welfare support; such entitlements can be more easily challenged (Jensen 2014).

According to Gedalof (2018, p.83) the changing narrative around disabled people encompasses several concurrent themes namely: a shift in the discourse around disabled people as vulnerable individuals deserving of charity to that of “benefit scrounger”; the reframing of the social model of disabilities’ recognition of the rights and language of independence and autonomy to one where disabled require state intervention, surveillance and discipline; and a growing lack of recognition of disablement viewing all disabled people as “work-able”, conferring status through their relationship to paid work. Indeed, Gedalof (2018, p.83) recognises that this narrative “eliminates any space in which to consider the complexities of a debilitated body”, and presumably one could also add mind. Interestingly, this accords with criticism of the social model of disability in ignoring the disabling aspects of impairment on people’s bodies and arguably people’s minds (Shakespeare and Watson 2010; Shakespeare 2013). Gedalof’s (2018) critique is compelling as she examines how the selective appropriation of the disability rights movement's language of independence and being more than a label is specifically linked by the government to work, thus supporting an able-ist agenda where a person's worth is measured by their workability which is regularly re-assessed with any lack of progress punishable through benefit sanctions.

The stigmatisation and shaming of disabled claimants is well reported (Garthwaite 2011; Newman 2011; Briant et al. 2013; Garthwaite et al 2013; Coote 2014; Garthwaite 2015; Baumberg 2016; Beresford 2016; Patrick 2016; Patrick 2017; Gedalof 2018). Indeed, the changing narrative of disabled benefit claimants as scroungers has also attracted a range of media criticism and academic research interest, arguably in light of the threat of furthering the oppression already experienced by disabled people (Briant et al. 2013; Baumberg 2016; Gedalof 2018). For example, Briant et al.'s (2013, p. 874) content analysis of five newspapers during the period 2010-2011 to a similar period in 2004-2005, found a significant change in the way that disability including mental health was reported, with an increase in the number of articles using derogatory language to describe disabled people; a growing lack of compassion towards disabled people; and a link between claiming disability benefit and intent to deceive. Briant et al. (2013) acknowledge that many derogatory terms used by the press reflect terms first used by politicians. Interestingly, some disabled people were considered more deserving than others, particularly those with a physical or sensory impairment who were viewed as having "triumphed over adversity"; whilst people with more invisible impairments such as mental illness, chronic pain or depression were viewed as potentially faking their symptoms (Briant et al. 2013, p. 884).

The government's justification for redefining disability categories through changing benefit entitlement and reclassifying "disabled people as non-disabled people who are pretending to be disabled" (Briant et al. 2013, p. 885) is evident in the fitness for work assessment where thresholds of ability have been elevated to consider those previously categorised as disabled now fit-for-work (Briant et al. 2013, p. 886). The language of reactivation of disabled people into work (Briant et al. 2013, p. 875) is an interesting one assuming that out-of-work and disabled benefit claimants are lying dormant and can be brought back to a working life with the flick of a switch or a change of batteries. It is an almost Orwellian concept and conjures up an image of

Fritz Lang's workers in the film Metropolis who appear robotic and downtrodden in a mechanistic type of employment whilst serving their higher order masters. Interestingly, Patrick (2016, p. 246) notes that the experience of out-of-work welfare claimants is not unique to the UK and cites examples from welfare reform in Germany where people living in poverty are now perceived as "threatening" replacing their previous position as a "threatened" population.

In further exploring this issue, Goffman's (1963, p.15) seminal theory of stigma is useful in recognising how people viewed as different or deviant become discredited, rejected and excluded through the belief that "the person with a stigma is not quite human". The term stigma originates from Greek and refers to a visible symbol that was cut or burned into an individual's body to publicly declare their negative moral status (Goffman 1963). According to Goffman (1963, p.14) there are three types of stigma: "abominations of the body" referring to physical impairments or deformities; "blemishes of individual character", including deception, mental illness, addiction, homosexuality, unemployment, and radical political beliefs; and "tribal stigma" associated with race and religion. Goffman (1963, p.14) recognised that stigma was not a quality or product of the individual and was interested in the strategies used by people to manage the accompanying feelings of shame, disgrace and the fear of being judged and discredited (Goffman 1963; Tyler 2014a). Shame is central to stigma and is defined as a situation where a person "is disqualified from full social acceptance" by failing to meet the standards set by other people, societies and cultures and thus facing exclusion and disapproval (Goffman 1963, p.9). Thus Goffman's (1963) notion of stigma has both a sociological and a psychological component. However, Goffman (1963) has received criticism for his view of disability and for focusing more on the person and less on the socio-economic structures and political power dynamics causing stigmatisation and inequalities (Perez 2014; Tyler 2014b; Tyler 2014c; Baumberg 2016).

Indeed, Baumberg's (2016) large-scale quantitative study is helpful in understanding contemporary views of benefits stigma from both claimants and non-claimants and adds significantly to the predominantly qualitative research in this area by providing statistical evidence of the scale of the problem in the UK. Baumberg (2016, p.183) recognises three types of benefits stigma namely: "personal stigma" where the individual devalues their own identity by the very need to claim benefits;

“stigmatisation” where there is a perception that other people will devalue the benefit claimant’s identity; and “claims stigma” where stigma is experienced during the process of claiming benefits through lack of privacy, long waits and the belittling experience of feeling judged and mistrusted. His results indicate that 34% of benefits claimants reported either self-stigma or stigmatisation from others with 27% of claimants less likely to claim benefits due to their experience of shame; 49% of claimants provided at least one shame related response in the survey; and 30% of claimants believed that they were not treated with respect when applying for benefits leading Baumberg (2016) to conclude that benefits stigma is not a peripheral issue.

Grover and Piggott (2013, p.373) explore how emotions maintain social order recognising that shame and embarrassment are moral emotions directed towards the self and associated with culturally acceptable behaviour; whilst disgust, anger and contempt otherwise known as the “hostility triad” also responsible for maintaining social order, target others as in the case of media attention towards out-of-work and disabled people (Briant et al. 2011; Grover and Piggott 2013, p373). Disgust about people’s morality leads to dehumanisation and gives authority and justification to treat people differently and thus marginalise and exclude groups and individuals that are viewed as potentially polluting society (Grover and Piggott 2013). Thus, there is a disconnect between the government’s ideal of welfare reform based on the premise of including disabled out-of-work claimants in work and society through a mantra of equality for disabled people, compared to how policies and the media are representing and further marginalising disabled people (Grover and Piggott 2013).

Interestingly, stigma may not lead to shame when there is a strong personal identity; when devaluation from others can be disputed; and when people redirect the label of undeserving to others (Baumberg 2016). Indeed, Patrick’s (2016; 2017) longitudinal qualitative research on the lived experience of welfare reform followed benefit claimants including those with disabilities over a five-year period to explore the extent their lived experience corresponded with the dominant political narrative of welfare reform. Patrick (2017) found that the most common response used by claimants for coping with the shame of receiving out-of-work benefits was a process that she termed “defensive othering” where stigma was deflected by benefits claimants onto those that they perceived as less deserving than themselves in order to strengthen their own sense of deservingness (Patrick 2017, p.168). Thus, shame and the internalisation of negative messages including poor self-esteem, which might further social exclusion for already marginalised people is avoided and self-identity is protected. Similarly, in Pemberton et al.'s (2016) study, participants were keen to deny any identification with worklessness, which they attributed to others. This unwittingly colludes with and supports the dominant narrative already espoused by politicians and the media as a form of social control and dilutes any potential collective challenge of solidarity to the current situation (Tyler 2013; Pemberton et al. 2016; Patrick 2017). Indeed, Tyler (2014a; Tyler 2014b) calls for further research focusing on the experience of neo-liberal influences on stigma, welfare, class, poverty, work and dis/ability. According to Baumberg (2016) benefits stigma could be reduced by calling politicians and the media to account for their continuing role in propagating stigma against benefit claimants; by making the process of claiming benefits more respectful; and by changing the structure of the benefits system to be more universal, more generous and less conditional. It remains to be seen whether the roll out of Universal Credit within the UK may have some positive influence on reducing benefits stigma. Interestingly, Ken Loach's (2016) film "I Daniel Blake" in poignantly highlighting some of these issues, reinforces Baumberg's (2016) recommendations.

2.4.7. At the time of writing

This research and writing period has witnessed successive Conservative governments with Boris Johnson currently prime minister, replacing Theresa May in July 2019, who followed David Cameron as prime minister in June 2016 as a result of the Brexit referendum. However, despite significant changes in leadership, the welfare reform agenda remains, focussing attention on championing the people who are in work and seeming to continue to disregard those who are not in work and struggling (Patrick 2017, p.5). For example, the 2017 government manifesto, Forward Together (Conservative Party 2017) claimed to have no further radical welfare reform intentions but continued to aim for one million more disabled people into work; and to roll out Universal Credit, providing a single monthly payment to replace other benefits. The rolling out of Universal Credit continues in 2020 despite significant criticism and evidence of increasing hardship and poverty due to prolonged waiting times and government bureaucracy. In opposition, the Labour

Party's social security manifesto (Labour Party 2018), pledged to change the culture of demonising those not in work and to end the regime of punitive sanctions. This return to a language of social security was likely an attempt to create distance from the Conservative government's focus on welfare dependency. In Scotland, social security was devolved on 1st April 2018 to the Scottish Government with employment services now operated by Fair Start Scotland (BBC News 2018). Following consultation, participation in work related activities including volunteering, is now voluntary and not linked to fear of benefit sanctions as in the rest of the UK (BBC News 2018; Hepburn 2018). Given that devolved powers for social security will not be fully operational in Scotland until 2021 (BBC News 2018; Hepburn 2018), it remains to be seen how this will impact on disabled people including those living with mental illness in Scotland.

2.4.8. Summary

This theme introduces conversations around welfare reform in the UK, summarising the key issues facing out-of-work disabled claimants including those living with mental illness. Whilst the government could be commended for attempting to support disabled people into work, welfare reform policies namely, conditionality and workfare, remain contentious, individualising social issues, redefining work- ability and failing to recognise wider socio-economic difficulties in the labour market, this further marginalising and socially excluding disabled people. Although studies have investigated the lived experience of welfare reform (Tyler 2014 a; 2014b; Baumberg 2016; Patrick 2016; Pemberton et al. 2016; Patrick 2017) and included some out-of-work disabled participants, no study has focussed specifically on out-of-work people with lived experience of mental illness who are volunteering in the context of welfare reform and no study has adopted a participatory methodology. This study is therefore well placed to fill this gap. The next section considers conversations in the literature on mental illness and recovery.

2.5. MENTAL ILLNESS AND RECOVERY

> …..recovery isn't about getting back to where you were before, it's about building something new. (Rethink Mental Health 2018, online)

Finally, this review turns to consider mental illness and recovery from a critical perspective. It begins by exploring the social model of disability before reflecting on the influence of the Mad Pride movement and critical psychiatry and concluding with a critique of the concept of recovery from mental illness.

2.5.1. The social model of disability

In the UK, the social model of disability (Oliver 1983) challenges the traditional, dominant bio-medical view of disability as a personal deficit in need of fixing by medical experts, including allied health professionals; and explains how this cultural discourse reinforces the social oppression and exclusion of disabled people through negative attitudes, pejorative language and environmental barriers (Shakespeare 2013). Influenced by the civil rights movement in the US and feminist campaigns, the model originated in the UK in the 1970s with a group of disabled people who formed the Union of Physically Impaired Against Segregation (UPIAS) aiming to stop the segregation of people with impairments and to provide opportunities for full participation in society where people would have control over their lives, live independently and have access to paid employment and productivity (Shakespeare 2013, p. 214). In their Fundamental Principles of Disability, they stated:

> …..in our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS 1976, p. 3)

Here, they distinguish between impairment, any functional or physical limitation within the person, which arguably also includes any mental or sensory limitations, and disability, the experience of social exclusion and restrictions on participation due to social and physical barriers enforced by society, which UPIAS (1976) assert has led to the systematic oppression of disabled people. In redefining disability, the model disputes notions of normality; challenges the medicalisation of people with disabilities in need of professional treatment and/or public pity; and shifts attention to a view of disabled people where the removal of externally imposed barriers is a moral, societal obligation that will enable full participation (Shakespeare 2013). Further, it recognises through emancipation that disabled people have the power to challenge negative perceptions of self, and by way of a collective identity, are in the best position to influence and manage services and organisations including those involving research activities (Shakespeare 2013). Indeed, an example pertinent to this study is the UK government's emphasis on gradations of impairment to distinguish between those who are more deserving than others, forcing disabled people into a victim mode and risking dividing a united disabled front (Oliver 2013). Arguably, the social model view of disability was initially narrowly influenced by UPIAS as white heterosexual males, with physical impairments (Shakespeare and Watson 2010; Shakespeare 2013). It is now widely recognised that people who experience mental illness also experience social exclusion and barriers to employment and housing and feel devalued and stigmatised by mental health identities and diagnostic labels (Harper and Speed 2012).

Whilst the social model of disability has been significant in redefining disability and applying political pressure from disability rights activists and disability studies academics, the model can also be considered flawed in its argument that disadvantage has nothing to do with individual impairment (Shakespeare and Watson 2010). In concentrating on the role of society and structural change to tackle problems faced by disabled people, the model ignores the complexity of disability and the disabling aspects of impairment on people's bodies (and one could add minds) where for many people particularly those experiencing chronic and degenerative conditions it is a combination of disadvantage from intrinsic impairment and social environments and attitudes that limits participation (Shakespeare and Watson 2010; Shakespeare 2013). Reflecting on criticism from disabled feminists that the model disregards disability as personal and experiential and denies the experience of disabled people's bodies, Shakespeare and Watson (2010) recognise the social model of disability as inadequate in conceptualising disability. Indeed, the model denies that impairment is a problem; that people are also disabled by their bodies; and that impairment is a valued embodied experience in the lives of disabled people (Shakespeare and Watson 2002; 2010; Shakespeare 2013). Further, Shakespeare and Watson (2010, p. 61) contend that building a model on a range of dualistic categories such as "disabled/non-disabled" and "oppressed/oppressor" is simplistic, generalist and homogenises diversity thus creating a disconnect between theory and personal experience. In moving beyond the social model, Shakespeare and Watson (2010, p. 73) suggest that much could be gained from research that pays attention to nuanced stories of the interplay between environmental and individual factors and the experience of disability from the perspective of people with impairments "to explore real lives lived by disabled people and an insight into their real worlds” rather than solely focussing on oppression and disadvantage.

A useful adjunct to the social model of disability is the affirmation model of disability. originally proposed by Swain and French (2000) and later critically explored and clarified by Cameron (2014; 2015). Cameron (2014; 2015) proposes the affirmation model as a tool to reveal the conflicts experienced by disabled people in creating positive identities in everyday encounters where self-image and understanding are formed by both structural inequity and individual experience; and to expose how negative assumptions about disability continue to affect the social relations encountered by disabled people in their everyday living. Swain and French’s (2000, p. 569) affirmative model, grounded in the views of disabled people and disability culture through the Disability Arts Movement, revealed positive “non-tragic” disabled identities that countered the dominant and presumptive personal tragedy and abnormality view of disability and impairment by non-disabled people and revealed how living with an impairment could be experienced as valuable and satisfying, validating a positive identity of being impaired and rejecting the dominant value of normality. Additionally, their affirmative model addressed criticism of the social model in demonstrating how positive disabled identities could encompass both impairment and disability and disabled people could take ownership of their impairment and their bodies (Swain and French 2000). Cameron’s (2014; 2015) affirmation model helpfully builds upon and clarifies Swain and French’s (2000) affirmative model to propose a useful framework including definitions of impairment and disability that recognise impairment as:

> …physical, sensory, emotional and cognitive difference divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society. (Cameron 2015, p. 118)

And disability as:

> …a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal. (Cameron 2015, p.118)

Thus, impairment is identified as difference rather than deficit and recognised as an “ordinary” rather than “extraordinary” element of the human experience challenging the dominant cultural narrative of impairment as abnormal (Cameron 2015, p. 118).

Furthermore, disability is recognised as a role which forms a productive as well as restrictive relationship in terms of what people are excluded from in their lives and more significantly includes the roles that people are required to adopt in relation to their impairment whether one of personal tragedy or denial of difference in response to the dominant societal discourse of what is considered normal (Cameron 2015). This extends and refines Cameron's earlier (2008, in McCormack and Collins 2012, p. 157) definition of disability as "the loss or limitation of opportunities to take part in community life on an equal level with others due to physical and social barriers" to reflect disability as a role that is both assigned to people with impairments and adopted by people with impairments themselves in response to everyday interpersonal interactions and wider societal discourse on disability and impairment. Cameron's (2014; 2015) research poignantly and powerfully illustrates the detail of every-day encounters of disabled people with non-disabled people to reveal how disabling social relations which he describes as "micro-aggressions and invalidations" occurring at the level of interpersonal interaction are "reproduced, re-enacted and reinforced" (Cameron 2015, p. 119). More specifically, he draws on Freire's (1976, p. 33 in Cameron 2015, p. 118) definition of critical praxis "involving reflection and action upon the world in order to transform it" as a means by which disabled people and their allies can bring critical awareness to everyday micro-aggressions and invalidations in the fight for emancipation and social change. Finally, Cameron (2014, p. 29) insightfully reflects on whether aspects of the affirmation model are implicit in the social model and notes that "access is not the same as inclusion… there is still a gap between being able to be there and being valued there".

This review now turns to consider the influence of the Mad Pride movement and critical psychiatry.

2.5.2. Critical Perspectives

Arguably, attention to mental illness, lacking in much of the early literature on disability activism, changed with the growth of Mad Pride, a politically active movement of current and former mental health service users and allies advocating that people living with mental illness should take pride in their mad identity and reclaim pejorative language of madness as positive (Lewis 2013). Originating in Canada in 1993 in response to the persistent stigma experienced by people living with mental illness, and now with international influence, the Mad Pride movement adopted Judi Chamberlin's (1978) earlier influential critique of psychiatric services and personal lived experience of mental illness, to reinforce: the abuse and dominance of biological approaches to psychiatry that over-rely on diagnostic labelling, medication, involuntary detention and restraint; the inconsistent scientific evidence to support neuro-biological theories of chemical imbalance in the brain; and the ignoring of evidence of wider psycho-social and socio-political causes (Chamberlin 1978; Lewis 2013). Adopting an emancipatory approach, Mad Pride advocate for alternative possibilities for recovery including full participation in decision-making and organisational governance as "consumer/survivors"; and emphasise peer support and self-management alternatives (Lewis 2013, p.121; Timimi 2013). These are gradually becoming integrated into government policies within the UK and accepted by critical psychiatrists keen to challenge the assumptions inherent in conventional practice including diagnostic labels and embrace a social model and more collaborative and ethical treatment approaches that confront biological reductionism and consider the complexity of socio-cultural, political and economic influences on mental illness (Middleton 2007; Bracken et al. 2012; Kinderman et al. 2013; Lewis 2013; Timimi 2013; Wright 2014). However, there continues to be a lack of choice for mental illness consumers and biological treatments in the form of expensive medication continue to dominate, driven by large profit-making pharmaceutical companies despite controversial side-effects and lack of sufficient evidence of effectiveness (Lewis 2013).

Furthermore, despite the emphasis on asset-based approaches, mental health diagnostic labels continue to emphasise individual deficits and pathology (Bracken et al. 2012; Harper and Speed 2012; Kinderman et al. 2013; Timimi 2013; Wright 2014). Indeed, opposition to mental illness diagnoses and the often inhumane interventions for people considered to have lost their sanity has longstanding historical roots in individual disputes, legal challenges, campaigns for raising awareness of alternative interventions, and through the critical writing of the anti-psychiatry movement (Lewis 2013). For example, in the 1960s R.D. Laing a Scottish psychiatrist, challenged the orthodoxy of chemical treatment for psychosis valuing instead the expression of feelings and experience, and viewed the origin of mental illness as a means of coping with an irrational world including the family, who were in turn influenced by wider organisations and society (Lewis 2013). Laing's views, which led to the development of therapeutic communities where people were encouraged to communicate with one another and were supported in their recovery with attitudes of dignity and respect, could arguably be viewed as precursors to peer support and principles of advocacy. However, Chamberlin (1978) questions to what extent psychiatrists are truly able to relinquish authority, suggesting that therapeutic communities can be misleading in proposing a neutralising of power. This suggests the continuation and hegemony of psychiatric positivism.

In understanding dominant discourses in mental health and specifically those arising from the interplay of power, knowledge and the body, Michel Foucault's (1961; 1982; 2002) contribution is significant. In Foucaultian terms, the dominant discourse of mental illness is determined by those with the power to classify illness, which has changed throughout history involving for example, psychiatrists, psychologists, priests and law makers (Foucault 1961). Foucault's (1982) interest in how people become objectified highlights the complex power relationships that have led to binary positions such as mad and sane, ill and healthy, good and bad which have further led to the adoption of methods of control. Indeed, Foucault (1982, p.180) criticises medical professionals for the level of control they hold over people's bodies and minds stating that "part of the power of these interpretive sciences is that they claim to be able to reveal the truth about our psyches, our culture, our society-truths that can only be understood by expert interpreters". This is exemplified by methods of surveillance including the gaze of the psychiatrist in mental illness and the panopticon as the all-seeing window in the incarceration of prisoners where all behaviour can be observed and noted as justification for the need for incarceration and professional intervention and control (Dreyfus and Rabinow 1982).

Foucault's (1982) archaeology of research digs down to expose for examination rather than interpretation, the process whereby knowledge and power impact on and are influenced by the body to re-present historical discourse, rules and conditions through things that are said and thereby enacted or made visible, for example, about madness and sanity (Dreyfus and Rabinow 1982; Stevenson and Cutcliffe 2006). Foucault's (2002, p. 36) archaeological method therefore describes the "interplay of the rules that make possible the appearance of objects during a given period of time". In this way, genealogy becomes a means to understand through archaeology how power influences current day concerns and practices, providing a tool to potentially challenge the position of the establishment, whether medical, legal or judicial and the accepted wisdom of its members (Stevenson and Cutcliffe 2006).

Foucault's method enables us to examine the continuities and discontinuities of how knowledge and rules of practice are influenced by power relationships where the rationale for adopting such rules of practice is often hidden, disguised or unconscious on the part of those holding power and influence (Foucault 1984). Interestingly, Foucault's concern is primarily with a description of what is said and what is seen rather than any sourcing of meaning, motivation or explanation (Stevenson and Cutcliffe 2006).

Attention to power relationships and debate between individual versus societal origins of mental illness continues today with the critical psychiatry and survivor movements campaigning for a radical rethink of what forms of knowledge are privileged, how mental health is conceptualised and how services are delivered (Bracken et al. 2012; Kinderman et al 2013; Timimi 2013; Wright 2014). Recovery is now a well-used term within mental health policy and practice yet despite being adopted by mental health service users and survivors as well as by statutory psychiatric services and third sector mental health organisations there is some confusion of definition (Harper and Speed 2012). This review now turns to consider key issues in recovery literature.

2.5.3. Recovery

> …..for many of us who are disabled, recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic, and we falter, we slide back, re-group and start again. (Deegan 1988, p.15)

The term recovery, recognising that people living with severe mental illness can improve sufficiently to lead productive lives, became prominent in the 1980s through the writing of consumer/survivors (Deegan 1988; Anthony 1993; Deegan 1996; Onken et al. 2007). Influenced by consumer/survivor writing Anthony (1993), championed recovery in professional literature to manage the effects of deinstitutionalisation and to promote a new vision for mental health services based on recovery principles (Anthony 1993; Onken et al. 2007). However there appears to be some tension between recovery as a process leading to empowerment and finding meaning, as highlighted in consumer/survivor accounts, and recovery as an outcome, as indicated in professional accounts (Lloyd et al. 2008; Meehan et al. 2008; Lal 2010). Indeed, Deegan (1988; 1996) in her poignant, painful and poetic account of her recovery from mental illness distinguishes between rehabilitation, a passive process of adaptation through mental health service provision, and recovery, a precursor to rehabilitation, which emphasises actively acknowledging and courageously conquering the trials of the illness to re-establish a renewed sense of self and intention both within and beyond the confines of the illness. For Deegan (1988, p.13) the lived experience of mental illness is first characterised by denial followed by a lengthy period of "despair and anguish" where simple tasks become impossible due to a sense of hopelessness and paralysis. Deegan (1988, p.14) describes the next stage of recovery as "the birth of hope called forth by the possibility of being loved" a period of slow, gradual rebuilding of the self through "hope, willingness, and responsible action" where the ability to do is discovered. Deegan (1988, p.15; 1996) indicates that this is not about being cured but about accepting limitations and beginning "to discover who we can be and what we can do" as active participants in the recovery process. Deegan's (1988; 1996) narrative is helpful in highlighting recovery as a deeply personal process (Anthony 1993; Leamy et al. 2011) that is more about liberation than cure (Bonney and Stickley 2008; Harper and Speed 2012).

Although recovery is recognised as deeply personal, there has been a lack of conceptual clarity of the nature of recovery (Harper and Speed 2012), thus prompting Leamy et al.'s (2011) systematic review, focusing on personal accounts and identifying core elements of recovery fitting the acronym CHIME standing for Connectedness, Hope, Identity, Meaning and Empowerment. Connectedness encompasses supportive relationships and connections to the community; hope suggests "optimism about the future" incorporating motivation, positive thinking, and having dreams and aspirations; identity involves overcoming stigma and redefining or rebuilding identity; meaning in life includes quality of life and meaningful social roles and goals; and finally, empowerment is having personal responsibility and a sense of control over one's life (Leamy et al. 2011, pp. 445-448). It is interesting that hope and optimism are conflated. According to Bruininks and Malle (2005, p. 324):

> …..hope is most closely related to wishing…hope is distinct from optimism by being an emotion, representing more important but less likely outcomes, and by affording less personal control…When people do have a high degree of control, they may no longer need to be just hopeful but can be optimistic because the outcome is now attainable.

Optimism therefore is a degree of belief and implies some attitude to a rational calculation or expectation which could be grounded in planning and focussed work, whereas hope often transcends optimism taking a favourable view whether through wishful thinking, blind unrealism, spiritual belief or chance (Dholakia 2017). Interestingly, the CHIME elements have resonance with Deegan's (1988; 1996) accounts and provide a conceptual framework for recovery to focus practice, research and measure outcomes other than symptom control and admission rates (Leamy et al. 2011). However, Leamy et al. (2011) acknowledge that focusing on personal narratives ignores wider socio-cultural issues of discrimination, stigma, community integration and employment opportunities. In contrast, Onken et al.'s (2007) ecological framework considers both the personal life context of the individual and the wider socio-cultural and environmental barriers that result in oppression, and the dynamic relationship between the two. Onken et al. (2007) suggest "hope" (individual), "opportunity" (environment) and "choice" (the interplay between the individual and the environment), "can promote or hinder recovery" (Onken et al. 2007, p. 10). Interestingly, we see hope being referred to again here rather than optimism. We therefore return to the point raised earlier by Shakespeare (2013) that it is this dynamic combination of personal impairment and wider ecological factors that may limit or support full participation, integration and inclusion and that any "personal disposition toward positive recovery must be complemented by a facilitating environment" (Onken et al. 2007, p. 19).

Indeed, critics of recovery agree that individualising what are inherently social problems conceals the structural causes of mental distress and prevents these from being explored from a more political and collective perspective (Onken et al. 2007; Harper and Speed 2012). Further, the over-emphasis on individual responsibility in recovery where the person is expected to confront their negative attitudes and cognitions to bring about change within their personal life endorses a political and neo-liberal approach of responsible consumers where distress is individualised, and any collective identity is denied (Harper and Speed 2012) as suggested earlier by Oliver (2013). In emphasising self-management of the mental illness experience as a personal tool for change, the onus of responsibility for managing the impact on wellbeing from conditions such as poor housing, unemployment, poverty and other social determinants of mental health problems is transferred to the individual rather than society (Harper and Speed 2012), thus raising the question of agency, choice and control. Finally, placing emphasis on strengths and assets merely reframes a deficit model by highlighting polar opposites rather than demonstrating a more liberating approach to the conceptualisation of mental illness (Harper and Speed 2012).

2.5.4. Summary

This theme has introduced critical conversations considering mental illness and recovery from a consumer/survivor and professional services perspective. Whilst the social model is helpful in focusing societal responsibility, it is the combination of disadvantage from intrinsic impairment and social environments and attitudes that limits participation (Onken et al. 2007; Shakespeare 2013). Empowering disabled people through self-management and self-determinism risks individualising social problems and prevents them from being explored politically and collectively (Onken et al. 2007; Harper and Speed 2012). This section has illustrated the personal experience of recovery and the personal and collective challenges for people recovering from mental illness. No study has been identified that consider the experience of recovery through volunteering from an inclusive and collaborative perspective. This study is well placed to fill this gap.

2.6. REVIEW CONCLUSION

This review sought to gain answers to four questions posed at the outset. Overall, these questions have been answered and gaps have been exposed. The literature on volunteering has highlighted a range of significant benefits for individuals and communities and although there is some indication that volunteering can contribute to recovery for people with mental illness, research evidence is limited and there were no studies identified adopting a PAR approach.

The challenges of volunteering appear embedded in the current UK socio-political context influenced by neoliberalism, austerity, welfare reform and the dominance of paid employment as central to citizenship where volunteering is perceived through a vocational lens. Additional tensions include volunteering as a potential form of employment substitution, and as a means of coercion and proof of fitness for work. More concerning is literature exposing the detrimental effect on the lives of out-of-work disabled welfare claimants through stigma and perceptions of deservingness.

Further, the pervasive debate between individual and societal responsibility has highlighted the risk of individualising social problems, preventing them from being explored politically and collectively. Occupational therapy literature predominantly supports a vocational perspective of volunteering viewing it as a stepping-stone to employment and as a preliminary stage in the vocational rehabilitation process where people may get stuck. This narrow focus would benefit from further exploration alongside consideration of how volunteering is conceptualised in relation to mental illness and recovery.

In summary, this literature review has highlighted limited empirical work exploring volunteering from the perspective of people with lived experience of mental illness in their recovery and no PAR study was identified from a volunteering perspective. The need for an in-depth exploration of this experience within the current socio-political context using a participatory methodology is therefore justified and this project has the potential to address these gaps. The next chapter outlines the methodology for the study.

CHAPTER 3: METHODOLOGY: RESEARCH STRATEGY

Within any research process, key elements require to be open to scrutiny, namely: the research strategy governing the choice of methodology linked to the desired outcomes; the theoretical perspective or philosophical stance informing the strategy including views on epistemology and ontology; the influence of the researcher's personal and political worldview; and finally, the methods and procedure used to gather and analyse data (Crotty 2003, p.3). Identifying these elements in depth ensures the soundness of the research and enables the outcomes to be convincing (Crotty 2003). This seems reasonable; however, the last ten years has witnessed a changing landscape of social scientific inquiry with a blurring of boundaries between research perspectives and paradigms and a toughening of perceptions of difference (Denzin and Lincoln 2013b). According to Lincoln et al. (2013, p. 200) "paradigms are beginning to interbreed such that two theorists previously thought to be in irreconcilable conflict may now appear, under a different theoretical rubric to be informing one another's arguments". Indeed, traditional positivist approaches embedded in a quantitative paradigm have been challenged by qualitative approaches from an interpretive paradigm; whilst a critical and emancipatory approach based on exposing and seeking to challenge inequalities and oppression in marginalised groups has gained recognition as an alternative paradigm questioning the assumptions of the other two (Oliver 1992; Kemmis 2008; Henn et al. 2009; Kemmis et al. 2014). Regardless of complexity, justifying the chosen methodology and underpinning theoretical influences lays the process out for scrutiny (Crotty 2003).

This chapter describes the research strategy and methodological choices adopted in this study, justifying a critical and emancipatory paradigm and why I chose participatory action research (PAR) as the methodological approach underpinning my research strategy. I begin with an exploration of critical social research and emancipatory disability research before exploring PAR in the context of a broader family of action research and considering the philosophical and theoretical perspectives aligned with critical PAR. I reveal my epistemological and ontological choices and my personal and professional worldview assumptions influencing and being influenced by a critical-emancipatory paradigm and PAR approach to this study. I conclude with the challenges and criteria for judging quality in PAR and finally, I consider how the PAR project sits within the overall PhD thesis. The following Chapter 4 describes the research process, design and methods.

3.1. Adopting a critical-emancipatory social research paradigm

Selecting an appropriate research paradigm is essential from the outset, guided by the purpose of the study and researcher assumptions about how new knowledge is best achieved (Henn et al. 2009). Competing paradigms have conflicting views of the nature of knowledge and how to judge knowledge claims and are generally polarised along a spectrum from a positivist paradigm, usually associated with quantitative research strategies to an interpretive paradigm, usually associated with qualitative research strategies (Henn et al. 2009).

The positivist paradigm asserts a scientific view of the world where knowledge of phenomena including the social world is directly observable and understood as facts that can be explained in terms of general laws of cause and effect (Henn et al. 2009). It originates in the work of the philosopher August Comte (1798-1857) who was interested in discovering the “truth” about the social world based on natural laws developed through scientific treatment through empirical observations of concrete facts, which challenged theological and abstract metaphysical beliefs at that time (Henn et al. 2009, p.12). Logical positivism, using an inductive approach through further observation to verify and apply the theory as a law to similar phenomena, was criticised by Karl Popper (1902-1994) who recognised a flaw in assuming that laws would apply to all situations given that potential situations might contradict previous observations that had not yet been explored thus leading to the contemporary positivist paradigm incorporating Popper’s hypothetico-deductive method of refuting or falsifying theories rather than verifying them, by putting them to the test against newly observed data in a “theory-then-research” approach (Hennn et al. 2009, p.14). Arguably however, a positivist approach fails to look beyond observable phenomena that it cannot test, and favours large-scale, statistically based projects placed under structured scientific conditions emphasising standardisation, researcher control and objectivity (Henn et al. 2009). Therefore, a positivist view of knowledge as truth and the rigorous methods associated with generating data appear to sit in direct contrast to the purpose and desired outcomes of this participatory study which is less concerned with testing a hypothesis, uncovering reliable facts, and explaining cause and effect and more concerned with exploring the complexities in the social world of volunteering from the perspective of people with lived experience of mental illness.

In contrast, the interpretive paradigm is concerned with knowledge that is socially constructed and a product of the context in which it is located and is based on understanding meanings and interpretations that are not directly observable, where the social world is studied in its natural state through, for example, participant observation or in-depth interviews, to understand naturally occurring behaviour (Henn et al. 2009, p.17). Interpretivism draws on the work of Max Weber (1864-1930) who argued that in developing our knowledge of the social world we should first seek to understand it from the perspective of the research participants in order to appreciate their behaviour and intentions, values, motivations and purpose behind it (Henn et al. 2009, p. 15). This paradigm encourages participants' subjective accounts to be expressed in their own words, accepting the importance of language and human behaviour as shaped by the meanings people have of their world (Henn et al. 2009). Research is generally small scale based on detailed descriptions of what is heard or observed with the researcher adopting an insider position with the intention of understanding rather than explaining actions and situations from which theory can evolve in an analytic-inductive method based on a "research-then-theory" approach (Henn et al. 2009, p.17). This paradigm is attractive in that it listens to participant voices in an attempt to interpret and understand human behaviour within the participant experience but is ultimately passive in accounting for or challenging the influence of power structures or history on that experience (Henn et al. 2009). Arguably, the interpretive paradigm seeks to understand rather than to challenge or change the participant situation, which is a key intention in my study. Additionally, participants may be vulnerable to the dominance of academic researchers enforcing their own subjective interpretations on them. Indeed, the power dynamic between researcher and participant appears to be less well articulated in terms of decision-making about purpose, method or involvement in data analysis making compatibility with a participatory approach less clear.

A third approach prominent in critical social research is the critical-emancipatory paradigm concerned with recognising and understanding the social, political and historical influences on human thought and action and specifically how social structures oppress and have historically oppressed certain societal groups including disabled people (Oliver 1992; 2002; Henn et al. 2009). A key premise is to expose inequality, exploitation and injustice; to give voice to excluded and marginalised groups; and to help clarify oppression in order to precipitate social change (Henn et al. 2009, p.17). Arguably, adopting a language of enabling voices to be heard by breaking down barriers for both listeners and speakers is more empowering and emancipatory (Maguire 2000). This paradigm encourages flexibility in research approach with adaptation of methods to realise emancipatory research goals (Henn et al. 2009). However, it has attracted criticism for being too politically orientated and contravening the notion of the researcher as neutral in the research process. Arguably, all research is inherently political, and no research is entirely "value-free" with some research agendas hidden or "suppressed" within conventional research (Henn et al. 2009, p.18). Levels of participation of marginalised groups within research and the researcher position are reoccurring themes that will be revisited.

This project set out to explore the experience of volunteering with a group of adults with lived experience of mental illness, engaged in unpaid voluntary work in the community through personal choice as part of their journey of recovery. The aim of the project was to hear about the benefits and challenges of volunteering as well as about socio-political and welfare systems that support people with mental illness to volunteer. People with lived experience of mental illness are often marginalised within society and are more likely to face social exclusion and social disadvantage. A critical-emancipatory paradigm is therefore best suited to guide this project to its desired outcomes with its emphasis on examining and understanding historical, social and political influences on the experience of volunteering and in enabling participant marginalised voices to be heard. Further, a key objective of this study was to produce something through action that would be of benefit to the group and/or the wider community, which reflects the critical emancipatory paradigm's commitment to social change. Therefore, in rejecting a positivist and interpretivist paradigm, this study adopts a critical-emancipatory social research paradigm.

Given the critical-emancipatory paradigm's flexibility in selecting methodology and method, this chapter now explains why I chose participatory action research (PAR) as the approach underpinning my research strategy. However, given that my study involves working with people with lived experience of mental illness, it seems necessary to first explore the influence of critical social research and more specifically emancipatory disability research before examining the fit between a critical-emancipatory paradigm, emancipatory disability research and PAR.

3.2. Critical Social Research and Emancipatory Disability Research

Emancipatory disability research sits alongside feminist research methodology under the umbrella of critical social research, a theoretical framework and movement of critical thought first developed as a critical theory of society by the Frankfurt School, in the period between 1923-1950, under the influence of a range of neo-Marxist scholars including Max Horkheimer and Theodor Adorno who through interdisciplinary philosophical and social critique including that of the arts and humanities, attacked the orthodoxy and perceived capitalist class bias of social research, proposing that research practice reinforced systems of oppression at the expense of social liberation (Henn et al. 2009; Cunningham 2014). Indeed, the Frankfurt school, a diverse group of cultural dissenters (Dant 2003), were strongly critical of positivism viewing it as lacking in sensitivity to human and social issues and unhelpful in providing any links to practice (Cunningham 2014). Critical theory therefore provides a theoretical interpretive framework for analysing and exposing oppression in marginalised populations and typically targets political ideology, capitalism, the mass culture industry, technology and the media including how language within the public arena has a tendency to reinforce oppression and marginalisation (Cunningham 2014). Modern culture viewed broadly as the way in which ordinary people live their lives in work, leisure, socially and as consumers is criticised for unnecessarily restricting people’s freedom to reach their full potential (Dant 2003). The role of critical theory is to enlighten people to liberate themselves from historical, cultural and taken for granted influences that create an experience of “unfreedom”, by imagining and acting differently through reasoned argument, resistance and non-acceptance of universal values and normative patterns of thinking and being (Dant 2003, p.163). Interestingly, critical theory with a background in interdisciplinary methods lends itself well to participatory and arts-based research practices with a focus on being accessible to all whilst dissipating disciplinary barriers and shifting power to research participants (Cunningham 2014).

Emancipatory disability research originated from the disability rights movement in the 1980’s-1990’s and was championed by Oliver (1992) in recognition of the lack of research capturing the experience of disability from the perspective of disabled people themselves or the social structures where disability is located; a lack of reference to political or policy issues; and the dominance of traditional research methods controlled by non-disabled academics as experts in the pursuit of scientific knowledge thus perpetuating an elitist hierarchy that precludes knowledge creation to advance emancipatory goals (Oliver 1992; 2002 Barnes 2003; Henn et al. 2009; Russo and Beresford 2015). Oliver (1992, p. 103) argues that in order to reverse the "alienation" of disabled people through positivist and interpretive research paradigms, the social relations of research production has to be reconsidered. Alienation here refers to the disabled person as research subject, typically estranged from involvement in the research process other than to meet the researcher's ends, thus aligning with a Marxist view of alienation "…from the product of research, from the process itself, from other research subjects and, finally, from the self" (Oliver 1992, p.103). Oliver (1992, p. 105) continues "…disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life". Indeed historically, positivist research has reinforced an individual pathology model of disability highlighting impairments and medical and rehabilitative interventions; whilst interpretive research in presenting the meaning of disability for disabled people has tended to remain at the level of expert researcher and informant and has failed to take cognisance of disability as social oppression or impact on improved services and quality of life (Oliver 1992; Stone and Priestly 1996; Oliver 2002). Furthermore, in previously favouring qualitative methods, emancipatory disability research has distanced itself from narrative methods that emphasise a personal tragic or heroic individualised view of disability at the expense of data that supports the collective experience of the structures of disablement (Barnes 1996; Henn et al. 2009). Emancipatory disability research therefore adopts the social model of disability as an epistemology to expose disabling societal structures that continue to marginalise disabled people (Oliver 1992). It disrupts the hegemony of academic research by giving control of the production of research to disabled people for disabled people through disabled organisation (Oliver 1992; Stone and Priestly 1996; Oliver 2002); and counters the argument for researcher objectivity by reinforcing the need for solidarity in anti-oppressive research (Stone and Priestly 1996). Calling on researcher commitment to emancipation Barnes (1996, p.110) states:

> …...there is no independent haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed.

However, the distinction between oppressed and oppressor is not always clear-cut with categories and social contexts changing over time and the latter including some disabled people in certain contexts (Barnes and Mercer 2006). Indeed, Barnes's (2002, pp.4-9) core principles of emancipatory disability research provide a useful benchmark for my study and will be revisited, namely:

1. User participation and control over all aspects of the research process or a commitment to work towards this.
2. Accountability to the disabled community.
3. Adherence to the social model of disability ensuring that the research focus considers the structures and processes, which create disability.
4. Challenging the discourse of objectivity in research by ensuring that ontological and epistemological positions and choice of methodology and data collection and analysis strategies are logical, rigorous and open to scrutiny
5. Flexibility in choice of methods to suit the nature of the research recognising that all data collection strategies have strengths and weaknesses.
6. The role of experience should be set "firmly within an environmental and cultural context, in order to highlight the disabling consequences of a society that is increasingly organised around the needs of a mythical, affluent non-disabled majority".
7. The research should produce practical outcomes that are meaningful for disabled people and the wider community.

The degree of participation of disabled people having research control and the position of the academic researcher are clearly articulated within this approach. However, the distinction between emancipatory and participatory research approaches is less clear and requires elucidation.

3.3. Participatory and emancipatory research approaches and levels of participation

Participatory and emancipatory approaches have different historical and social roots (Zarb 1992; French and Swain 1997; Traina 2016). Emancipatory research has its roots in the disability movement, civil rights and political action whilst participatory research was developed by non-disabled researchers to challenge hierarchical research relationships redefining subjects as active participants who shared ownership of research projects that tackled community based social problems and were orientated to community action (French and Swain 1997; Traina 2016). Participatory research, whilst potentially supporting the social model of disability, is not directly associated with it (Traina 2016). Interestingly, Zarb (1992) contends that working in partnership and involving disabled people in a meaningful way through participatory research is a prerequisite to emancipatory research. For participatory research to be authentic, disabled people should not just take part but should be involved in all stages of the research process including the design and evaluation (French and Swain 1992; Zarb 1992). However, Zarb (1992) cautions that increasing participation does not constitute emancipatory research until disabled people are in full control of the research process and all research decisions. The question of who controls the research is a significant one in distinguishing between emancipatory and participatory approaches and Zarb (2002, p. 128 in Henn et al. 2009, p. 43) proposes critical evaluation of existing research through the following questions:

1. Who controls what the research is about and how it will be carried out?
2. To what extent are disabled people involved in the research process?
3. What opportunities exist for disabled people to shape the research outputs and influence future research?
4. What happens to the research outputs?

Zarb (1992) further distinguishes between participatory and emancipatory approaches stating that the latter contributes significantly to the empowerment of disabled people. However, the notion of empowerment is not unproblematic. Oliver (1992, p.111) recognises Freire’s (1972) view “that empowerment does not exist as the gift of a few who have it to be delivered to those who do not; people can only empower themselves”. The issue for emancipatory research is therefore not “how to empower people but, once people have decided to empower themselves, precisely what research can they do to facilitate this process" (Oliver 1992, p. 111). This requires researchers to "put their knowledge and skills at the disposal of their research subjects…to use in whatever ways they choose" (Oliver 1992, p.111). Indeed, tokenistic participatory strategies involving disabled people and not confronting systems of oppression leave disabled people positioned in oppressive ways (Oliver 2002); and failing to give ultimate control to the research participants for research agendas and resources, or challenging the distinction between researcher and researched, positions disabled people as less than those in control (Oliver 2002). Participation is also complex. Examining the extent of research participation Biggs (1989 cited in Cornwall and Jewkes 1995, p. 1669) outlines four categories namely, "contractual": when people take part in enquiries or experiments; "consultative": when people are asked for their opinions and consulted before interventions are made; "collaborative": when local people and researchers work together on projects designed, initiated and managed by researchers; and "collegiate": when local people have control over the process and work together with researchers in a process of mutual learning. Arnstein (1969; 2011, p. 5) provides a typology of eight levels of participation depicted as a series of rungs on a ladder from "non-participation" through "tokenism" to "citizen control" (Figure 2):

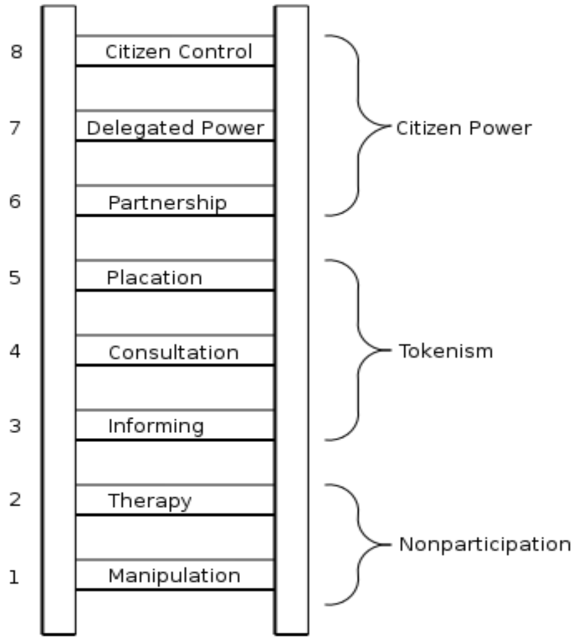

Figure 2: Arnstein's (1969) ladder of citizen participation (in Arnstein 2011, p 5.)

Noteworthy is that the bottom rungs, associated with manipulation and therapy are things done on or to people through for example a passive form of education or treatment; whilst the middle rungs represent the opportunity for people's voices to be heard but without the power to influence or decide (Arnstein 1969; 2011). The top three rungs represent increasing decision-making authority from enabling negotiation through "partnership" to full managerial power associated with "citizen control" (Arnstein 1969; 2011, p. 5). Partnership here represents negotiation and planning through shared power and decision-making in line with agreed ground rules (Arnstein 1969; 2011).

Arnstein's (1969) ladder whilst still influential, has been criticised for being simplistic, linear, uni-dimensional and reductionist assuming a hierarchical approach and homogeneity thus negating the complexity of citizen involvement and how for some people "participation" in itself may be a goal (Arnstein 1969; Tritter and McCallum 2006; Arnstein 2011, p.5; Carpentier 2016). Further, it ignores blocks to genuine participation such as paternalism or resistance to sharing power on the part of the power holders or distrust and lack of knowledge for those without power (Arnstein 1969; Tritter and McCallum 2006; Arnstein 2011; Carpentier 2016; Kotus and Sowada 2017; Beresford 2019). It overemphasises power at the expense of process failing to account for the conditions in which participation is likely to work, specifically the dimensions of social trust, open cooperation and information flow which are key to collaborative problem solving and transparency (Hurlbert and Gupta 2015; Carpentier 2016; Kotus and Sowada 2017). Indeed, socio-political change occurring since the ladder's inception has led to significant democratic transformation as well as substantial social polarisation leading Kotus and Sowada (2017, p. 79) to propose extending Arnstein's (1969) ladder to include categories of citizen "awakening" (the beginning of engagement in discussion) and "rebel action" (through social protest and confrontation) to reflect stages of radical action in protest against coercion and manipulation in order to combat negative effects of globalisation and declining civil rights. In recognising some improvement in user participation in health, social care and research agendas Beresford (2019) highlights continuing inconsistencies through competing ideological and neoliberal political agendas between service users and the state including lack of funding opportunities for user-led organisations to remain sustainable and engage more equitably in user-led research. Despite the wide-ranging limitations of Arnstein's (1969) ladder, it remains helpful in emphasising gradations of participation thus giving a language to enable some assessment of power divisions and participant involvement in the research process (Arnstein 1969; 2011; Carpentier 2016).

Whist the intention in my study is to align with a critical-emancipatory paradigm, a participatory research approach is more suited to the process and desired outcomes of this study and serves the research intention of working in “partnership” as in rung six of Arnstein’s (1969; 2011, p. 5) ladder through shared decision making with people with lived experience of mental illness in a meaningful way. I also wish to move beyond Biggs’s (1989 cited in Cornwall and Jewkes 1995, p. 1669) “collaborative” mode to reflect a more “collegiate” position. Further, I am persuaded by Cornwall and Jewkes (1995) view that a key element in participatory research is the attitude of the researcher rather than the method alongside continuing self-awareness and reflexivity. Given that this is a self-funded doctoral project following a set of institutional guidelines in a process to achieve an outcome that is ultimately personal and academic, it is difficult to envisage how this could be truly emancipatory research in terms of full ownership and citizen power and control of all aspects of the research process. This will be revisited when considering how the participatory research project sits within the PhD thesis. Having explored the underpinning research paradigm and associated influences and highlighted the complexity of participation, this section now turns to explore PAR.

3.4. Participatory Action Research (PAR)

This section introduces and justifies PAR as the orientation to inquiry for this study. It considers two strands of evolution firstly, from the broader perspective of action research, a pragmatic utilitarian approach originating in Europe and the USA in the 1940s in response to a need for change and secondly, from an emancipatory and ideological perspective influenced by Paulo Freire’s pedagogy of the oppressed in the 1970s addressing power relationships and using collective consciousness to produce new knowledge for social change (Loewenson et al. 2014) leading to the development of Kemmis’s (2008) politically orientated critical PAR.

PAR can be described as a research approach emphasising collaborative participation between members of a community and skilled researchers to produce knowledge that is relevant to the community, extending theoretical understanding of a particular situation with a plan for social change (Pant 2014). It is a process of research, education and action where participants in the course of transforming reality, transform themselves (Schugurensky 2014). PAR privileges practical knowledge and rebalances power dynamics regarding what constitutes knowledge and the flow of information by utilising a bottom-up approach that mobilises communities to influence policy and solve local problems (Pant 2014). It transforms the role of those traditionally viewed as the subjects of research to be active in the research process as agents of change (Baum et al. 2006; Loewenson et al. 2011; Loewenson et al. 2014) and challenges research approaches whose sole focus is on advancing knowledge (Pant 2014). Baum et al. (2006) suggest PAR differs from other qualitative methodologies in that it aims to improve health and reduce health inequities by involving people in reflecting and taking action to improve their own health or situation. Indeed, PAR's distinct focus on collaboration, political engagement and social justice has action as an outcome (Brydon-Miller et al. 2013). It is a collaborative methodology where participants take ownership of the research process to increase their understanding of their shared situation and problem-solve to address key issues confronting them (Koch and Kralick 2006). PAR methodology reflects the values inherent in co-production in public service delivery and seeks to engage with communities in bringing about real change in people's lives. According to Brydon-Miller et al. (2013) PAR research philosophy is built upon the notion that knowledge generation is a collaborative process in which each participant's diverse experiences and skills are critical to the outcome of the work. They state:

> …..PAR combines theory and practice in cycles of action and reflection that are aimed toward solving concrete community problems while deepening understanding of the broader social, economic, and political forces that shape these issues. (Brydon-Miller et al. 2013, p. 347).

This approach believes that participants are experts in their own situations and are empowered to define the meaning, direction and implications of the project. This facilitates participant ownership and ensures that the research itself is developed in direct response to current need. This methodology focuses on action and ensures that research outcomes are concerned with both knowledge generation and practical outcomes or solutions. Solutions developed by individuals who are 'experts' in their own experience arguably have more impact and relevance than those developed by external professionals or researchers (Koch and Kralick 2006). As Reason (1994, p.10) states:

> …..we can only truly do research **with** persons if we engage with them as persons, as co-subjects and thus as co-researchers: hence co-operative inquiry, participatory research, research partnerships. [emphasis in original]

PAR is therefore research for action and has a social and political obligation. Connection between social theory and social action is an essential element of PAR where theoretical frameworks are integrally connected to politics, examining power dynamics, exploring the nature of participation, and actively contributing to the struggle for social justice (Brydon-Miller et al. 2013). Although interpretive strategies are aligned to constructionism, these seek to understand rather than to challenge and change which is the essence of PAR. According to Pant (2014, p. 584) the key principles of PAR can be summarised as a commitment to research that is collaborative and equitable in terms of contribution, responsibility and expertise rather than research where power is unexamined and taken for granted; a commitment to empowered participation through shared decision-making and negotiation in all stages of the research process; and a commitment through the research process to critically and systematically clarify and create awareness of issues, design strategies for action and then re-evaluate for impact and social change.

PAR sits within a broader framework of action research approaches that share a belief in the value of social practice where knowledge is generated through reflection on action designed to create change "in the service of human flourishing" (Reason and Bradbury 2008, p. 1; Brydon-Miller et al. 2013; Kemmis et al. 2014). According to Reason and Bradbury (2008, p.1) PAR is "not so much a methodology as an orientation to inquiry that seeks to create participative communities of inquiry in which qualities of engagement, curiosity and question posing are brought to bear on significant practical issues". As such it can be considered "a philosophical orientation towards coming to understanding with others" (Scott-Villiers 2014, p.374). Indeed, action research generally rejects traditional research methods where the external expert represents the perspective of the participants in the setting; and critically reconsiders the relationship between the researcher and the researched valuing research conducted by people "from within the practice traditions" who might otherwise be research recipients (Reason and Bradbury 2008; Kemmis et al. 2014, p. 5). Action research is believed to have originated in Europe from the work of Jacob Moreno, the German born founder of psychodrama, who in rejecting a positivist scientific outlook, was interested in participants being actively involved in conducting social research by and for themselves (Kemmis et al. 2014). Moreno's approach influenced the work of Kurt Lewin in the 1940's, a German social psychologist interested in group and organisational dynamics, who in adopting a pragmatic problem-solving approach to social research, recognised that social action involved a spiral of cycles of planning, taking action then observing and evaluating that action in a continuous movement requiring further planning, action, evaluation and reflection (Kemmis et al. 2014; Pant 2014). Thus, action research is viewed as a cyclical, iterative process "of action and reflection on and in action" (Zuber-Skerritt 2018, p. 516) that integrates "knowing and doing" and avoids any gap between knowledge and practice and therefore any difficulty in applying research findings to practice (Reason and Bradbury 2008, p.1). However, Lewin's action-reflection spiral has been criticised as overly simplistic and his research approach appears to have perpetuated a position of the distant academic rather than one of facilitating participation and challenging power dynamics (Kemmis et al. 2014; Pant 2014). Indeed, Kemmis et al. (2014) caution that the researcher requires to remain alert to any self-deception that self-interest and participant interests are one and the same whilst support from outsider consultants should be examined for conflict of interests from that of participants (Kemmis et al. 2014). These are important points, which will be revisited later in this thesis.

The notion of changing social practice by addressing key problems with others through a dynamic series of action spirals is what links a diverse range of action research approaches in for example, conservation and ecology, international aid and development, education and health who despite holding different action research titles, share a commitment to recognising people's capacity to become active participants in research that is geared towards making improvements in their own settings and practices (Reason and Bradbury 2008: Kemmis et al. 2014). Indeed, the principles underpinning action research of "self-reflection and critique through dialogue, collaboration, mutual learning and action" became the basis of PAR (Pant 2014, p. 583). However, despite similarities underpinning action research approaches there are significant differences in focus from pragmatic, functional and economic to emancipatory; and from improving individual educational or nursing practices, to improving business outputs and efficiency, to working collaboratively with disempowered and marginalised communities (Reason and Bradbury 2008;

Kemmis et al. 2014). The latter is indicative of PAR from an emancipatory paradigm and reflects the significant influence on PAR from the Brazilian educationalist Paulo Freire (1921-1997).

Paulo Freire's (1970) Pedagogy of the Oppressed is a widely cited source of PAR inspiration through his writings on knowledge creation, participation and action and his belief that people as the subjects of their own history can address injustice through collaborative research and action (Schugurensky 2014). Freire (1970) documents his experience of adult literacy in Brazil through critical pedagogy and the pursuit of emancipatory action involving dialogue, reflection and action to overcome subordination, colonisation and oppression, emphasising the power of education as a political tool (Pant 2014). Freire was an educator, theorist, writer, philosopher and political activist who through personal experience of living in poverty in rural Brazil developed a sense of respect for and solidarity with others; and through exposure to liberation theology became interested in issues of inequality, emancipation and social justice (Schugurensky 2014). Freire developed participatory systems of governance and educational programmes for workers and their families based on dialogue and self-management with groups supporting study and action and encouraging participation, debate and finding collective solutions (Schugurensky 2014). Indeed, Freire (1970) was influential in bringing literacy to marginalised Brazilian peasants in a form of political pedagogy that not only taught literacy skills but also enabled people to find their voice and through "critical reflection and collective transformative action" to participate politically in the development of a more democratic society (Schugurensky 2014, p. 369). According to Schugurensky (2014, p. 369) Freire's model for social transformation is a triangle of three key concepts where PAR plays a crucial role, namely: "humanization" as the direction of the transformative project; "education" as the main activity to move in that direction; and "politics" as the recognition of the ideological and power struggles that support or challenge these changes. Freire's (1970) emancipatory approach was concerned with recognising power dynamics by raising critical consciousness and then addressing this through collective organisation to develop new knowledge that could be used for positive social change (Loewenson et al. 2014). Through "problem posing" (Freire 1970, p.80) and asking thought provoking questions that encourage participants to ask their own questions, participants "learn to question answers rather than merely to answer questions" Schor (1993, p.26).

This process of “conscientization” (Freire1970, p.104) where people are engaged in critical thinking about their situation was an important antidote to previously didactic and passive forms of banking education where information is deposited into students who are passive objects in the learning process (Macedo 2014) and enabled people to begin to recognise the potential for transformation and to imagine an alternative reality. Awareness therefore is not an end point but precipitates critical reflection and action, which are entwined and contribute to social transformation (Schugurensky 2014). Freire’s model of PAR promotes a partnership between the researcher and the participants or communities to work collaboratively in a way that leads to action for change and where power is deliberately shared between the researcher and the researched (Baum et al. 2006). Therefore, the academic researcher as partner in the process must be prepared to critically examine issues of identity; power dynamics and privilege including how his/her multiple identities inform and shape engagement with participants (Brydon-Miller et al. 2013).

Freire’s (1970) writing generated insights that had international resonance triggering Orlanda Fals Borda (1925-2008) a Columbian sociologist who was engaging peasant communities in their own research, to coin the term PAR and organise the first PAR conference in Cartagena, Columbia in 1977 (Schugurensky 2014). Fals Borda was particularly influenced by Freire’s humanistic and profoundly respectful approach in solidarity with those oppressed along with his commitment to integrating knowledge of people’s reality with concrete interventions reached through cycles of reflection and action and political action (Schugurensky 2014). Freire (1970) emphasised that all people have the ability to be knowers and creators of their world where they have awareness of their oppression and a desire to terminate it, thus researchers should respect people’s capacity and right to be involved in the production of knowledge (Schugurensky 2014). PAR from a Freirian perspective is:

> …..collaborative and liberating…an approach that encourages the active participation of researchers and participants in the co-construction of knowledge, the promotion of critical awareness and an orientation towards transformative action…it is about naming the world and changing the world. (Schugurensky 2014, p. 370)

This study was further influenced by critical PAR (Kemmis 2006, p.96; Kemmis and McTaggart 2014; Kemmis et al. 2014) defined as a practice-changing practice where participants create critical communities and public spheres to "develop a critical and self-critical understanding of their situation" and how these are "shaped and re-shaped discursively, culturally, socially and historically". In line with a critical-emancipatory paradigm, critical PAR challenges conflict and oppression and seeks to bring about change (Kemmis 2008). In proposing a definition of critical PAR, Kemmis (2008) presents a set of arguments drawing on connections to critical theory, specifically Jurgen Habermas's (1996 cited in Kemmis et al. 2014, p.34) notion of communicative spaces and public spheres where people can explore issues as they occur, change their understanding and transform what they do in practice (Kemmis and McTaggart 2014). Kemmis (2008, p.123) believes that critical PAR must work "in the conversations and communications of participants about crises and difficulties confronted by social systems and the lifeworlds in which people find meaning, solidarity and significance". The focus is on identifying and reflecting on "sayings", "doings" and "relatings" in other words considering what people think and say in their current practice; what they do in their practice; and how they relate to other people and things in their practice (Kemmis and McTaggart 2014, p.208).

Indeed, according to Kemmis and McTaggart (2014) communicative action is when participants are free to participate and to reach unenforced consensus through agreement and understanding about what to do in a particular situation rather than reaching a goal that may be strategic or serve one or two individuals over others. Communicative action is guided by what is true, authentic and morally right and proper in the participants' circumstances (Kemmis and McTaggart 2014). Public spheres are therefore networks of voluntary and autonomous participant communication involving interested parties and those normally excluded from discussion, in an attempt to dismantle hierarchical barriers and "insider" and "outsider" positions to open up communicative spaces (Kemmis and McTaggart 2014, p.210). This leads to the potential for communicative action and challenge to "practice architectures" that hold practice in place and reproduce existing ways of doing things (Kemmis and McTaggart 2014, p.210). Kemmis and McTaggart (2014, p.211) argue that the purpose of critical PAR is not about creating academic knowledge but more about contributing to history and "transforming the work, lives and situations of people in the interest of rationality, sustainability and justice".
The next section reviews key philosophical ideas underpinning PAR.

3.5. Epistemology

Epistemology guides relevance of methodological choice and identifies what knowledge is privileged in the research process (Hathcoat and Nicholas 2014). It is concerned with ways of knowing or how we come to know what we know and provides a rationale for what kinds of knowledge are possible and who can be a knower (Crotty 2003; Berryman 2019). It involves studying the "nature, limitations and justification of human knowledge" asking questions about "the relationship between the knower and the known and how knowledge claims are justified" (Hathcoat and Nicholas 2014, p.302). Three epistemological positions were initially considered namely objectivism, subjectivism and constructionism (Crotty 2003). As discussed earlier, objectivism with its positivist stance of one objective truth to be discovered by the observer, where the world can be measured with certainty and precision and has meaning prior to and independently of any consciousness of it (Crotty 2003) was rejected as incompatible with critical PAR due to its view of reality as independent from individual experience and interpretation. Further, objectivism dictates a strong distinction between the knower and the known, which is at odds with researcher-participant engagement and denies the value of co-created knowledge (Hathcoat and Nicholas 2014).

In contrast, subjectivism believes that there is no objective or external truth and that knowledge is subjective and wholly created by humans as a result of subjective experience and awareness which can be at an individual level or that of a community (Hathcoat and Nicholas 2014). Knowledge is therefore a matter of perspective and the knower cannot be separated from the known. Although subjectivism rejects a dualistic world where distance is deemed necessary to eliminate bias between the researcher and the object under investigation (Hathcoat and Nicholas 2014), it too was rejected in favour of constructionism. Constructionism contends that truth and meaning are constructed and emerge through interaction and engagement with the object under investigation (Hathcoat and Nicholas 2014). More specifically, social constructionism is concerned with meaning making that is influenced by social processes and is not solely a product of the individual (Wimpenny 2010). Indeed, PAR's theoretical philosophy fits well with a constructionist epistemology, where knowledge, truth & meaning are socially constructed & where the criteria for judging reality or validity comes from community consensus of what is regarded as real, useful or has meaning in terms of shaping action within the research and the community (Lincoln et al. 2013). Constructionism was therefore adopted as an epistemology for this study due to its compatibility with PAR methodology.

Furthermore, PAR has specific views about where knowledge comes from. For example, PAR emphasises multiple ways of knowing and challenges forms of knowledge generation that position non-dominant groups as outsiders. According to Brydon-Miller et al. (2013, p.352):

> …..PAR stems from the understanding that knowledge(s) are plural and that those who have been systematically excluded from knowledge generation need to be active participants in the research process, especially when it is about them.

Additional epistemological considerations become necessary when recognising PAR as future orientated facilitating change through action with inquiry grounded in democratic practices based on situational knowledge generating unique outcomes in specific socio-cultural settings (Hathcoat and Nicholas 2014). PAR prizes practical knowledge and the creation of new knowledge that has utility for individuals and communities (Reason and Bradbury 2008; Brydon-Miller et al. 2013). Thus, practical knowing is privileged in this study as distinct from knowledge that can be generalised across settings. This is derived from the notion of praxis (Freire 1970) a type of knowing where people acting on ideas, transform and improve their situation in a problem focused way (Hathcoat and Nicholas 2014). Indeed, Freire (1970) believed that everyone has the ability to be a knower and creator of their world thus prompting researchers to recognise that people have the right to participate in the production of knowledge (Schugurensky 2014). This PAR project is therefore underpinned by a value driven commitment to knowledge that is co-created that values practical knowing and praxis leading to transformation and change. Further, citing Reason & Bradbury's (2006) "extended epistemology", Kindon et al. (2007, p. 13) recognise the value of participant reflexivity in the research process to draw on "diverse forms of knowing to inform action" recognising that "to practise the radical…it is not enough to understand the world, but that one has to change it for the better" (Kindon et al. 2007, p. 13). They suggest that PAR in recognising reality as socially constructed, naturally opens space for generating knowledge through creative and innovative methods where many explanations are possible for one phenomenon (Kindon et al. 2007).

3.6. Ontology

Ontology, the study of being, is concerned with the nature of existence and reality, and answers the question “what is real?” (Crotty 2003; Loewenson et al 2014, p. 21). It is closely related to epistemology in that talking about the construction of meaning is linked to the construction of meaningful reality (Crotty 2003). Different ontological positions are important as they inform the relationship between the subject or knower and the object or known and therefore inform the research approach taken. Although various ontological positions may be used to approach PAR, they must consider “the participatory role of the action researcher” and “the quest of the action researcher to change the underlying structure of reality in an effort to promote justice, equality or democracy” (Nicholas and Hathcoat 2014, p. 570). According to Loewenson et al. (2014) paradigms of inquiry encompassing ontological positions can be viewed on a polarised scale from positivism, through post-positivism, critical theory and constructivism, to participatory. Positivism adopts an ontological position of naïve realism believing that the world can be viewed objectively; that reality is independent of the human mind or the experience of human involvement; and the aim of research is to objectively describe things within the world to find a single, observable reality or truth (Loewenson et al. 2014; Nicholas and Hathcoat 2014). Post-positivism assumes an ontological position of critical realism and differs from naïve realism in acknowledging that reality can only be viewed imperfectly with some subjective evidence being required to gather a more holistic picture thus acknowledging reality as involving a range of physical and constructed factors and forces (Loewenson et al. 2014, p. 20). Critical theory adopts historical realism as its ontological position viewing reality as constructed not only through social but also historical processes whereby individual consciousness is shaped by historical and economic forces as well as cultural, political, ethnic and gender values which are clarified over time (Loewenson et al. 2014; Nicholas and Hathcoat 2014). Constructivism, espousing a relativist ontological position posits that reality is individually and socially constructed and that its very existence is dependent on a range of mind and social factors thus cognition, emotion and social groups or structures are believed to provide meaning and denote reality and are therefore relative to specific contexts (Nicholas and Hathcoat 2014). Finally, a participatory paradigm adopts an ontology of participative reality where reality is subjective and co-created and can be accessed through subjective experience and action (Loewenson et al. 2014).

Indeed, PAR reflects an ontology whereby participants are perceived as active agents with the capacity for reflexivity and self and social change (Kindon et al. 2007). According to Pain et al. (2007, p.29) it is by being open to a range of realities rather than believing in one reality waiting to be detected that enables PAR to make a difference through:

> …..collaborative knowledge production and knowledges performed intersubjectively in and through research processes. The politics of most PAR practices are never fixed but are both a politics of becoming and betweeness where knowledge, analysis and action emerge between co-researchers and participants.

In returning to the subject-object duality or the relationship between knower and the known, Nicholas and Hathcoat (2014, p.571) argue that the participatory action researcher in exploring social contexts problematizes this relationship by being:

> *…..*a participant in reality rather than a detached observer…[which] places the researcher in the same ontological position as the reality being examined. [Thus]…by virtue of direct participation, the researcher becomes both the knower and the known.

Nicholas and Hathcoat (2014) propose that the boundary between epistemology and ontology is collapsed due to the participatory nature of PAR, which is less concerned with maintaining objectivity and more concerned with "states of reality that are dynamic and changeable by human agency" (Nicholas and Hathcoat 2014, p. 571). Views of reality are accepted as value laden and PAR "can attempt to maintain the status quo, deconstruct or demolish structures of power and authority, solve problems, or democratize social structures through participative interaction" (Nicholas and Hathcoat 2014, p. 571). Indeed, in discounting PAR as a serious methodological approach, critics highlight the lack of possibility of objective findings due to the absence of separation between the knower and the known through participatory engagement (Nicholas and Hathcoat 2014).

This study therefore rejects a positivist naïve realism ontology recognising that it is unsuited as a position of inquiry for something that is not directly perceptible (Given 2008). The subjective experience of the researcher, associated value judgements on the research and the research knowledge that is generated in light of this PAR study can never be viewed as objective truth (Loewenson et al. 2014). Additionally, a naïve realism ontology that aims to examine reality unhampered by human contact is in direct contrast to the ontological position required to support the PAR aim of changing reality (Nicholas and Hathcoat 2014). This study also rejects a post-positivist critical realism ontology which although recognising that reality cannot be known in a direct way and consists of both physical and socially constructed entities, considers that some beliefs or truths are more plausible than others and that knowledge claims should be empirically tested under conditions whereby they could also be refuted (Given 2008). Whilst a critical realist ontology is recognised as compatible with action research, the blurring between the position of the knower and the known in this study cannot provide a route to an objective epistemology (Nicholas and Hathcoat 2014).

Given that this project aspires to collaboratively identify strengths and weaknesses of socio-political and welfare systems that support people to volunteer with a view to exploring the potential for change, it is interested in how socio-political realities have historically shaped and continue to influence situations of inequality. A historical realism ontology in line with critical theory is therefore attractive in that it enables reality to be critically examined from a historical, cultural and political perspective (Scotland 2012). Indeed, historical realism considers reality as constructed by the interaction between language and an independent world where language can be used as a dynamic of power to both empower or weaken (Scotland 2012). Through a critical theory paradigm, historical realism seeks to judge reality by considering how things should be; to alter reality through human action; and to challenge conventional social structures to expose issues of hegemony, social justice and inequality (Scotland 2012). It is therefore well suited to a PAR methodology in seeking to reveal reality through Freire’s (1970) process of critical consciousness raising to realise social emancipation and change through praxis, a simultaneous process of repeated action informed by reflection (Scotland 2012, p. 14). This study is therefore ontologically aligned with historical realism. Further, this study aligns with the constructivist ontological position of relativism taking the view that different people inhabit different worlds constituting for them diverse ways of knowing. Social constructionism is relativist recognising that how things are, is due to the sense we make of them, which is interpreted through a culturally and historically situated lens. Therefore, description or narration cannot be viewed as a mirror representation of reality but as meaningfully constructed within a particular community (Crotty 2003). Finally, given the focus of reflection and action implicit in PAR and occurring simultaneously as praxis, this study also aligns with a participatory ontological position of participative reality believing that through a shared experience these diverse ways of knowing can be co-created through participatory reflection and action which in developing critical consciousness leads to a view of reality as open to transformation (Loewenson 2014). A participative reality ontology leads to a methodology that supports collaborative inquiry and action; that is practical and grounded in shared experience; and aims “not only to explain or predict but also to understand and transform reality” (Loewenson 2014, p. 22). These three ontological positions provide a structure for this study to contest dominant systems that outline the study of reality (Nicholas and Hathcoat 2014). According to Nicholas and Hathcoat (2014, p. 572) although there are a range of ontological ways to approach action research, what unites action researchers is “their efforts to change the content of reality” in a mutual search for mutual good.

3.7. Axiology and Personal Worldview

Axiology describes our understanding of and assumptions about what is valuable and includes the personal beliefs, values and ethics that shape our actions (Zuber-Skeritt 2018). This section outlines my beliefs, values and ethics to demonstrate how these have influenced my actions and decisions about and within the research process. Creswell (2009, p.6) prefers the term “worldview” to describe how the researcher’s beliefs about the world and the nature of research shape and guide the research approach. I find Creswell’s (2009, p.9) “advocacy and participatory worldview” helpful in recognising issues of social justice, going beyond an interpretivist approach to constructionism based on understanding, to promoting social change and social inclusion for marginalised individuals and communities through participation and action. This worldview is political in nature and emancipatory challenging inequality associated with a dominant neoliberal paradigm that supports individual accumulation of wealth and destroys social justice (Zuber-Skerritt 2018). In addressing social issues, it draws on a collaborative approach with participants, embedded in a view of people as interdependent, empowering them through the research process in the pursuit of change (Zuber-Skerritt 2018). Kindon et al. (2007, p.13) agree and cite Reason and Bradbury (2006) who argue that PAR researchers require a worldview that is reflexive, viewing inquiry as a democratic process of coming to know. An advocacy and participatory worldview provide the philosophical underpinning for my position as researcher in this PAR project.

In addition, as a researcher I bring my own set of values, experiences and ways of knowing which are embedded in the personal and professional. In terms of my worldview, the notion of making a difference resonates with my professional background as an occupational therapist working in a range of mental health settings. Indeed, PAR has particular congruence with occupational therapy, each valuing the importance of partnership, collaboration and action with the potential to challenge occupational injustices (Bryant et al. 2011; Kramer-Roy 2011; 2015; Bryant et al. 2017). As an occupational therapist, I am also interested in the premise that engaging in meaningful occupation, in this instance volunteering, can benefit health and wellbeing for individuals, groups and communities. Indeed, as a newly qualified occupational therapist I was a founding member of a multi-agency group of community partners including Edinburgh Volunteer Exchange (now Volunteer Edinburgh), the Scottish Association for Mental Health (SAMH) and Penumbra in the mid 1980s promoting volunteering as therapy as a way to improve mental health for patients in the Royal Edinburgh Hospital, through participation in volunteering within the hospital and the community. Further, as a mental health practitioner working for many years in NHS hospital and community settings, I bring a professional centric understanding of mental illness and recovery that is ameliorated by a commitment to supporting social justice through the social model of disability. I acknowledge the complex and dynamic interplay between the person, their experience of mental illness and their environment and I am drawn to Cameron’s (2014; 2015) affirmation model in its support of ways of being that embrace difference as an “ordinary” element of the human experience recognising the need to reflect on my own assumptions and those underlying other people’s to notice and challenge everyday disabling social relations (Cameron 2015, p. 118). My professional understanding of mental illness is also influenced by psychodynamic, person-centred and humanistic ways of working along with recognition of the subjective and often uncertain nature of human experience. For example, a psychodynamic way of working “incorporates an understanding of the unconscious in what is done and said (or not said) within the therapeutic encounter” between the person, the therapist and the occupation including recognising and thinking about emotions that arise in this encounter and acknowledging that occupations are simultaneously real and symbolic (Piergrossi and Gibertoni 2013, p.105). In terms of person-centredness I subscribe to the Rogerian belief that people with support, dignity, compassion and respect have the ability to determine their own needs and reach their potential (Anderson 2001). This aligns with a humanistic understanding rooted in the work of Rogers (1977) and Maslow (1998) emphasising human flourishing through purpose and meaning, and self-determinism, through creativity and thoughtful action, to realise aspirations (Vanderweele 2017). In this regard, I can be described as an outsider researcher as I neither have a recognised mental illness nor am I currently volunteering however, I subscribe to Oliver's (2002) view that what is more important in developing less alienating research is in the degree of control rather than a necessity for the researcher to have lived experience. As an educator I recognise the transformative power of education. As a citizen I am committed to a human rights-based approach and the principle of meaningful participation in decision making contained in the "nothing about us without us" (Charlton 1998, p.3) user movement. I am attracted to the South African concept of Ubuntu roughly translated as "I am because we are" celebrating interdependence and the power of community and solidarity in effecting positive change. This philosophy of community espoused by Nelson Mandela and Desmond Tutu contrasts markedly with neoliberal values of individualism and competition as well as values of independence as espoused traditionally by the occupational therapy profession (Hammell 2018). Indeed, Heron and Reason (2008, p. 369) in exploring a participatory worldview grounded in loving kindness rather than manipulation and control state that "participation is our nature: we do not stand separate from the cosmos, we evolved with it, participate in it and are part of its creative force".

3.8. PAR Limitations and Quality Criteria

PAR has a number of limitations in relation to design and process including the degree of participation and sharing of research control (Pant 2014). Academic researchers may be unfamiliar with the methods that can be used and may not be skilled in community negotiation (Loewenson et al. 2011; Pant 2014). Additionally, PAR has been criticised for manipulating community participation to realise predetermined researcher agendas and for appearing to offer research control to participants whilst retaining overall control (Pant 2014). Indeed, there may be conflicting views about whether the community can be organised to define the research question, or whether this should be developed by the academic researcher from the outset (Pant 2014). Clearly the PAR process requires researcher sensitivity to understand the needs of the community and it is often time-consuming due to the emphasis on building trusting relationships to enable continual reflection, discussion and participation (Cornwall and Jewkes 1995; Loewenson et al. 2011; Pant 2014). Communities may be sceptical in investing time and energy when there is little guarantee of direct benefit or may lack interest in taking part (Cornwall and Jewkes 1995; Pant 2014). Notions of participation may be more significant to the researcher than to the marginalised community and rather than reflecting democracy may be more in line with western imperialism (Cornwall and Jewkes 1995). More significantly, participation, dialogue and emancipation are not guaranteed outcomes of the process where divergence amongst participants may make consensus on decision-making and action difficult and where many of the problems affecting communities and the potential solutions appear to be located in higher echelons of authority (Loewenson et al. 2011; Pant 2014).

In terms of measuring quality, neither the positivist view of validity nor the interpretivist notion of trustworthiness is adequate in measuring the action-orientated and practical knowing outcomes of PAR (Reason and Bradbury 2008; Hathcoat and Nicholas 2014). According to Hathcoat and Nicholas (2014, p.305) any evaluation of the quality of PAR "tends to be utility focused in that useful knowledge leads to valued transformations". Reason and Bradbury (2008, p.43) support Moser's (1975) benchmarks including "transparency" where participants can track the whole PAR process; "compatibility" between the research aims and the methods used to achieve them; and authenticity in participant researcher knowledge of the research situation. Loewenson et al. (2014, p. 43) suggest that a strong test of validity of method in PAR is the extent to which participants are able to "input their experience; check, correct and reach a shared consensus on collective results of the group; and discuss and reflect on patterns and differences to reach a consensus on the collective findings".

In challenging concerns about validity in PAR, Anderson and Herr (1999, p. 16) propose five validity criteria, namely:

1. Democratic validity: ensuring a wide spectrum of perspectives on the issues are consulted and that all participant voices are represented accurately with outcomes relevant to the context.
2. Outcome validity: ensuring action orientated outcomes from the research lead to some form of resolution of the problem.

3. Process validity: ensuring that the research methodology is appropriate and qualitative strategies are used to enhance trustworthiness for example: “reflexivity, triangulation, prolonged engagement, participant debriefing and member checking”.
4. Catalytic validity: ensuring there is an active commitment on the part of the researcher and the participants to “facilitate change within and beyond the research setting”.
5. Dialogical validity: ensuring there is critical dialogue with peers about research findings and actions to challenge the findings for inconsistencies, biases and failure to include key stakeholders.

Interestingly, there are some parallels here with Barnes’s (2002) summary of the core principles of emancipatory disability research and Zarb’s (2002 in Henn et al. 2009, p. 43) questions to critically evaluate research as discussed earlier. The validity of this study is revisited in Chapter 10, reflecting on the research process and whether the study met the research aims and objectives and participation expectations.

3.9. Production and diffusion of new knowledge: situating the PhD thesis within PAR action research cycles

According to Fals Borda (2011, p. 85) traditional practices of publishing and disseminating research evidence acquired through academic pursuits that detach enquiry from publication, are incongruent with PAR and the “search for people’s power” where published material is considered part of the continuous PAR cycle of evaluation and action. He states:

> …..all the knowledge obtained in the communities…does not belong to the researchers or to the activists themselves, but continues to be the property of the investigated community, which has the first right to know the results, discuss and direct them for its own purpose, and authorize their publication. (Fals Borda 2011, p. 85)

Indeed, devolving research knowledge, not necessarily confined to written word, to the respective community reinforces the importance of praxis and facilitates collective transformation and social change (Fals Borda 2011; Hathcoat and Nicholas 2014). However as previously stated, this raises a tension for the doctoral student engaging with PAR, where dissemination of knowledge sits within a wider

University requirement for the production of a thesis to be submitted for examination independent from but inclusive of the research findings and PAR process where PAR as an ideology, with its set of ideas and beliefs is contrasted with PAR as a methodology, based on method and procedure (Zuber-Skerritt 2018). In distinguishing between collaborative PAR aimed at social change and independent research in preparing and writing the doctoral thesis with the intention of making an original knowledge contribution, Perry and Zuber-Skerritt (1992, p. 204) offer a model illustrating the difference and relationship between thesis research, core research and thesis writing (Figure 3):

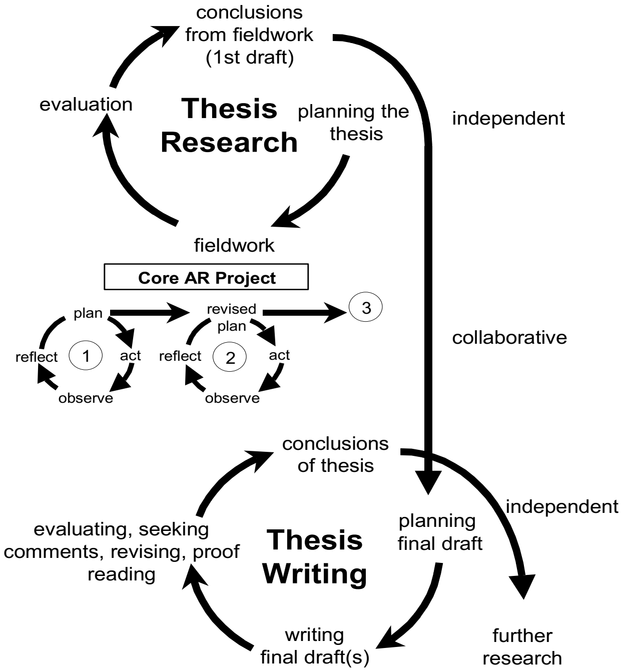

Figure 3: Relationship between thesis research, action research and thesis writing (Perry and Zuber-Skerritt 1992, p. 204).

Figure 3 depicts an interesting and clear distinction with the contribution of the core collaborative action research project, sitting within and informing the doctoral thesis as a form of literature; whilst the doctoral thesis is produced independently by the doctoral candidate to ensure an original contribution to knowledge (Perry and Zuber-Skerritt 1992; Zuber-Skerritt and Perry 2002; Zuber-Skerritt and Fletcher 2007; Zuber-Skerritt 2018). This model helpfully highlights the distinction between the research intention for the core participatory project and my research aims and objectives for the overall thesis, as explored in Chapter 4.

Summary

This chapter has provided an overview of the theoretical arguments influencing the choice of methodology in this project, proposing PAR as situated within a critical emancipatory paradigm and exploring the nature of participation. The next chapter outlines the research process and methods selected in the research design including participant recruitment and ethical issues.

CHAPTER 4: RESEARCH PROCESS: DESIGN and METHODS

Having established PAR as the methodological approach to this study from a critical-emancipatory paradigm, this chapter describes the study design and methods that were used during the research process. I begin by presenting the research aim and objectives before exploring PAR methods and my rationale for selecting preliminary interviews and participatory action research groups. I then describe how I recruited participants and introduce the research setting and collaborative partner. I follow this with a description of the stages in the research process and examine how the participatory process shaped the original research intention. This chapter concludes with consideration of ethical issues and presents a timeline of the research process.

4.1. Research Aim and Objectives

This project set out to explore the experience of volunteering whilst working in collaboration with a group of adults with lived experience of mental illness, who were engaged in unpaid voluntary work in the community through personal choice as part of their journey of recovery in order to answer the following preliminary questions.

1. What are the strengths and weaknesses of socio-political and welfare systems that support volunteering from the perspective of the volunteers?

2. What changes might people with lived experience of mental illness be empowered to make through the participatory action research process?

These questions led to the formulation of the primary aim for this doctoral research, namely:

To hear about the benefits and challenges of volunteering, as well as to explore the positives and negatives of socio-political and welfare systems that support people with lived experience of mental illness to volunteer, with a view to producing something through action that would be of benefit to the group and/or the wider community.

In considering research objectives, I recognised that these could change as a result of the participatory action research process and therefore initial objectives were:

1. To explore the experience of engaging in voluntary work for people with lived experience of mental illness.

2. To explore the benefits and challenges from the volunteer perspective.

3. To explore the benefits and challenges from the volunteer involving organisation (VIO) perspective.

4. To engage and empower participants through the participatory action research process to collaboratively identify strengths and weaknesses of socio-political and welfare systems that support volunteering and explore the potential for change based on the experience of volunteering.

5. To generate knowledge through a process of reflection and action by formulating an action plan to consider how best to address, present and disseminate the data gathered for example, through the production of something of benefit to the group and/or wider community. The product could be a written guide or arts-based film, exhibition etc. for volunteer organisations; prospective volunteers with lived experience of mental illness; local government; health and social care professionals; community organisations; friends, families and carers. Findings would also be published in a journal and/or presented at a conference.

6. To reflect on how change has been brought about at an individual, group and wider community level through generating the product and by participating in the research project. This could result in further action where action plans are generated in a continuing cycle, which could be sustained independently by the group if they so choose.

Further objectives were added in light of the questions raised by the literature review, namely:

7. To explore the experience of volunteering with lived experience of mental illness in the current socio-economic climate in the UK.

8. To reflect on the usefulness of occupational therapy literature in conceptualising volunteering for people with lived experience of mental illness.

9. To reflect on the extent that the study findings fill a gap and extend the literature on volunteering with lived experience of mental illness.

Perry and Zuber-Skerritt's (1992) model, presented in the previous chapter (Figure 3), illustrating the difference and relationship between thesis research, core research and thesis writing is helpful here in avoiding confusion between the research aims and objectives of the PAR project and any wider aims and objectives of the Doctoral thesis as represented in objectives 8 and 9 above.

In order to meet the PAR aims and objectives, the research question for this study became:

How can people with lived experience of mental illness who are currently volunteering be collectively engaged and empowered through the PAR process to collaboratively identify the benefits and challenges of volunteering, as well as to explore the positives and negatives of socio-political and welfare systems that support them to volunteer, with a view to producing something through action that would be of benefit to the group and/or the wider community?

The next section explores the process whereby the research question, aims and objectives could be realised.

4.2. PAR Methods

A key principle in any PAR project is that the research focus should emerge from and be led by the participatory community and that the research design, methods and process require a certain fluidity and flexibility of reflection, decision-making and action. However, this may be at odds with requirements for academic doctoral studies where the initial research proposal and ethical approval prior to recruiting participants requires a degree of certainty of research aim, methodology and methods from the outset. Whilst complying with academic requirements, it was my intention to keep the research aim and objectives loosely structured to enable participants to shape the project according to the issues that were most prevalent and relevant to them at that time.

In keeping with the notion of flexibility, I was influenced by Denzin and Lincoln's (2103a, pp.7-9) description of the researcher as a "bricoleur", a metaphorical "quilt maker" who adopts a form of improvisation in practice that is pragmatic, strategic and self-reflexive in deploying a range of personal and professional skills, methods and techniques in a creative and responsive way to bring together different perspectives from "the personal to the political, the local to the historical and cultural". Interestingly, the verb "bricoler" originates from the French description of unexpected movement in sport requiring the sportsperson to draw on their skill, experience and intuition in making an unplanned change to manage a situation of complexity and uncertainty (Hase 2014). Thus, bricolage enables the researcher to take a multi-methods approach to best address the research question and is compatible with PAR where there is a degree of trial and error and a need to be adept and responsive to changing circumstances (Hase 2014).

In valuing multiple forms of knowledge in the PAR process, Brydon-Miller et al. (2013) agree it is possible to take an eclectic approach to using existing methodologies as well as creatively developing innovation in methodology. Indeed, being able to flexibly move between and combine methods traditionally thought of as qualitative or quantitative is essential for a research strategy driven by a process of collaborative inquiry that is determined by the issues confronting the community that cannot be fixed in advance (Baum et al. 2006; Killett 2006; McIntyre 2008; Wimpenny 2010; Brydon-Miller et al. 2013; Chevalier and Buckles 2013; Loewenson et al. 2014). Furthermore, multiple, triangulated methods capture inter-connected individual, social, institutional and cultural layers (Torre 2009). Choice of methods includes interviews, surveys, focus groups and utilising existing statistical information where participants shape the questions to be pursued (Fine 2014). Furthermore, with the focus on generating dialogue and co-creating knowledge through interaction, a number of arts-based methods are valuable in forming and recording the PAR process, offering channels for expression and the opportunity for challenge and change (McIntyre 2008; Kramer-Roy 2015). Indeed, arts-based methods, sometimes mistakenly perceived as an inferior approach to research, can make a valuable contribution to the final outcome e.g. storytelling, visual arts, maps, photography, photo diaries, performance, indigenous and media arts and innovative use of technology (Loewenson et al. 2014). These methods in reflecting a rich understanding develop new ways for socio-political action and strategies for change which are instilled with hope and participant agency (Brydon-Miller et al. 2013).

From the outset this project proposed two methods of qualitative data collection with scope for additional methods depending on participant discussion and agreement as the collective progressed namely: a preliminary individual interview or conversation; and participatory action research groups. The rationale for selecting these methods will now be explored.

4.2.1. Rationale for preliminary individual interviews/ conversations

Torre (2009) reminds us that participation is not automatic but rather an on-going process of negotiating conditions and building relationships over time. To that end I decided that a preliminary individual conversation with each prospective participant would be a useful way of beginning that relationship whilst being able to explain more about the project, answer questions and potentially reach a position of agreed and informed consent. The process for gaining informed consent will be considered later under ethical considerations. This initial conversation, forming stage one of the research process, also gave me an opportunity to assess whether participants met the inclusion criteria and to discuss any concerns about mental health and relapse signature. Once consent was agreed, the conversation could then continue loosely following a series of semi-structured questions around volunteering history and self-management of mental health. I was however mindful of Oliver's (1992) caution that the interview process presents the interviewer as expert and the interviewee as inexperienced, thus mirroring not only a situation of oppression but also the dominant idea of disability as an individual problem. It was therefore important for me to view this meeting as a conversation that offered an opportunity to hear more about volunteering as someone who had not volunteered and to be curious about what people did in their volunteering, why they did it and what they felt they got out of it. Further, it gave the participants an opportunity to ask questions about me, and my research intention, and to discuss their hopes or reservations about the focus, the process and the potential outcome. I was also mindful that this preliminary conversation with each project participant would remain confidential and could not be shared with the other participants and therefore although I viewed it as an important aspect of data collection contributing to the findings for this thesis, it had to be kept separate from the participatory project and the participatory discussions of fellow participants.

I devised a preliminary interview and conversation guide based on semi-structured questions (see Appendix 3). All conversations were audio-recorded and transcribed verbatim. Participants were provided with a copy of the transcript along with a summary of key points from the interview for checking and comment. Data analysis of the interviews can be found in Chapter 5 and findings are reported in Chapters 6-9.

4.2.2. Rationale for participatory action research groups

In selecting participatory action research groups, I was influenced by their utility as a non-directive qualitative method of achieving PAR objectives by engaging participants in all stages of the research process to create social change (Loewenson et al. 2014; Logie 2014). PAR groups offer opportunities to co-investigate socio-political and health inequalities with people who share similar backgrounds, in this case volunteering with lived experience of mental illness, thereby facilitating appreciation of experience, thoughts and recommendations on complex issues (Logie 2014). Drawing on the notion of public spheres and communicative spaces as discussed earlier, PAR groups can become a form of public sphere encouraging communicative action where people are enabled to explore issues as they occur, challenging the “legitimacy” and “validity” of their understanding to ask questions about what is really going on in order to change their understanding and transform what they do in practice (Kemmis and McTaggart 2014; Kemmis et al. 2014, p.34). PAR groups provide a valuable forum for considering thought provoking questions in line with Freire’s (1970, p.80) notion of “problem posing” and engaging participants in critical thinking about their situation through “conscientization” (Freire1970, p.104) as discussed earlier.

Trust is key to success, with the researcher initially responsible for setting the tone in creating a warm, respectful, equitable and safe space, so that important issues in peoples’ lives and differing perspectives can be shared; and a range of patterns and trends can be captured through shared identification with personal stories, leading to a positive and supportive experience for participants (Logie 2014). However, whilst collective discussion is often driven by consensus, it is important to recognise difference in perspective and experience through contradictions and exceptions (Loewenson et al. 2014). Furthermore, conducting more than one group with the same participants potentially allows for saturation to be reached where no new themes emerge (Logie 2014).

I was also mindful that there are limitations and challenges to group work most notably, that people may choose not to share feelings and experiences or may omit information that does not portray them in a positive light (Willig 2013; Logie 2014). In terms of group dynamics, some voices may be more dominant than others; there may be a tendency to replicate normative discourses; and mixed ability in the group may lead to different levels of comfort in articulating personal stories, views and experiences (Logie 2014). Further, it may be difficult to assure complete confidentiality, as despite recognising the importance of agreeing ground rules from the outset to encompass confidentiality and willingness to respect and listen to each other (Willig 2013), the researcher has no control over what may be shared by participants outwith the group setting (Logie 2014).

PAR groups differ from other focus group approaches in terms of requiring a longer timeframe, usually around 6 months; utilising community organisations and venues; and involving the group as decision makers, peer researchers, data analysts and disseminators of the findings (Logie 2014). The ideal size of the group is usually between 5-10 participants with 6-8 optimal for sensitive issues and each group may last between 90 -120 minutes (Willig 2013). This reflected my intentions for this project.

Following consent, all PAR groups in this project were audio-recorded and transcribed verbatim. The preliminary PAR group topic guide (Appendix 4) was devised by me on the understanding that it would be influenced by participant discussion during the initial PAR group. The actual participatory group process as shaped by the participants will be discussed in the next section. Data analysis of the

PAR groups can be found in Chapter 5 and the PAR group findings are reported in Chapters 6-9.

In exploring alternatives, I ruled out a community based approach to citizens' juries a form of co-operative enquiry through multi-stakeholder dialogue where different perspectives from invited speakers or "witnesses" can be debated as a basis for reflection and action, thus learning about the past and the present to influence the future (Wakeford 2014, p.100). My view was that this would be too prescriptive by me from the outset but could be incorporated in some form if so desired by the participants.

4.3. Recruiting Participants

Given that the project was located in the city of Edinburgh, participants were sought from that community. Participants consisted of adult members of the general public who were currently volunteering through personal choice and who had lived experience of mental illness. Careful consideration was given as to how to define lived experience of mental illness. For this study, people were required to have a mental health diagnosis and to consider themselves to be in a stage of recovery. My reasoning was that I wanted to avoid placing undue pressure on people who may be vulnerable following a recent acute stage or relapse of their mental illness; or who may be subject to compulsory community treatment measures under the Mental Health Care and Treatment (Scotland) Act 2003 and therefore considered in law to have significantly impaired decision making in relation to their understanding of their mental illness and the need for medical treatment.

Consideration was also given to the age of participants and I decided to avoid being overly restrictive, to focus on adults aged sixteen and above and not to impose any upper age limit. This was in recognition that many older people choose to volunteer and that by restricting to working age was potentially ageist and may privilege issues around employability. I also reasoned that those under 16 years may have additional developmental and educational considerations and may be better served by a project specifically for younger people. Having excluded literature on older people and volunteering in the literature review, I recognised that this would need to be revisited in light of recruiting older participants.

Further, I was mindful that mental health is not a static phenomenon and that some participants although initially meeting the inclusion criteria may experience fluctuations in their mental health and that a relapse of mental illness may occur for some people during the course of the project. Indeed, one participant missed several group meetings but returned when feeling well enough to participate. Having a preliminary individual conversation prior to the start of the PAR groups was essential in providing an opportunity to discuss issues such as relapse signature if participants so wished. In addition, having prior experience of working in mental health settings was invaluable in understanding and having empathy for the challenges associated with living with mental illness.

Finally, consideration was given to people's capacity to engage in the research process and how different capacities might affect the research process. I consciously wished to involve people with a range of volunteering backgrounds and experiences and so I was not prescriptive as to a specific type of volunteering. I also recognised that people could be at different stages of recovery and that this may impact on participation and ability to articulate experience as well as group cohesion. My intention was to remain open and to value all experience as equally valid. Indeed, a more important inclusion criteria for me was people's curiosity about the project and willingness to reflect on and share experience with a view to working together in a group setting to produce something useful for the group or wider community. I recognised that it would be my role in the first instance to respectfully manage and contain different experiences, expectations, abilities and personalities within the research process and specifically the PAR group settings. Although a novice researcher, I was experienced in group working in both education and mental health settings and competent in recognising and facilitating group dynamics, respecting all contributions and abilities. Participants were selected in accordance with the inclusion and exclusion criteria in Table 1, (Appendix 5).

From the outset of this project, I had in mind that an initial sample size of ten participants would be a good beginning for the first preliminary interview stage.
This would allow for a core group of six to eight participants to continue and reflected my anticipation that some participants may choose to opt out of the project, deciding not to take part in the PAR groups. The small sample size was chosen to reflect the qualitative nature of the research in terms of the semi-structured

interviews and PAR groups. It was also pragmatic in relation to considering transcription times and group dynamics where the core working group should not be too overwhelming in size to allow people's voices to get lost, nor too small to put undue pressure on participants/co-researchers to participate.

In beginning the recruitment process, an A5 recruitment flyer was designed (see Appendix 6), advertising the project and asking interested people who met the criteria to contact me via e-mail or telephone for more information. Recruitment was therefore purposive and convenient, devised to be self-selecting on the part of the potential participant thus reinforcing the inclusion criteria of curiosity and willingness to engage rather than any attempt to ensure a balanced representation of age, gender and experience. Following discussion with my supervisory team and Volunteer Edinburgh, as the community stakeholder, I advertised for suitable participants initially through Volunteer Edinburgh's mailshot network and then with other local volunteer organisations. Agreement was secured with Volunteer Edinburgh to circulate the recruitment flyer in their e-bulletins, which were circulated to around 3000 volunteer subscribers and to approximately 900 volunteer involving organisations (VIO) subscribers. The project was also advertised on Volunteer Edinburgh's social media platforms. In addition, I circulated additional flyers by hand to a local mental health service that engaged volunteers, explaining the project and requesting potential participants to contact me.

Within a few weeks, I had received emails and telephone messages from several potential participants and after answering preliminary questions I forwarded the project information sheet (see Appendix 7) detailing the nature of the project including possible benefits and potential risks, to those interested in taking part. Prospective participants were then invited to discuss the project with myself and clarify any issues, either face to face, or by further telephone or email contact, before making a decision to verbally consent to take part. Informed consent and the process for securing written consent will be revisited later in this chapter. Some people recognised that although interested and eligible, they were unable to make the commitment to attending a series of groups due to personal issues such as time commitment or travelling distance and asked to be kept in mind for any further projects of this nature. A few months later, I had met with eight participants who had agreed to take part in the project, signed the consent form and had completed the stage one preliminary individual interview. Given that responses had significantly slowed down, I decided to go ahead with the stage two PAR groups remaining open to additional people potentially joining at a later date. Following the preliminary interview, one participant decided he was unable to commit to the PAR groups due to other commitments and so the participatory group began with seven participants. Over the course of the group meetings and following concerns from participants about dropping attendance, an additional two participants were recruited to join groups four and five. They had friends involved in the project, met the inclusion criteria and were keen to participate. This brought the total participant number to ten, with nine participating in the PAR groups. Chapter 6 details participant experience and background.

4.4. Research Setting and Collaborative partner

The preliminary individual interviews and PAR groups took place at Volunteer Edinburgh's premises in a central Edinburgh location in a bright well-equipped meeting room space with access to refreshments. Volunteer Edinburgh are a third sector organisation committed to placing and supporting individuals with experience of mental health issues through volunteering opportunities in a variety of volunteer involving organisations (VIOs) and have significant links with volunteers; a wide range of third sector voluntary organisations; and mental health and social care services throughout the city of Edinburgh. The decision to use a space offered by Volunteer Edinburgh was pragmatic. Firstly, the central Edinburgh location was more accessible by a range of bus routes than the University campus. Secondly, a community venue rather than an academic setting served to reinforce the project as community orientated and participants as co-researchers rather than subjects in academically driven research. Thirdly, it legitimatised the volunteering aspect of the project as endorsed by a reputable third sector organisation. Finally, the meeting space was offered free-of-charge and as the project was reliant on personal funds this was more attractive than paying for a private venue. In hindsight, the decision to locate the project in Volunteer Edinburgh's premises may have compromised neutrality, which will be revisited in Chapter 10.

4.5. Participant shaping of the research process

Given that participants in PAR have a central role in identifying the problem, formulating research questions, collecting, analysing and interpreting data, formulating and communicating conclusions and implementing an action plan (Schugurensky 2014), my initial research proposal to meet university doctoral requirements was anticipated to change and be shaped by participant engagement. The initial proposal envisaged five stages in the research process including an opportunity for participants as co-researchers to interview volunteer involving organisations (VIOs). However, participants did not view this as necessary or desirable during the research process and rejected this stage. This section demonstrates what the original proposal was and how participants modified this. This is summarised in Table 2 below:

Stages:	Original Proposal:	Participant Modified:
Stage 1	Data collection of participant experience of volunteering with lived experience of mental illness through individual conversations using semi-structured questions.	Carried out as in original proposal.
Stage 2	A series of participatory action research groups with participants from stage 1 generating the research questions and discussing, sharing and critically reflecting on personal and collective experiences of volunteering with lived experience of mental illness. Generating themes through collective analysis of transcripts through a cyclical and spiral process of simultaneous critical reflection and action involving a combination of planning, acting, observing and reflecting. Additional potential to: include evidence from the literature on volunteering and mental health; develop a shared understanding of research methods and qualitative and quantitative data analysis; identify and prepare for research that participants may wish to carry out alongside the researcher in stage 3.	Carried out as in original proposal. However, the emphasis in the original proposal of discussing evidence from the literature; developing further skills in research methods and data analysis; and identifying further research for stage 3 was collectively rejected by participants as not necessary or desirable.
Stage 3	Carrying out additional research proposed by the participants in stage 2. For example, co-facilitated focus groups with members of VIOs. Agreeing focus group questions, transcribing, collectively analysing and generating themes for discussion in stage 4.	Participants rejected this stage as not desirable or necessary.
Stage 4	Continuing PAR groups emphasising critical reflection and action. Participants accessing transcripts/ themes from stages 2 and 3. Generating knowledge by analysing and critically reflecting on the themes uncovered by the data through a continuing cyclical and spiral process of simultaneous critical	Carried out as in original proposal minus stage 3 input.

	reflection and action involving a combination of planning, acting, observing and reflecting. Devising an action plan to consider how best to address, present and disseminate the information gathered through the production of something of benefit to the group and/or wider community.	
Stage 5	Reflecting on the outcome of action and/or product and how change has been brought about at an individual, group and wider community level through generating the product in stage 4 and through participation in the research project. This dialogue may result in further action, which could be sustained independently by the group if they so choose.	Outcome of action achieved by producing briefing paper for Scottish Government. Reflection on product achieved in part through e-mail correspondence with individual participants due to personal circumstances preventing further group meetings.

Table 2: Proposed and actual stages in the research process.

Following stage 1 conversations, a date for the first PAR group was agreed and thus began stage 2 of the research process. Since PAR is an inductive, flexible approach to research it was not possible to determine the number of PAR groups that would be required or the exact methods that would be used. The research process therefore involved listening to and working with the participants at their pace and with their agenda in order that their voices could be shared and heard and thought about in a collaborative and respectful way. In total five PAR groups took place spanning a five-month period.

I facilitated each participatory group supported by someone from my supervisory team as co-facilitator, when available. All discussions were audio-recorded (no participant agreed to be video-recorded) and participants agreed to me transcribing each group discussion and identifying preliminary themes or findings to bring back to the next group for analysis, discussion, consolidation and validation thus building on analysis in a cumulative way. Thus, participants in stage 2 were actively involved in generating the research questions and discussing, sharing and critically reflecting on their personal and collective experiences of volunteering with lived experience of mental illness. During this stage, participants were encouraged to ask critical and thought-provoking questions of themselves and each other to extend their understanding of their experience as a volunteer with lived experience of mental illness on a journey of recovery within a particular socio-political context. Indeed, each subsequent PAR group revealed deeper levels of critical analysis, reflection and understanding in line with “conscientization” (Freire 1970, p.104) or critical consciousness raising where participants were totally engaged in critical thinking about their situation. Generating themes through discussion and collective analysis of transcripts therefore became a cyclical and spiral process of simultaneous critical reflection and action that continued through stages 4 and 5 through a combination of planning, acting, observing and reflecting. This was not only evident during each PAR group but also in the spaces in-between groups with participants continuing to critically question and reflect on themes and relevant issues prior to, during and after each group bringing these thoughts and questions back to the next group. Collaborative data analysis of the PAR groups is discussed further in Chapter 5.

Given that the frequency of PAR groups needed to allow for data analysis to be conducted within and between meetings it was agreed to meet on a monthly basis to ensure continuity, motivation and commitment. PAR groups were scheduled for afternoons, mainly at the request of participants who disclosed in the preliminary interview that they had difficulty getting up in the mornings; and it was agreed that they should last no longer than 90 minutes. This decision was pragmatic taking into consideration issues such as personal commitments, travel, concentration, predictability and length of time for transcription. All group meetings took place during office hours in a private room in Volunteer Edinburgh premises with facilities for tea and coffee making. Indeed, each PAR group began informally with me welcoming people, providing refreshments and reimbursing travel expenses. The first few meetings focused on introductions with people sharing their experience enabling participants to get to know each other and establishing norms and ground rules. Discussions focussed on describing participants’ experiences in relation to the research themes, reflecting on the emerging picture, evaluating socio-political systems and experience whilst being mindful of the need to identify actions for improving such systems and experience. The format and agenda were negotiated by participants and based on critical reflection and asking thought provoking questions to aid discussion of the key themes arising from the previous group from both transcriptions and collective memory.

In facilitating stage 2, I was open to supporting participants becoming empowered stakeholders in the research process in generating further research questions. I was also open to using a range of creative and arts based participatory methods to support discussion and always had paper, coloured pens and a flip chart at the ready. As an occupational therapist, I felt skilled in using creative media to facilitate discussion but was also mindful that participation is a process and does not depend on using a particular method. Inspired by the literature on creative methods including techniques such as participatory diagramming to frame, organise and make collective decisions, brainstorming, spider diagrams, flow diagrams, matrices and timelines, I was open to moving from verbal discussion to incorporate other arts based methods such including photo-voice, photo-diaries or visual maps to generate data and stimulate debate, information exchange and understanding. However, the group appeared unwilling to try other methods preferring discussion to remain at a verbal level.

My initial proposal for stage 2 included the opportunity to discuss and become informed on the literature on volunteering with lived experience of mental illness; the opportunity to become skilled up and develop a shared understanding of research methods and qualitative and quantitative data analysis; and to identify and prepare for further research that participants may wish to carry out alongside the researcher in stage 3 such as interviewing VIOs to gather their views of involving volunteers with lived experience of mental illness. However, the group rejected these ideas viewing stage 3 as unnecessary and undesirable.

Stage 4 proceeded in the absence of stage 3 as a continuation of the PAR groups emphasising critical analysis of the transcripts and reflection on the themes uncovered by the data from each group discussion with a view to generating further knowledge that might inform the final action, outcome or product phase of the project. Thus, continuing the cyclical and spiral PAR process of simultaneous critical reflection and action from phase 2 involving a combination of planning, acting, observing and reflecting whilst continuing collective analysis of transcripts from previous group meetings to reach a consensus on what action, outcome or product the group would find beneficial. I anticipated that stage 4 would involve formulating an action plan that considered how best to address, present and disseminate the information gathered. This would be through the production of something beneficial to the group and/or wider community: potentially a written guide or arts based film, exhibition etc. for volunteer organisations; prospective volunteers with lived experience of mental illness; local government; health and social care professionals; community organisations; friends, families and carers, potentially using photo-voice as a tool for both process and product. However, this stage was challenging for everyone due to difficulties in coming to a consensus about the final action or product. This is explored later in the thesis.

Stage 5 was necessary in thinking about how change has been brought about at an individual, group and wider community level through generating the product in phase 4 and by participating in the project. Stage 5 builds directly on the experience of stage 4 reflecting on action and taking further action. This continues the iterative cyclical process of observation, exploration, knowledge construction and action involving critical dialogue and collective reflection thus building a community of inquiry and change, which may result in further action (McIntyre 2008). In this way, action is evaluated and modified in order to move in new directions. The action in PAR is therefore viewed as both process and product or outcome. Stage 5 was achieved in that an agreed outcome of action was to produce a joint briefing paper with Volunteer Edinburgh to inform the Scottish Government's call for information to inform the Social Security (Scotland) Bill. However, given that personal illness prevented a sixth PAR group taking place, further reflection on the outcome of that action had to rely on e-mail correspondence with individual participants. This is revisited in Chapter 10 when reflecting on the research process.

PAR is therefore a systematic and cyclical action-reflection process enabling participants to prioritise the issues that are important to them; dialogue and reflect on their experiences; and plan and take actions on those issues that are meaningful and achievable in their lives (Koch and Kralik 2006; McIntyre 2008). Freire (1970) recognised that critical reflection and action must take place at the same time in a concept he called praxis where they mutually enlighten each other and where critical consciousness can develop leading to further action (Loewenson et al. 2014). According to Freire (1970) praxis must occur in dialogue with others and include a participatory element (Ospina and Anderson 2014, p. 19). Praxis therefore becomes a process whereby in dialogue with others "the individual in transforming the world, is himself or herself transformed" (Macedo 2014, p. 182). In this way, participants cease to view their situation as "a dense, enveloping reality or a blind alley" and instead as a "historical reality susceptible of transformation" (Freire 1970, p. 58 in

Baum et al. 2006, p. 856). Indeed, Freire (1970, p. 41) suggests that “reflection without action is sheer verbalism or armchair revolution and action without reflection is pure activism, or action for action’s sake” neither of which can produce transformation. This circular and spiral process of PAR involving a combination of planning, acting, observing and reflecting is represented by Loewenson et al. (2014, p. 13) in Figure 4 below demonstrating a spiral of repeated cycles of collectively organising and validating experience, problematizing, analysing and critically reflecting on that experience whilst simultaneously considering and identifying action, taking and evaluating action and finally organising, validating and sharing new knowledge when the spiral begins again. According to Loewenson et al. (2014, p. 14) the experience of action alongside learning from action and transforming reality becomes the impetus for a new round of collective, self-reflective enquiry that may draw on wider knowledge from other relevant sources to inform further analysis and action. Indeed, whilst the PAR groups became the main focus for this process critical analysis, problematizing and self-reflection was also occurring in the spaces between group meetings with participants reflecting on points raised by themselves and others in light of their continuing experience and new collective knowledge.

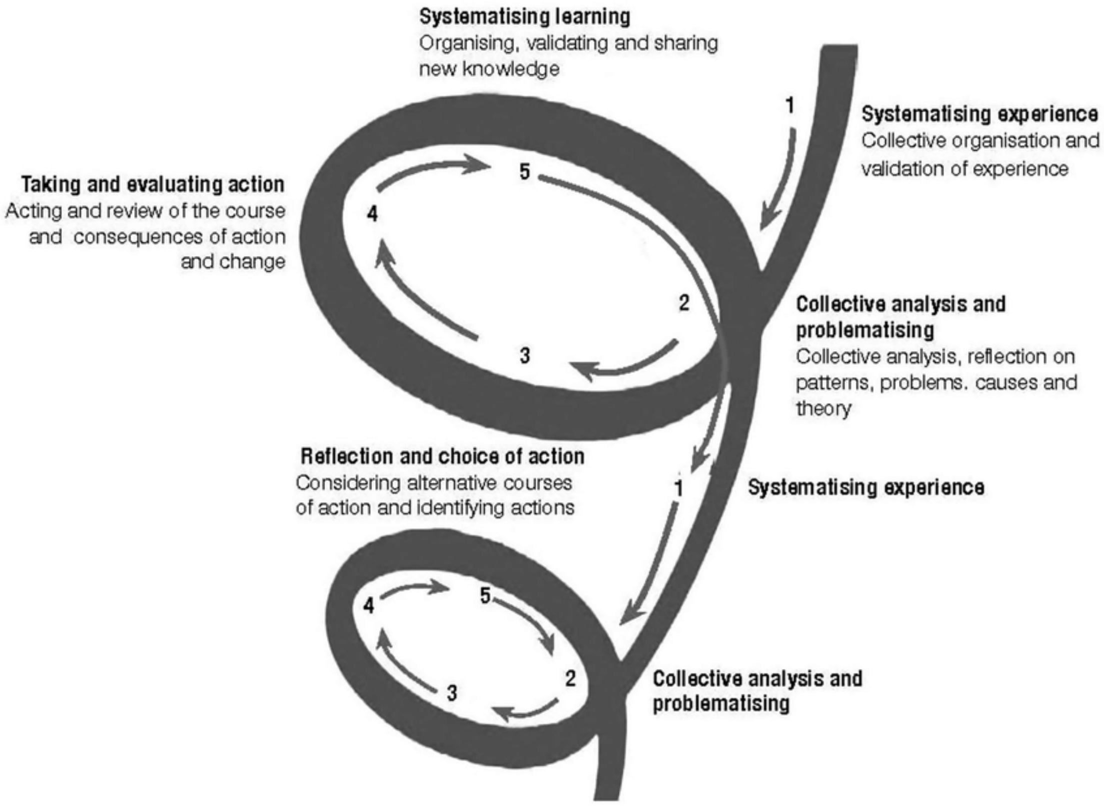

Figure 4: The cyclical and spiral process of PAR (Loewenson et al. 2014, p. 13).

4.6. Participatory Ethics

Ethical approval was granted by Queen Margaret University in July 2015 and included an agreement in principle from the collaborative partner Volunteer Edinburgh (see Appendix 8). In seeking ethical approval, I was guided by Durham University's Centre for Social Justice and Community Action (2012) ethical principles for community-based participatory research such as mutual respect, equality and inclusion, democratic participation, collective action and personal integrity. I was further guided by Torre's (2009) participatory action research framework outlining conditions for collaboration and prompting me to think about "what needs to be in place within the collective to facilitate participation?"; and "who is made vulnerable by the research?". This section presents an overview of how I considered ethical issues in my relationship with the participants in terms of informed consent, practice ethics and participatory ground rules, confidentiality, beneficence and non-maleficence.

4.6.1. Informed consent

Following advertising the project those interested in taking part were forwarded the project information sheet and invited to discuss the study with the researcher before making a final decision to consent. Initial face-to-face conversations took place as timely as possible from the first inquiry to capitalise on interest. During this conversation, prior to any interview commencing, verbal agreement to participate in the project was confirmed and the consent form was discussed and signed. The participant consent form (see Appendix 9) contained separate statements to avoid any confusion over a blanket type of consent and to give participants choice for example, about whether they agreed to be either audio or video recorded. However, no participants agreed to be video recorded. Participants were also made aware that they could withdraw at any time without giving a reason. The process for obtaining informed consent is outlined more fully in Appendix 10.

4.6.2. Practice ethics and participatory ground rules

The Centre for Social Justice and Community Action (2012) presents a set of principles that became a useful practice guide for this project including negotiating ground rules with the participants in the first participatory group. In practice I wished to adopt a participatory ethical mind-set influenced by mutual respect, equality and inclusion, democratic participation, collective action and personal integrity. This meant ensuring accessibility of group meetings and providing space and encouragement for people to share their voice, be heard, learn from each other and be motivated to share their knowledge with a wider audience. Personally, I recognised the need to reflect on my power and status to encourage collective decision-making and to be open to challenge; and to negotiate expectations, specifically what counts as positive change and action.

In negotiating ground rules, we agreed on the importance of personal integrity where people would be honest, respect confidentiality and share what we were comfortable with. We also agreed to mutual respect where everyone would listen to each other and respect diverse perspectives. In facilitating democratic participation, we agreed that people would communicate in a language that everyone could understand. We also agreed that the responsibility for interpreting the data would be done collectively and that any outcome would be in the form of collective action that would make a positive difference. The Centre for Social Justice and Community Action (2012, p.9) suggest establishing a “working agreement” to include preferred method for communication and for delegating responsibility. As such, the group agreed on the frequency and timing of the meetings and outwith meeting times, the majority of the group agreed to be contacted via email, with the exception of one participant who preferred written correspondence to her home address. The group delegated responsibility to me for transcribing the audiotape and presenting a summary analysis of the key themes but took collective responsibility for exploring these and debating these further. My reflections on the success of the participatory research process including adherence to participatory ethics is explored in Chapter 10.

4.6.3. Confidentiality and handling personal data

In handling personal information, I recognised the importance of ensuring anonymity and confidentiality. All identifying information was stored securely in a locked cabinet in QMU within the Division of Occupational Therapy and Arts Therapies to comply with QMU policy, or in electronic format in password protected folders in a computer on a secure server. All data generated during the project was stored separately from other identifying personal information and could only be accessed by myself. Any personally identifying information was removed from the interview and groups transcripts including locations and names of specific mental health and voluntary organisations. However, the names of larger organisations remained when the name did not compromise the personal identity of the participant. Participants' names were substituted for initials for the benefit of PAR group participants analysing and discussing the group transcripts, whilst pseudonyms were allocated in reporting of group and individual data in the thesis. Data from the individual interviews was deemed confidential to that participant and was not shared with the group. According to the Centre for Social Justice and Community Action (2012) there may be times in relation to research outputs where participants and organisations may wish to be named and credited for their achievements or challenges and this requires on-going discussion.

To aid confidentiality, I had initially anticipated that no two participants would volunteer in the same organisation. However, in hindsight, this was naïve and could not be guaranteed through purposive and convenience sampling. Indeed, some participants had heard about the project through word of mouth and had established friendships and/or prior knowledge of each other through contact with Volunteer Edinburgh, thus emphasising confidentiality when agreeing group rules was essential. With regard to ownership of the data generated from the participatory groups and acknowledging that the University claims ownership of work generated through doctoral studies, I recognised a potential tension between institutional power and the community empowerment philosophy of PAR. In order to avoid any ambiguity or potential academic exploitation, it was important that participants were made aware of this from the outset.

4.6.4. Benefitting Participants

Given that the focus of PAR is emancipatory, I anticipated that there would be a number of potential benefits to participants themselves and also to the wider community. Benefits to participants included opportunities to share their volunteering experiences with others in similar situations, to learn from others and to gain new insights into the benefits and challenges of volunteering with lived experience of mental illness from the perspective of others. By nature of the group experience, benefits included opportunities to give and gain support with the potential to feel understood and not alone and the potential to develop a peer support network that could be self-sustaining if participants were interested. Further, the collaborative research process enabled participants to acknowledge their expert status; to learn about and experience participatory research methods through reflecting on their situation; and to gain skills in analysing data and debating and reflecting on key themes emerging from the data that they had generated and contributing to decisions about how this could be best disseminated.

In terms of output there was potential to make a valuable contribution to the literature through the generation of knowledge that could be shared with a wider audience including the voluntary sector and the professional and academic community. Indeed, it was anticipated that the PAR process would offer participants the opportunity to positively contribute to improving the experience and information available to people with lived experience of mental illness and thus influence their own experience of volunteering and the lives of current and future volunteers through creating something that could be shared with the wider community. Additional anticipated benefits from this project were to the wider volunteering sector in gaining an understanding of the benefits and challenges of volunteering for participants and in potentially reviewing and evaluating their support mechanisms for volunteers with lived experience of mental illness in light of this. To myself as researcher in gaining research expertise in participatory and collaborative methods; and being privileged to work collaboratively with and share in the experiences of people with lived experience of mental illness who are volunteering. To the wider research community in gaining an understanding of the challenges and benefits of volunteering for people with lived experience of mental illness; and the challenges and benefits of carrying out participatory action research in practice. To policy makers in hearing the voice of people with lived experience of mental illness who are volunteering and thus inform decision makers about ways to best support and address issues raised by the research.

4.6.5. Avoiding Harm/ Non-maleficence

My primary concern regarding potential risks was to monitor the safety and wellbeing of individuals including myself during the contact stages of the project and to minimise the risk of any physical or psychological harm. I recognised that the research experience might trigger difficult memories and emotions and people may feel unsafe; participants may dislike sharing experience within a group; participants may be taking part at difficult emotional and psychological times in their lives; and sharing experiences in a group may compromise confidentiality. The preliminary conversation provided an opportunity for participants to highlight any health issues that they felt I needed to be aware of and to discuss any concerns regarding participation. This included identifying any relapse signature and potential individual support mechanisms.

To combat potential risks, I ensured that the research focussed on the volunteering experience; that all contact was carried out in a venue in a community setting and not in isolating circumstances where I would be unable to call for assistance if necessary; and I enlisted a group co-facilitator with experience of working with vulnerable adults, to assist me where necessary with group discussion and dynamics. Group rules including a focus on confidentiality were negotiated with participants from the outset and reinforced at each group meeting. In addition, external support was identified as available to participants during the research process. Although I considered myself a skilled occupational therapist with significant experience working in mental health settings and in facilitating group work with vulnerable adults, I recognised the importance of both keeping detailed reflexive field notes to record my experience and seeking regular supervision with my supervisory team. Indeed, reflexivity is important on the part of the primary researcher not only in recording my experience and ideas about volunteering in order to make any meaningful contribution, but also for on-going examination of my "own voice, action and effects of these on the research process" paying specific attention to use of power and influence (Wimpenny 2010, p. 93). My reflection of the research process with reference to power and participation and problems encountered is explored further in Chapter 10.

4.7. Project and Thesis Timeline

The project and thesis timeline required being compatible with the allocated university PhD time for completion of doctoral work on a part-time basis. The actual project and thesis timeline can be viewed in Table 3 below. Overall, the project took approximately eight years from conception to final thesis submission and included nine individual interviews and five PAR groups. A sixth PAR group, planned for May 2016, had to be cancelled due to personal illness. Thereafter, all further communication took place via email to ensure that the action element of PAR could be achieved. The timeline also indicates academic outputs as conference papers and workshops.

September 2012	Commencement of PhD studies
April 2013	Outline proposal approved
June 2014	Probationary viva passed
July 2015	QMU Ethical approval granted
September 2015	Project advertised
October -Dec 2015	Preliminary Individual Interviews with Informed Consent
January 2016	PAR Group 1
February 2016	PAR Group 2
March 2016	PAR Group 3
April 2016	PAR Group 4
May 2016	PAR Group 5
June 2016	PAR Group 6 cancelled
July-August 2017	Further communication with participants via email
August 2017	Collaborative Action: joint paper submitted with Volunteer Edinburgh in response to Scottish Government call for evidence to inform the Social Security (Scotland) Bill (Appendix 16)
September 2017	HUNTER, H. and HILLS de ZARATE, M., September 2017. *Negotiating Transitions in Borderline Times*. Workshop. ECARTE 19th European Arts Therapies Conference. Krakow, Poland (Appendix 11)
September 2017	HUNTER, H., 2017. *Is Volunteering Voluntary?* Oral presentation abstract accepted for the Occupational Science Europe Conference, Hildesheim, Germany (Appendix 12)
May 2018	HUNTER, H. and FINDLAY, M., 2018. *Is Volunteering Voluntary: an exploration of the dark side of volunteering.* Oral presentation. World Federation of Occupational Therapists Congress (WFOT) Cape Town, South Africa (Appendix 13)
June 2018	PhD assessed seminar 2 completed
Aug 2019-Feb 2020	Suspension of studies due to ill health
May 2020	Thesis submission

Table 3: Project and thesis timeline

Summary

This chapter has outlined the research process including the methods selected in the research design, participant recruitment and ethical issues and how participants shaped the research process. Chapter 5 discusses data analysis and identifies themes to illustrate the research findings.

CHAPTER 5: DATA ANALYSIS

Data analysis in participatory action research is the process of exploring meaning and gaining understanding through participation and collaboration. This process usually forms the basis for further action and new knowledge or theory generation. Data analysis can be complex and challenging as the narrative method of data collection often generates large amounts of data, yet it can be the most specialised and least well understood stage in the research process (Kara 2015). Taking a transparent and systematic approach and creating a clearly documented audit trail of all steps taken is recommended (Higginbottom 2015). This chapter presents an audit trail documenting data analysis for this project. It begins by considering how I made sense of the data before separating the data analysis process into two parts. Firstly, from the perspective of the individual interviews, and secondly, the analysis of the PAR groups.

According to Rowley (2014), there is no one way to conduct data analysis and action researchers have customised other approaches to qualitative data analysis, drawing on for example narrative, thematic, discourse and grounded theory analysis. She states:

> …..the only thing that is certain is that the process starts with a diverse set of data and concludes with a coherent account or narrative…the process is iterative, and the data is interrogated in different ways. (Rowley 2014, p.240)

Indeed, the process generates “an increasingly refined conceptual description” which arises from the data and is grounded in it (Rapley 2011, p.276). In making sense of the data, the nine individual interviews and the five PAR groups were subjected to different types of qualitative data analysis. The individual interviews, initially designed to introduce each participant to the researcher and the research process and gather relevant background information, were recognised as confidential to the researcher and participant. Therefore, any collaborative analysis could only be at a didactic level between participant and researcher. A general thematic data analysis was therefore felt to be suitable. Given that the data from the transcribed PAR groups was a significant part of the PAR process, this followed a practice of collaborative data analysis with participants. These processes will be explored in turn.

5.1. DATA ANALYSIS: Individual Interviews

The nine transcripts from the preliminary interviews were subjected to thematic analysis, which according to Willig (2013, p.57) is "a method for recognising and organising patterns in content and meaning in qualitative data"*.* This involves methodically working through the qualitative data "in order to identify common threads of meaning, to group these together into categories of meaning and to then cluster these into higher order themes" Willig (2013, p.58). Thematic analysis is a generic method for analysing qualitative data, allowing "theoretical flexibility" on the part of the researcher, through attention to the research question and epistemology to clarify the status attributed to any theme thus ensuring a meaningful theoretical and epistemological context (Willig 2013, p.58). In adhering to Willig's (2013) advice, the research question was revisited alongside the epistemological position of the researcher and the study, and a reminder of the interview intention. The individual interviews were set up to explore people's experiences of volunteering, both current and past, alongside their lived experience of mental illness, and to consider any benefits and challenges of volunteering for people with lived experience of mental illness. The interviews also provided a baseline relationship between researcher and participant in order to better facilitate interaction within the PAR groups. Implicit in this, although not originally stated at the outset, was an interest in gaining an understanding of people's perceptions of the conceptualisation of volunteering and how it may be represented by various organisations such as the third sector, the government and the media.

Guided by DePoy and Gitlin's (1994, p.138) discussion on the interpretation of the meaning of everyday experience as found in phenomenological research and the belief that "meaning can be understood only by those who experience it", I was interested in seeking emergent information from participants rather than imposing an interpretative framework on the data. Thus, in the interpretation of the data I was dependent on the willingness of those interviewed to express and reveal their experiences. In addition, adhering to a social constructionism epistemology, I was interested in multiple ways of knowing and thus finding meaning that was influenced by social processes, not solely a product of the individual (Wimpenny 2010). Finally, influenced by critical theory, I was interested in looking for any shared understanding of how power dynamics might shape people's truths and worldviews. Various data analysis approaches were explored and debated for their ease of fit including those with a participatory focus (Koch and Kralik 2006; Higginbottom 2015); those with an emphasis on psychoanalytic thinking and reflexivity (Hollway and Jefferson 2000; 2012); those using a grounded theory approach (Charmaz 2006); and those advocating a more general thematic analysis (Dey 1993; Coffey and Atkinson 1996; Boyatzis 1998; Braun and Clarke 2006; 2013; Clarke and Braun 2017; Richards 2015). Although an inductive approach was felt to be desirable in that any findings would derive from the data rather than be predetermined by theory or previous research (Rowley 2014), specific types of inductive data analysis were ruled out. For example, content analysis due to its narrow focus on categorising textual units through counting frequency of words and concepts; narrative analysis with its focus on how stories are told in the interview; framework analysis as this requires a pre-set approach with a priori concepts and themes and leading questions; and grounded theory with its emphasis on theoretical development and testable propositions through a constant comparison and theoretical saturation approach.

Although an interpretative analysis would seem to fit with what could be viewed as a phenomenological intention of the interviews, which are seeking participant, lived experiences, perceptions and meanings of volunteering, an interpretative phenomenological analysis would need to be supported by a phenomenological methodology, which I considered inappropriate for this participatory project. Further, any interpretive analysis adds a subjective, theoretical and political layer on the part of the researcher's lens (Braun and Clarke 2013). This may provide an alternative story to that of the participants and ultimately "transforms data from the words participants tell us, into a story about these words" (Braun and Clarke 2013, p.64). Therefore, I rejected an interpretative analysis because I wanted to stay true to the participatory nature of the overall research methodology, where ethical issues of researcher power and privilege would hopefully be mitigated through privileging participants' voices throughout the research process (Braun and Clarke 2013). However, given that this is a doctoral piece of work I recognise that some interpretation is necessary in demonstrating a degree of critical and reflexive thinking, but an interpretative analysis will not be universally adopted as a guiding framework. In coming to an informed decision, it was important to be mindful of Rapley's (2011, p.274) caution that qualitative data analysis practices can never be easily summarised by a neat label or abridged into a set of precise steps or guidelines to be followed. This became apparent as I found myself searching for a recipe where none seemed to exist that fitted my needs exactly.

For example, Higginbottom's (2015) qualitative participatory research data analysis provides useful guidance during the analysis process but offers little evidence of any participatory element other than ensuring that interpretations are shared with participants to achieve credibility. Alternatively, Koch and Kralik (2006, pp.48-50) advocate a "storytelling analysis protocol" as part of their seven-step participatory action research (PAR) approach where individual transcripts are analysed, and a storyline is formulated by the researcher. The storyline is then verified by the participant and shared with co-participants. A final storyline is co-constructed and validated by all participants. Although this appears to be a good collaborative approach, my interviews were not part of a collaborative research element and therefore confidentiality between researcher and participant needs to be upheld. On reflection, I decided that I could still incorporate the storyline element into my data analysis process by determining significant statements from each interview before summarising these into a story for verification/ co-construction by each participant.

5.1.1. Thematic analysis: individual interviews

In analysing the nine individual interviews I adopted Braun and Clarke's (2006; 2013) approach to thematic data analysis due to its clarity of process (Table 4):

	Phases	**Description of the process**
1.	Familiarising yourself with your data	Transcribing data, reading and re-reading the data, noting down initial ideas.
2.	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3.	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4.	Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic "map" of the analysis.
5.	Defining and naming themes	On-going analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6.	Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples…relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table 4: Thematic data analysis phases adapted from Braun and Clarke (2006, p. 87; 2013, pp.202-203).

This was supplemented with key data analysis ideas and techniques from other authors, which were seen as compatible and offered more depth of consideration of the data. My approach to each of these phases is summarised below with the exception of phase 6, which underpins chapters 6,7,8, and 9 on research findings and chapter 10, which discusses the findings in light of the research focus and the literature reviewed.

PHASE 1: Familiarising myself with the data and developing an analytic sensibility:

The nine individual interview transcripts were allocated pseudonyms to ensure anonymity and read several times. Alongside reading each transcript, I played the audiotape recording of each interview to focus my attention on the interview as a whole as well as the manner of the spoken words in terms of inflections, hesitations, long pauses, emotionality and use of humour. This also served to re-check the accuracy of the transcripts in their representation of the participant’s voice and to gain insight into each participant’s communication style. This deep immersion in the data is recognised as an important first step in familiarising the researcher with the language and wording used by participants and in highlighting patterns and ideas for coding (Braun and Clarke 2006; 2013; Richards 2015). Guided by Hollway and Jefferson’s (2000; 2012) view that the whole is greater than the sum of the parts, I recognised the importance of holding the data as a whole in my mind rather than relying on a computer assisted data analysis package which might fragment and store data “outside” my mind. It could be argued that preliminary data analysis begins during data collection and that reflexive analysis captured following initial field notes after each stage of data collection signals up and coming themes (Higginbottom 2015). This reinforced for me the need to consider all of the data at this stage, including reflexive notes (Hollway and Jefferson 2000; 2012). My reflexive journal was therefore included in this phase and was consulted for any significant comments prior to and following each interview. See Text Box 1 for an example of reflexive field-notes made after the initial interview with Polly and subsequent reflexive thoughts.

.....insisted on sitting in the corner rather than next to me. She had a cold, which she didn't want to pass onto me. I made an awkward comment…Felt humbled by her experience – an amazing pioneer/ advocate/ campaigner and political activist….an extraordinary woman with amazing drive, twinkly eyes and passion.	Reflexive Thought: Awkwardness of first meeting; getting a sense of each other; like walking on eggshells; keen to get it right for her and sensing my own clumsiness – maybe picking up on her anxiety? Difficult past shaping her current values and beliefs. Strength and vulnerability co-existing.

Text Box 1: Reflexive field-notes.

During this phase, I annotated each transcript with rough notes in the margin referencing possible themes and highlighting text line by line according to that theme. These rough notes or memos represented my initial observations, thoughts and questions and were summarised, clarified and extended on each reading. I found these memos helpful in beginning to take a step back from the data, to read between the lines, and to make creative links. The memos related to a variety of observations and questions including references to subject matter, attitudes, incongruences, ways in which questions had been interpreted, and with hindsight, comments on missed opportunities for discussion and elaboration. Braun and Clarke (2013, p.205) refer to these as "noticings" considering them as a "rush of ideas" which act as "memory aids" and "triggers" for further analysis. See Text Box 2 for an example of noticings from an excerpt of the initial interview with Alexander:

…..of course you're only supposed to do one project at a time in volunteering. I thought oh, I'd like to do two, because I was doing nothing else. So I went and did that. I fairly enjoyed working, eh, volunteering at the [city garden]…	• motivation/ keen • interesting that "working" changed to "volunteering". I missed an opportunity to pick up on that. Will check across transcripts.

Text Box 2: Noticings.

During this phase I was mindful of Braun and Clarke's (2013) caution that although personal experience shapes how we read data and is a great analytic resource, it can also potentially limit what we see in the data. The skill is to develop an "analytic sensibility" by reading actively, analytically and critically to consider what the data actually means (Braun and Clarke 2013, p.205). In this phase I found it helpful to use reflexive questions to cluster responses by asking myself "What is going on here?" (Look); "What is being reflected on here?" (Think); "What action is being proposed?" (Act); "What really matters?"; and "What is significant?" (Higginbottom 2015, p.61; Koch and Kralik 2006, p.49)

PHASE 2: Generating initial codes across the entire data set:

Once preliminary notes were generated, I identified initial codes that reflected the fundamental components of the data (Boyatzis 1998) beginning to organise it into meaningful groups (Braun and Clarke 2006; 2013). Initial codes were generated from selecting instances from participant's responses to the semi-structured questions that I had posed in the interview. I identified three initial broad patterns or codes namely: positive aspects of volunteering; negative aspects of volunteering; and other aspects of volunteering. Working through each transcript, I highlighted data extracts on every transcript in three different colours to represent these three initial codes. These data derived or topical codes were supplemented by my researcher derived codes (see Text Box 3), which were my attempts to identify "implicit meanings" within the data and to identify "assumptions and frameworks that underpin what is said in the data", and lead to a more interpretive analysis (Braun and Clarke 2012, p.207). In this way, I made additional notes on each transcript about the frequency of certain comments, interesting contradictions and any points that required further clarification that I named memos.

Data Extract	**Coded for: topical/ interpretive**
…..where I worked before, I could identify them…it's a part of being a "cheeky chappy",… "Jack the lad" and they would be the ones that would insist that you represent them to get the better component. (P7: Doug)	Negative /Stigma "Jack the lad" = chancer; Negative/ Othering of others; Negative/ Perceived as cheating the system.

Text Box 3: Data with topical and interpretive codes applied.

I worked methodically through each transcript line-by-line, chunking text into broad and distinct codes until all of the transcripts had been summarised, categorised and colour coded. My initial codes were extended, and a new code was generated to give four categories:

1. Positive aspects: including perceived benefits of volunteering.
2. Negative aspects: including challenges of volunteering.
3. Contextual aspects of volunteering: including political, health and social care systems; development of services including advocacy; and contradictions.
4. Background Information: including gender, work and volunteering history, future aspirations, lived experience of mental and physical illness, and initial researcher thoughts and interpretations.

Next, I drew up a potted biography for each participant summarising their work history, volunteering experience, health status, motivation, pre-occupations and aspirations. This was drawn from the interviews, my reflexive field notes, and additional interpretative notes. I then created a table for each participant keeping in mind Higginbottom's (2015, p.61) and Koch and Kralik's (2006, p.49) questions from phase 1 to aid reflexive thinking about the data from each interview: what is going on here?; what is being reflected here?; what is being proposed? A storyline was created for each participant using significant statements from the individual interview including a relevant quote to capture the experience in the participant's words (Koch and Kralik 2006). This was shared with individual participants along with a copy of their interview transcript for transparency of process and as an attempt to ensure rigour and internal validity through member verification.

To better view this phase of the analysis and to compare and contrast participant history, synopsis and key concerns, I also created a large visual chart (see Image 2 below) of the initial codes on coloured post-it notes across the entire range of interviews. Rowley (2014) acknowledges the benefit of developing visual representations through charts, tables and mind-maps to visualise the data and thus aid analysis and understanding. This visual representation was useful in highlighting diversity of views, illuminating ambiguities and contradictions, and any agreement and disagreement between participants, including those relating to role and gender (Rowley 2014).

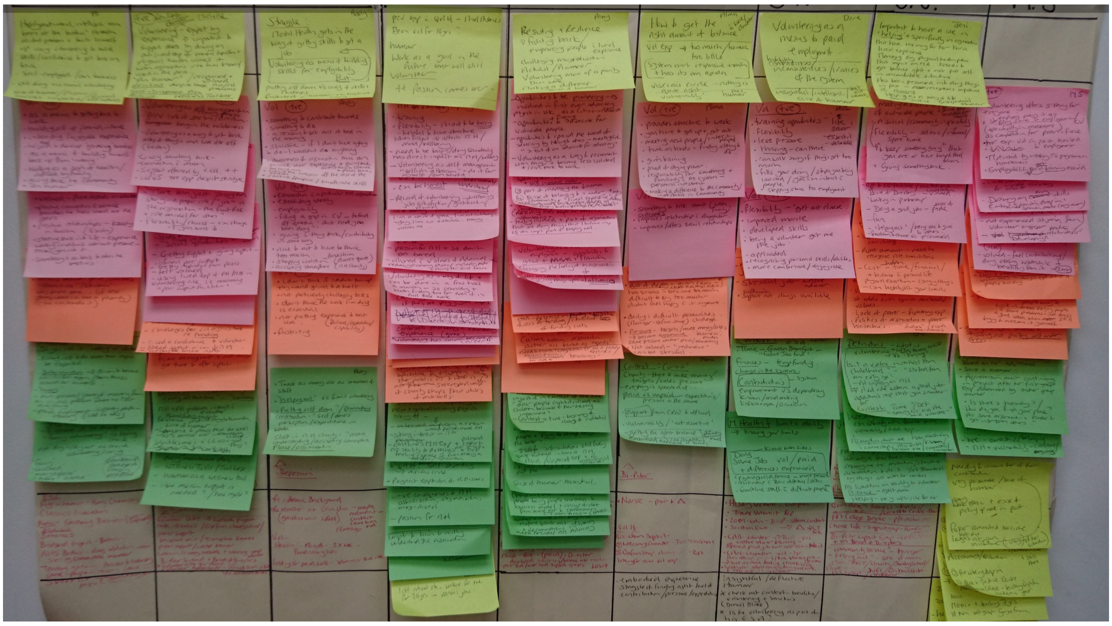

Image 2: Initial codes and memos across nine interviews.

Finally, I created tables for each of the three initial codes with examples generated from each participant. Thus, the data could be considered across the data set as well as within each initial code. Tables represented a comparison of positive aspects of volunteering; a comparison of negative aspects of volunteering; and a comparison of contextual aspects of volunteering.

PHASE 3: Searching for themes:

This phase broadens the analysis from codes to themes by sorting codes into potential themes and collating data extracts within themes (Braun and Clarke 2006). Codes may be combined and relationships between codes and themes examined with some codes refined and ultimately discarded and new sub-themes and levels of themes created. In searching for themes, I began by considering each of my codes in turn. On closer inspection, I realised that codes appeared more complex than first suggested by the data and rather than sorting many codes into fewer themes, I first needed to review and expand each code into broader themes. A detailed examination of each code revealed a number of interconnecting ideas, which could be further expanded into themes and sub-themes. See Appendix 14 for first thoughts and emerging themes from initial codes. An extract from positive aspects of volunteering is presented in Table 5 below:

Code:	**Emerging Themes:**
1. Positive aspects of volunteering	A. **Self-management and journeys of recovery**: gaining skills; training; building self-up; employability and getting back to work; building relationships; having structure and purpose; reason to get out of bed; keeping flexibility in line with mental health and ability; keeping well and out of hospital; “selfish altruism” – do it for own benefit. B. **Lived experience, identity and belonging:** aligning with own values; expert by experience; volunteering as a career and a way of life. C. **Making a difference:** giving something back; feeling valued and empowered; community connectedness; stirring things up; challenging the system; influencing.

Table 5: Emerging themes from initial codes: positive aspects of volunteering

PHASE 4: Reviewing and refining the themes:

This next phase seeks to refine themes and to discard themes that do not have sufficient data to support them. In refining the themes, I was looking for coherent patterns and ease of fit within the coded extracts and whether my individual themes accurately reflected the meanings evident in the data as a whole (Braun and Clarke 2006). Guided by Ellingson's (2008 in Higginbottom 2015, p.62) advice on the benefits of "crystallization" meaning a reflective consolidation period where no analysis is undertaken, I took a break from the data for a period to enable me to return to the analysis revitalised and with the potential to see things afresh. Through further analysis, I mapped the three themes and their sub themes onto a table, looking for similarities and difference within and across themes as well as ensuring that important data had not been omitted from the data set as a whole. Appendix 15 describes the rationale for the four refined themes, presented in Table 6 below:

Revised Themes:
1. "Selfish Altruism": journeys of recovery through volunteering: including personals stories, experience, values and self-management
2. Volunteering as a career: influence, identity and belonging.
3. The volunteering context: reflections on time, place and contradictions.
4. Challenges and contradictions.

Table 6: Phase 4 data analysis refined themes.

PHASE 5: Defining and naming the final themes:

In this phase, through on-going analysis, I was keen to identify the essence of each theme and to ensure that final themes reflected the overall story of the data. Braun and Clarke (2006) advise that final themes should be clear, concise and easily understood. Through further reflection and analysis, I decided to collapse the four revised themes into two clear and distinctive final themes with sub-themes as follows:

1. "Selfish Altruism": Journeys of recovery through volunteering:
    - Volunteering as a career: influence, identity and belonging
    - Challenges to recovery
2. The Volunteering Context: Reflections on time and place:
    - Contradictions and Kafkaesque experiences
    - Tensions between paid employment and volunteering

My experience of this thematic analysis process was "not linear, but undulating and convoluted" (Higginbottom 2015, p.60) and iterative where my first thoughts were tested until I reached a new understanding of the data. I was heartened to read Willig's (2013, p.66) statement that a good thematic analysis is "the product of a combination of theoretical knowledge and understanding, as well as the ability to systematically yet creatively thematize and interpret data. It is certainly not an easy option!". The next section considers the data analysis of the five PAR groups.

5.2. DATA ANALYSIS: Participatory Action Research Groups

Involving participants in data analysis is an important part of democratizing the research process. However, participants may opt out, or are excluded from this stage given the time and high-level literacy skills perceived to be required. Indeed, Schaal et al. (2016, p.164) note that academics are often viewed as the "experts" in data analysis and more able to carry out this stage of the research process. An inclusive approach where collaborative data analysis opportunities are made available requires participants to be viewed as assets and trained in data analysis techniques (Flicker 2014). This values the contribution and expertise of all partners, promotes co-learning and develops capacity in the community for equitable participation in research (Schaal et al. 2016). Although, inclusive research practices are growing, collaborative data analysis practices do not always follow the politics of inclusion and remain variable and contentious with academic researchers dominating this research stage (Jackson 2008; Nind 2011; Flicker 2014). Collaborative practices are time-consuming and engaging community partners in a meaningful way can be challenging requiring a strong collaborative project structure to enable data analysis to be "transparent, relevant and accurate" (Westhues et al. 2008, p.715). Additional pitfalls in adopting collaborative analysis include acknowledging that different participants will hold different perspectives and that there may be disagreement with opposing sub-groups emerging; that complex power relations and group dynamics require skillful handling; and that nurturing a communicative space that promotes trust and openness and ensures that all voices are heard is essential (Wimpenny and Savin-Baden 2012). This section outlines my approach to collaborative data analysis with participants and PAR group data in order to highlight how decisions were made and demonstrate transparency of process.

5.2.1. Collaborative data analysis: A process of decision-making

In deciding the type of collaborative analysis approach to take, I considered a range of possibilities from available literature including training participants in data analysis methods (Jackson 2008; Daley et al. 2010; Nind 2011; Schaal et al. 2016); pairing participants with academic researchers to agree codes in collaborative discussion

(Cashman et al. 2008: Schaal et al. 2016); coding in teams through experiential and conversational learning (Foster et al. 2012); and paying community members as research team assistants (Daley et al. 2010). I also considered the DEPICT model of collaborative analysis as outlined by Flicker and Nixon (2014 pp. 617-621) a six stage process involving "Dynamic reading" of subsets of transcripts, "Engaged codebook development" to organise the data, "Participatory coding", "Inclusive reviewing of categories", "Collaborative analysing" and finally "Translating" to create a dissemination plan. In reviewing these options, I noted that these were mainly large-scale funded projects involving a range of researchers and stakeholders. Interestingly, the majority of these approaches assume that data generation has already occurred, and that data analysis is the next step in the research process. I decided that although laudable, training participants in data analysis was outwith the scope of this project and given that I was the only academic researcher in this small-scale study, the pairing suggested by Schaal et al. (2011) was not possible. I decided to take a more fluid and pragmatic approach and was guided by Kara's (2015) view that maximum participation comes from making the process accessible which can be aided by integrating data analysis with data generation. More specifically, I was influenced by Paulo Freire's (1970, p.80; p. 104) method of "problem posing" leading to "conscientization" or critical consciousness raising where participants by asking critical questions about their situation are empowered to recognise the potential for transformation and change. According to Macedo (2014, p. 179) conscientization is a commitment to critical reflection and transformative action by marginalised groups with a central educational objective of awakening:

> …..the knowledge, creativity and constant critical reflexive capacities necessary to demystify and understand the power relations responsible for their marginalisation and, through this recognition, begin a process of liberation.

In beginning to best facilitate this process, I decided to consider the PAR group transcripts, not solely as my researcher property, but as objects of critical reflection by the group including myself and the participants in their role as "critical co-investigators", who through dialogue, would support me to reform my reflections in light of their reflection. Following consultation with the participants, the transcripts of group sessions became collective products owned and curated by the group and not data belonging primarily to me; and analytic strategies for determining salient points were developed within the group (McIntyre 2008). Thus, data was simultaneously generated and analysed by the group in a collegiate approach reflecting Freire's (1970, p. 104) process of "conscientization" where awareness was not an end point but rather precipitated simultaneous critical reflection and action through cyclical reflective action spirals to reveal the potential for social transformation (Schugurensky 2014). I was also mindful of Koch and Kralick (2006, p.28) PAR principles to structure group discussions and analysis, namely:

1. Look: building a picture of participants' experiences and understandings.
2. Think: interpreting and evaluating participants' experiences and understandings.
3. Act: formulating solutions to identified issues or identifying future action.

Finally, I was cognisant of Higginbottom's (2015) reminder that the interactive element in any group data is often ignored in favour of focusing on individual speakers. I therefore sought to notice conversations that demonstrated consensus or divergence with individuals changing, modifying or strengthening their viewpoint in conversation and discussion with others.

5.2.2. Stages in the collaborative analysis of the PAR groups in this project

Participants agreed that PAR group discussions would be recorded and transcribed by me following each of the five meetings. During the process of transcription, I annotated first thoughts and preliminary emerging themes that I took back to the participants at the next PAR group for further discussion, analysis, critique, consolidation and validation. Copies of transcripts were also made available to participants. Thus, data analysis and data generation were combined, and analysis was iterative, cumulative and co-constructed through on-going discussion with themes revisited and revised at each PAR group meeting. Each group followed a similar format beginning with time for initial reflection on the previous group. See Text Box 4 for an example of this initial stage.

Polly: It was really interesting listening to the wealth of experience but also people's passion.
Pete: Yes, there just seemed to be a common theme. Everyone talking about how much volunteering meant to them. How it was important to them and how it was really important to give them a sense of purpose and meaning. That was coming across quite clearly to me.
Heather: …and people feeling a real synergy with their own values, with the volunteering that they did. So, that kind of connection with an organisation or a group

that meant something to you as a person…. where you felt you were making a difference…
Polly: And I think about how that would contribute to a sense of mental wellbeing, but also people talking of the alternative impacts being involved in paid work and things where actually there wasn't that connection with values, would be the opposite, and have a negative impact on mental well-being.
Doug: It's interesting that, isn't it.
Julie: Yes it was interesting hearing your experience Doug with moving from one context [to another] …

Text Box 4: Initial reflections: group 2.

Conversations around initial reflections often raised new themes to be explored when participants added to and shared evidence based on their experience. Freire (1970, p.97) calls these "generative themes" which often have cultural and political significance in the context of the participant's lives. He noted that:

> …..the process of searching for the meaningful thematics should include a concern for the links between themes, a concern to pose these themes as problems, and a concern for their historical-cultural context. (Freire 1970, p.108)

An example of a generative theme can be seen in Text Box 5. In this case a darker side to volunteering.

Julie: …there's all kinds of dynamics at play…and even individuals can make or break a volunteering experience. I know of someone who worked in a charity shop and because the paid manageress was not up to doing the job properly, the whole shop was unhappy...the volunteer…had had his own business…so it was glaringly obvious to him what could be done…and he was in no position and wouldn't have been welcomed, if he had offered help…
Doug: He would have been resented there.
Julie: Totally resented. So, there is this other dynamic…there is this darker side and resentment can build so quickly…

Text Box 5: Generative theme following reflective stage: group 2.

Following this initial period of reflection and space for new themes to emerge, I would share the themes I had picked up from listening to the recording of the previous group and during transcription. I depicted this in a concept map with themes and linking statements, sometime drawing on direct quotes from individuals, which I shared with group participants to promote further discussion, critical reflection and analysis (see Text Box 6).

Heather: …it was really interesting listening to the recording from last time…I pulled out what I saw as some of the key themes and…you were just talking there Polly about passion, I don't know if I put passion down, but you are right, passion ought to go in there…This is just my listening to it for the first time but we can all add to it and change it. The thing I was picking up was certainly the values bit we talked a lot about and the ethos of the organisation…
Pete: It's key.

Heather: …and people talked about "we" and "us" rather than "they" in terms of the organisation...Somebody said it was a "family atmosphere" and "being accepted" … People talked a lot about…using your experience to help others have a voice…and that all fitted too with this sense of altruism…and I remember Doug you said "you go the extra mile for people"…also, Amy said "people are depending on you when you are volunteering", that also helps to give you the motivation to get out of bed…and then there was all sorts of things to do with "flexibility" and…we had a big discussion…about paid [work] versus volunteering…I think Pete you said that often volunteering was "tailored to the individual"…so often organisations would say "What is it that you can offer?"…
Doug: They didn't in your example though [turning to Julie] the charity shop where the guy was resented and ignored.
Heather: So that's something that we need to think about too then, the darker side, the negative side of things…

Text Box 6: Bringing themes back for further analysis: group 2.

Through "problem posing" (Freire 1970, p.80) and asking thought provoking questions that encourage participants to ask their own questions, Schor (1993, p.26) suggests, participants "learn to question answers rather than merely to answer questions". This became evident in each of the PAR groups where participants through group discussion became interested in questions such as: "What are the boundaries and the differences around volunteering?"; and "Is it different from paid work or paid workers?" which led to further debate amongst participants that generated further questions such as "Are volunteers treated differently from paid workers?"; and if so, "What is all that about?". In this way, participants became curious about similarities and differences in attitude and experience and sought to demystify power relationships by posing questions to discover for example, how volunteers are treated in different organisations and to what extent they are valued as individuals. Participants reflected on how mental illness was portrayed in the media and were curious about each other's experience of welfare reform. By critically reflecting on these and other pertinent issues participants began to value their own voice; to expose taken for granted thinking including how language is used to distort reality (Macedo 2014); and to extend their understanding of their experience as a volunteer with lived experience of mental illness on a journey of recovery within a particular socio-political context. Indeed, each subsequent PAR group revealed deeper levels of critical analysis, reflection and understanding in line with "conscientization" (Freire 1970, p.104) or critical consciousness raising where participants were totally engaged in critical thinking about their situation. This process enabled them to recognise their position in the world; to demystify the dominant forces impacting on their volunteering experience and expose whose interests are ultimately being served; to consider the potential for transformation; and to imagine an alternative reality (Macedo 2014). Further, this iterative, cumulative and co-constructed process over five group meetings confirmed how critical reflection and action were occurring simultaneously through cyclical reflective action spirals to reveal the potential for social action and transformation (Schugurensky 2014). According to Freire (1970, in Baum et al. 2006, p. 856) "human consciousness brings a reflection on material reality whereby critical reflection is already action". Indeed, as previously stated Freire (1970) recognised that critical reflection and action must take place at the same time in a concept he called praxis where they mutually enlighten each other and where critical consciousness can develop leading to further action (Loewenson et al. 2014). Praxis therefore becomes a process whereby "the individual in transforming the world, is himself or herself transformed" (Macedo 2014, p. 182); and participants cease to view their situation as "a dense, enveloping reality or a blind alley" and instead as a "historical reality susceptible of transformation" (Freire 1970, p. 58 in Baum et al. 2006, p. 856). As new themes emerged and sub-themes developed, I found that my role was to keep us reflecting on and evaluating the emerging picture and to guide us into identifying potential actions for improving socio-political systems and experience. In considering how best to represent themes in order to evaluate them more objectively, the participants decided that words and phrases were more favourable than using visual images such as pictures and photographs. Therefore, words and phrases formed the basis of group discussions and this analysis. Over the five PAR groups, participant agreed themes emerged (see Table 7 below):

Group:	Participants:	Agreed Themes:
1	Miranda Pete Polly Amy Doug Julie	**The benefits of volunteering**: • Synergy with personal values • Passion • Developing confidence and skills • Altruism and making a difference • Feeling valued • Opportunity and Flexibility • Support and Training • Boundaries and differences
2	Archie Pete Polly Doug Julie	**The darker side of volunteering**: • Volunteering and paid work • The volunteer voice • Volunteer: selection, support and training
3	Polly	**Challenges and change:**

	Doug Julie	• Welfare benefits and volunteering • Getting the balance right • Where is there room for change?
4	Miranda Polly Megan	**Where do we go from here? What action is required?** • Age, stage, resilience and negative impact from government pressures. • Where are we going? What will we do?
5	Pete Julie Megan Jess	**Ideas for Action:** • Feasibility without duplication or tokenism • Lobbying MSPs? • Challenges of DWP: "Keep Volunteering Voluntary"

Table 7: Participant agreed group themes.

5.3. Data Analysis Final Themes:

For the final stage of analysis, I considered the themes from the interviews and the PAR groups for similarities and differences. Perhaps unsurprisingly, themes were generally consistent across the two methods of data generation and were therefore merged to form three final themes and associated sub-themes as depicted in Figure 5 below:

Figure 5: Final themes and their associated sub-themes.

In conclusion, the aim of this chapter was to make the data analysis process transparent. The final themes from the data analysis process are presented as findings in Chapters 6-9 and then explored at a more critical level of analysis and interpretation in Chapter 10.

CHAPTER 6: INTRODUCTION TO THE FINDINGS

> …..I found that it’s well, a reason to get out of bed in the morning…without that kind of structure then, this almost sounds like a tautology, but if I don’t have anything to do then I wouldn’t do anything. (Archie, interview)

This chapter introduces the research findings following data analysis described in Chapter 5. It introduces the participants and explores group dynamics through examples of interactions and conversations. The subsequent three chapters 7, 8 and 9 describe one of the three final themes from the combined findings of the thematic analysis of the individual interviews and the participatory analysis of the PAR groups. These themes and associated sub-themes are presented in Figure 5:

Figure 5: Final themes and their associated sub-themes.

In staying close to participants’ voices quotations are presented from individual interviews and PAR group interactions, aiming to provide a nuanced account of each theme. Where direct quotations are offered, personal identifying details have been removed to preserve anonymity. Given that interactive elements are often ignored in favour of focusing on individual speakers (Higginbottom 2015), conversational findings are also included. These reflect consensus or divergence with individuals changing, modifying or strengthening their viewpoint in conversation and discussion with others; and represent the mutual respect, support and camaraderie that became evident amongst participants over the course of the project. The three themes and their sub-themes are not presented in any hierarchical order but are considered to have equal weight and reflect progression from positive representations of volunteering to critical, culminating in reflections on potential action. As such, they mirror both the process of, and progress within this project.

6.1. Participants

This section introduces the participants presenting their volunteering experience, lived experience of mental illness, and participation in terms of attendance. It concludes with consideration of group dynamics.

All participants were given a pseudonym to assure anonymity and comply with research ethics. Participants were also allocated a number denoting the order in which they were recruited from P1 to P10. However, pseudonyms are preferred over numbers to personalise participant contribution and voice. Ten participants agreed to take part in this project. All were adults of working age and under 65 years old. Four were male; six were female; all were of white British ethnicity, predominantly Scottish; and all were living in the same Scottish city. Nine participants took part in individual interviews with the exception of Jess, where timing precluded an interview due to the late stage in her joining the group. All participants were invited to attend the PAR groups from the outset with the exception of Megan and Jess who were recruited at a later stage (Megan at group 4 and Jess at group 5). Nine participants took part over the five PAR groups with the exception of Alexander, who although first to be recruited, was unable to attend any of the group meetings due to other commitments. All participants attended more than one group meeting with the exception of Archie, Amy and Jess who attended one group each. Polly and Julie were the most consistent contributors attending four out of the five group meetings. Table 8 provides an overview of participant involvement.

Participant	Pseudonym:	Interview	Group
P1	Alexander	Yes	No
P2	Miranda	Yes	1, 4
P3	Archie	Yes	2
P4	Pete	Yes	1, 2, 5
P5	Polly	Yes	1, 2, 3, 4
P6	Amy	Yes	1
P7	Doug	Yes	1, 2, 3
P8	Julie	Yes	1, 2, 3, 5
P9	Megan	Yes	4, 5
P10	Jess	No	5

Table 8: Participant involvement.

As per the recruitment criteria, all participants had lived experience of mental illness. Many participants had experienced significant mental illness which had affected their mood, motivation and energy levels, preoccupied their thinking, limited their self-confidence and made social interaction challenging. All participants recognised the fluctuating nature of their mental health. All participants had adopted a range of self-management techniques and personal coping strategies to promote mental wellbeing; and some were continuing to take medically prescribed medication to alleviate the symptoms of their mental illness. Several participants had also experienced significant physical health problems some of which were ongoing.

All participants had significant experience of volunteering and were volunteering at the time of the project. Six participants had been supported in finding their volunteering placement through Volunteer Edinburgh's health and wellbeing team. The remaining four (Archie, Pete, Polly and Julie) had no previous contact with Volunteer Edinburgh. All participants had a history of paid employment and Alexander was currently in employment. For other participants, employment had been curtailed due to health issues (Miranda, Pete, Amy, Megan) or funding cuts and redundancy (Archie, Doug). Archie and Doug were actively looking for paid employment whilst Polly regarded herself as having made a career as "an advocate for advocacy" and had followed this path regardless of whether this was paid work or volunteering. Why participants chose to volunteer will be considered in more detail in Chapter 7. Table 9 summarises participant experience of volunteering and employment. Names of specific volunteering projects have been removed to preserve anonymity. General charity names remain to illustrate volunteering scope and interest. Volunteer Edinburgh projects have been included to demonstrate transparency in relationship.

Volunteering Experience: *current	Employment: *current
Alexander: Horticultural project; homeless charity; project for people in recovery *substance misuse steering committee.	Classics graduate. agrochemist. *teaching recovery skills; *gardening business.
Miranda: WRVS café; Oxfam shop; peer support; (WRAP) trainer; recovery network steering group; 2011 volunteer award; pre-retirement talks; *director mental health charity; *Vol. Ed. ambassador.	NHS laboratory technician.
Archie: *Mental health charity fundraising.	Academic research contract – redundancy.

Pete: *Volunteer advocacy worker; volunteer trainer; *vice-chair on board of directors.	Employed for 20yrs resigned after serious mental illness.
Polly: Supporting people with learning disabilities; older people; teaching makaton; community action; women's mental health; survivor groups; advocacy; mental health charity trustee; recruiting & training for mental health helpline. *Volunteer coordinator for 24/7 helpline.	Mature graduate. Citizens Advice Bureau. Director of mental health organisation. Developed peer & user led support groups and advocacy service.
Amy: Victim Support; welcoming committee; *Oxfam shop.	Registered Nurse.
Doug: Oxfam bookshops; welfare adviser, Citizens Advice and local community welfare adviser volunteer. *Adviser with Vol. Ed. older people's project.	University lecturer; trade unionist; Government employee; welfare adviser until funding withdrawn.
Julie: Community-work; music-club secretary; NCT; church; flower arranging; SWRI; art groups; chair of arts centre; neighbourhood support; choose life support group. *Mental health charity group co-facilitator & *Board of Directors.	Mature graduate arts degree; creative business: design, textiles; teaching.
Megan: Homeless charity; museum LGBT project; CAB; peace & justice centre; TEFL; Vol. Ed: pre-retirement talks/ interviewer/ Spanish drop-in. *Museums accessioning & restoration; *Vol. Ed. Health & Wellbeing Team; *RNIB.	Social science graduate; TEFL: Spain/ Mexico. UK housing; welfare rights training; bar work.
Jess: Mediation; homeless project; collective advocacy; *Vol. Ed. admin.	*Performance poet

Table 9: Participant experience.

Participant experience was rich in diversity. Volunteering pre-dated illness for some participants and there was synergy between employment history, educational background and volunteering choice. For Alexander, it was gardening, for Doug it was citizens and welfare rights, and for Julie it was arts based. Additionally, there was a link between participants' lived experience of mental illness and choosing to volunteer with a mental health charity or through advocacy supporting people living with mental illness. Archie, Julie and Miranda volunteered with local mental health charities. Pete and Polly were involved with advocacy and peer-support projects.

6.2. Dynamics and Conversations

This section highlights evidence of group dynamics in an attempt to demonstrate the lively discussions and conversations that can't always be appreciated through individual quotes. Participants appeared fairly comfortable sharing their perspectives and experiences within a group setting and there were many instances of camaraderie and support through shared experiences, laughter, agreement, and mutual respect. Indeed, participants were generally highly articulate and did not need a lot of encouragement to share their views. Some of the participants knew each other prior to joining the group. Miranda and Julie volunteered together; and Megan, Jess and Miranda were familiar with each other through Volunteer Edinburgh's health and wellbeing team. In the following example, participants reflect light-heartedly on a shared experience of working in a charity shop and the benefits of getting first pickings on the goods donated. What is apparent is the ease and spontaneity of their conversation in the first group:

> **Miranda:** You get the choice as soon as they come in.
> **Doug:** Absolutely…
> **Miranda:** Yeah, I volunteered at Oxfam for a while…
> **Pete:** It's all the best stuff, all the volunteers [get].
> **Miranda:** Mind you, some of the bags we used to open. They're awful really. People putting their old trousers in and shoes and everything.
> **Julie:** And not having washed them.
> **Miranda:** Yeah, that's absolutely true.
> **Doug:** Another thing that surprised me about charity shops is how much theft they have to put up with.
> **Miranda:** Oh, I know.
> **Doug:** This woman was telling me that they don't put expensive items near the door because people will steal them.
> **Miranda:** Yes, that's right and there's no security whatsoever because you've not got the tags.
> **Doug:** I felt naive.
> **Miranda:** Yeah, you would think nobody would do that. Yep**.** (Extract, group1)

Laughter was familiar in the group as was a degree of playfulness, respect for each other's experiences and curiosity. There were many instances of people being genuinely interested in each other's experience by asking questions, complimenting each other and offering practical support through passing on contact details or advice. Here, Julie compliments Doug on his positive attitude:

> **Julie:** How long have you been with [project name]?
> **Doug:** Oh, not long, only since before Christmas. I only just started like, but you get into it like.
> **Julie:** Because you're wonderfully positive. (Extract, group 1)

A common occurrence within the group was when participants, in discussing a shared experience, in this case being a mental health service user, understood immediately the perspective being raised and responded with laughter as a way of validating their shared experience, in this case cynicism regarding mental health service provision:

> **Polly:** Mental health services are supposed to have a more holistic understanding and to acknowledge that mental health and wellbeing relies on a variety of supports being available…things like community care planning…what medical treatment people need for their…mental health condition…also do they have access to housing? Do they have access to income? They are supposed to look at these things and have concerns about people being able to access income and a means to live.
> **All**: Laugh. (Extract, group 2)

Interestingly, quieter members within the group, namely Amy and Archie, despite having a lot to contribute, only attended one group each. Reasons for dropping out were not always known and may have been due to a range of factors including lack of interest, confidence, realising the group did not meet expectations and/or fluctuating mental health. Doug decided to leave during group 3 when he explained that he had contributed all that he could and wished to avoid repetition. At this stage participants agreed that in order to move things on, it would be useful to recruit new members to the group. Thus, Megan and Jess were later additions, Megan joining group 4 and Jess, group 5. At times, one or two participants appeared to dominate, which served to silence others. This was particularly evident in group 4, leading Megan to voice her apprehension about returning, feeling she had nothing much to offer, nor space to offer it in. Overall, there was a sense of commitment to the group task. Whilst there was little divergence in the group, sometimes individuals changed or modified their viewpoint in response to others.

Having introduced the participants and described relevant background information, the following chapters present the findings from the final themes. Chapter 7 presents “Selfish Altruism: Journeys of Recovery Through Volunteering”; Chapter 8, “The Darker Side of Volunteering”; and Chapter 9, “Reflection and Action: Keeping Volunteering Voluntary”. Although themes are presented as distinct from one another for coherence of reporting, they are not mutually exclusive and should be viewed as inter-related.

CHAPTER 7: “SELFISH ALTRUISM”: JOURNEYS OF RECOVERY THROUGH VOLUNTEERING

Figure 6: Theme 1: “Selfish Altruism”: journeys of recovery through volunteering.

This first theme describes the benefits of volunteering as experienced by participants and specifically how volunteering contributes to recovery in promoting positive mental wellbeing. It contains two sub-themes: self-management and recovery; and volunteering identity, belonging and influence (Figure 6). The chapter begins by explaining the title before introducing the benefits of volunteering as reflected through the two sub-themes, which are explored in turn. The title “selfish altruism” came from Pete when he explained how although volunteering offers him an altruistic opportunity to contribute to others, he volunteers for his own benefit:

> …..I find it’s helpful for me to have quite a bit of structure to my day…the less active I am, the more I’ll perhaps ruminate about things and it can have an impact on my mood. So, the volunteering, when people find out what I do they quite frequently say things like “that’s really good that you do that and people must really be thankful that you do that”, and I always say well that’s an element of it but it’s really **selfish altruism**, I do it for me more than anything else. I do it for what I get out of it. The fact that I’ve perhaps helped someone else is good as well but it’s really for my own benefit that’s why I do it. (Pete, interview)

All participants shared Pete’s view, recognising the two-way nature of volunteering that whilst giving to others altruistically they were also receiving significant personal benefit, hence the selfish reference. Indeed, the range of personal benefits experienced by participants were substantial and included having a structure, purpose and a reason to get out of bed; meeting new people and building relationships; gaining confidence and skills; feeling valued and having something to contribute. Significantly, these were viewed as central to keeping well and remaining out of hospital. Some participants recognised an important link with employment, viewing volunteering as a stepping-stone to returning to paid work and that training received through volunteering could aid employability. A positive volunteering experience could also provide the first sense of job satisfaction that had previously been elusive. All participants recognised the importance of giving back to the wider mental health community because of their own mental health experience. Here Archie talks about why he volunteers with a mental health organisation:

> …..I've been a service user you know. I've used their services in the past. I was almost…hoping to give something back as it were…even though I don't…work on the cutting edge…I like to think I'm contributing in some way. (Archie, interview)

This notion of giving back will be explored in the second sub-theme: volunteering identity, belonging and influence.

7.1. SELF-MANAGEMENT and RECOVERY:

This first sub-theme explores how participants initiated the process of volunteering in terms of readiness and finding their place. It presents how participants manage their wellbeing in light of their volunteering experience and fluctuating mental health and the factors that help and hinder recovery. In order to navigate this sub-theme, Figure 7, below depicts a cycle of the key elements that emerged indicating fluidity of topics and progression. Self-management was recognised as crucial to the notion of a recovery journey and therefore the cycle begins and ends with this. Each of these underlying elements is now considered in turn.

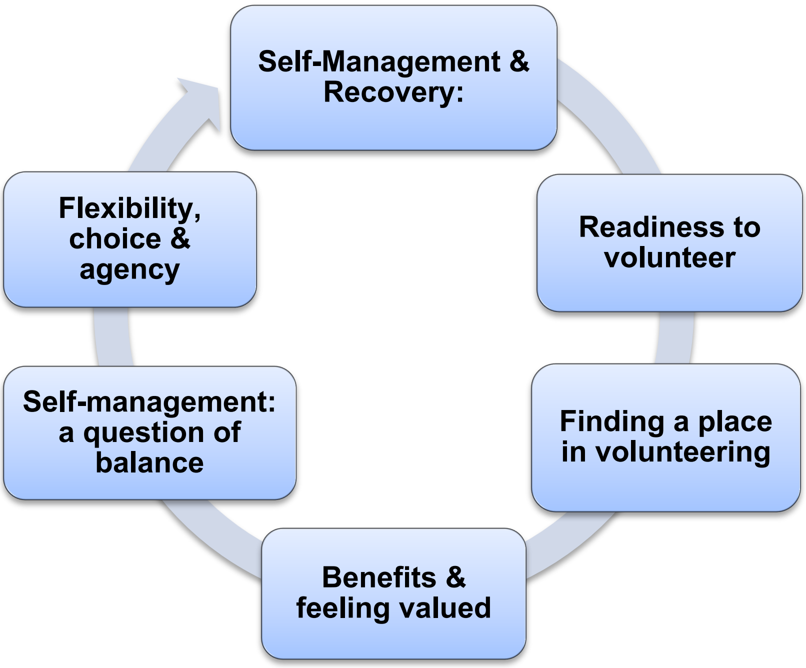

Figure 7: Self-Management and Recovery: contributing elements.

7.1.1. Readiness to Volunteer

All participants shared their experience of what had initially motivated them to volunteer. This was usually prompted by a period of mental illness or “breakdown” as it was more commonly described. Here Megan reveals how she began to volunteer:

> …..I primarily started volunteering when I had quite a bit of a breakdown with depression, so when I was feeling able I started with one voluntary job and it’s been over eleven years now and I’m still volunteering. (Megan, group 5)

Having something to do was viewed as integral to the process of recovery and included having a structure, purpose and a reason to get out of bed as the conversation with Archie at the beginning of chapter 6 revealed. Here, Doug recognises the negative impact on his mental health of having nothing to do.

> …..having all day to yourself is a great thing, but for me it’s not. It’s a dangerous thing. Too much time on my hands is not a good thing for me. (Doug, interview)

Amy too, recognised the importance of volunteering as having something to do.

> ..…I need structure and it offers a structure to your week, you know…you have to get up and out to get there for your shift and whatever. (Amy, interview)

However, it could take time to recover sufficiently to reach the point of feeling confident enough to volunteer. Here, Pete shares a poignant account of his experience of readiness for volunteering following significant mental illness:

> …..I had a real, prolonged, quite serious crisis…I didn’t feel capable of working…and I had to resign from my full time job. It was about 3-4 years really before I began to recover sufficiently to feel capable of being involved in things…I was quite withdrawn, didn’t leave the house very often…and I was quite unstable in terms of health…After I began to recover a little bit, I began to think about, you know, I don’t want to just sit in the house doing nothing for the rest of my life but opportunities are going to be rather limited because I was beginning to come to terms with the fact that I probably wasn’t capable of working…I finally plucked up the courage to go down to the Job Centre Plus to get a benefits application…I became aware of the possibility of volunteering opportunities. I got in touch with the Volunteer Centre…and…I spotted an opportunity for [advocacy project]. So, I made an application…and forgot all about it and about 6 months later, they got in touch with me saying we’re doing a new intake of potential volunteers would you like to come along and find out about what it is that we do? ...I’ve been involved in advocacy ever since. (Pete, interview)

Sometimes readiness was recognised by others who suggested volunteering and provided support to take that first step. For Miranda, it was her CPN (Community Psychiatric Nurse) who introduced her to the idea of volunteering and then Volunteer Edinburgh staff who supported her from there:

> …..I have my own experience of living with bi-polar disorder and I had spent several years being in the wilderness and not doing much really with my life…My health deteriorated…it was really difficult to manage…because when my mood was high I didn't look after myself properly…similarly when I was low, I was in my bed and didn't eat properly or get exercise, so I wasn't in a really good place…I ended up in the [mental health hospital] for 3 months. When I came out I thought, you know, that was about my 6th episode and I feel like it's like a revolving door so I really need to get on top of things and start looking after myself…So…I came along to the Volunteer Centre. My CPN had taken me along. I wasn't really ready at that time but…I did a couple of computer classes and that kind of gave me more confidence. (Miranda, interview)

Interestingly, Megan when volunteering with Volunteer Edinburgh's health and wellbeing team would meet prospective volunteers in order to match them with a suitable volunteering opportunity. Here she describes the issue of readiness and how volunteering suits varying abilities because it can be graded in terms of challenge:

> …..we used to get people who weren't ready and often the people's problems with drug and alcohol abuse and you could just tell…get a sixth sense…You have to be ready for it.. and quite often they would want to work in the area helping people that had addictions and that wasn't a good idea and they couldn't understand why going right back into that isn't good when you're still trying to overcome it yourself…Sometimes there had been poor hygiene and just a kind of dishevelled look…which is also suggesting they weren't quite at the stage yet of coping…You could find something for them because you get baby steps. Start with something that's not too taxing. (Megan, interview)

7.1.2. Finding a place in volunteering

Despite feeling ready to volunteer, participants revealed that finding their place in volunteering was not always straightforward and that often they were in competition with the general public for popular volunteering places. This meant that some volunteer engaging organisations would hold interviews. Following a breakdown with depression, Megan managed to secure a volunteer placement in the museum but believed that she had slipped in "through the backdoor" by already being involved in a project that was jointly curated by the museum. Following this project, she was invited to volunteer on further projects relating to the museum's collection.

> …..and I'm still there (whispers). (Megan, interview)

Megan considered herself very fortunate to be in this position, emphasised in the extract above where she whispers to me perhaps as if in disbelief or worried that by speaking it out aloud might change her fate. Her pleasure in volunteering was evident and it seemed that the variety of tasks she did added to her view that she had found her place:

> …..I still do enjoy it…about 4 weeks ago, I was up at the museum cleaning muskets which was quite good fun. And I was doing some restoration work the other week there just as a change you see, accessioning is what I was taken on to do…they had all these posters. It was like Aids, safe sex…T-shirts from marches, whistles, och, it was just lots of stuff that we want to put in the exhibition. (Megan, interview)

Sometimes first encounters were not always positive. Amy who had had several volunteering experiences was to some extent still looking for her place:

> …..I can't remember how I heard about Victim Support but I went along and had an interview…and they kind of trained you up for the work and that, so I did that for just about a year. And the reason I left was I found that I was being given cases that were far more serious. And I felt out of my depth, you know and I felt it was difficult to say to them that I was having problems and I didn't feel happy with it any more…Many years went by and I decided to have another look at doing volunteering and I went to a school…and I was helping with the activities, and that was OK until the tutors started not to come and they were asking me to take a class and I felt "I can't do that, I'm not qualified to do that" you know? So that didn't last, you know, and I felt a bit disheartened about it all…I felt really frustrated and I was on the bus coming home and I thought you know, dammit I'm just going to get off the bus and the first charity shop I come to, I'm going to go in...and I've been there…well I've just left there, and that's nearly two years I was with them. (Amy, interview)

Amy introduces an interesting theme here about flexibility, choice and getting the balance right between what the volunteer experience entails and what participants feel able to contribute. She adds rather candidly:

> …..sometimes I think, because I've had experiences that haven't worked out in the past, I'm a little but cautious…I don't want to take something on that's going to give me too much responsibility because I can't handle that. I don't handle that well not any more anyway. I used to but not now. (Amy, interview)

In finding a place in volunteering, a number of factors appeared to influence choice of which organisation to volunteer with. A volunteer engaging organisation with an understanding of mental health was crucial in helping people to feel supported and able to be honest about their mental wellbeing including their potentially fluctuating capacity to volunteer. Some participants viewed mental health charities as more understanding than other organisations and this often influenced choice. Here, Archie shares his experience:

> …..I think it does help that because they are a mental health charity they're perhaps a little more understanding than, you know, somewhere else might be…an accepting atmosphere. I think because they have all worked with…people who have experience of mental health issues…they sort of understand about me having a bad day. (Archie, interview)

Several participants specifically valued the positive support they had received from Volunteer Edinburgh's health and wellbeing team at vulnerable times in their lives. Other influencing factors were whether organisations offered training; were familiar to people already; if the experience could provide work experience for future employability; and more importantly if the organisation had synergy with participants' passion and interest. The example provided earlier by Megan about following an interest in working in the museum emphasises the importance of passion as does Doug's conversation with Julie about his love of books in group 1:

> **Julie:** Have you always volunteered through your life or is it a very recent thing?
> **Doug:** Sporadically, I always liked to volunteer in Oxfam bookshops, that kind of thing I've got a wee bit of history or volunteering, aye.
> **Julie:** What was the first thing you ever did - can you remember?
> **Doug:** I think it was the Oxfam bookshop in [city name]. I used to like doing that.
> **Julie:** Was that because you had an interest in books? It was a good fit?
> **Doug:** Aye (laughs). Well, I got to price the secondhand books so I could price them according to my budget.
> **All:** (laugh) (Extract, group 1)

Having made a volunteering connection, all participants agreed that volunteering provided them with a range of positive benefits, which enabled them to take charge of and manage their mental health and wellbeing as part of their recovery.

7.1.3. Benefits of Volunteering and Feeling Valued

In addition to having structure and a reason to get out of bed, participants voiced a substantial range of personal benefits including meeting new people and building social relationships; gaining confidence and having a more positive outlook; developing skills; having something to contribute; and feeling valued. Here, Miranda reveals how social relationships could extend beyond volunteering:

> …..the other volunteers were very supportive and understanding…and so you got to know them and got a bit more confident…and it led onto other things because I got friendly with a couple of volunteers and we would meet up for coffee you known, between volunteering. (Miranda, interview)

For Amy, it seemed to come as a surprise that people would want to keep in touch with her once she had decided to leave:

> …..I mean even today it was very touching, the staff had written a card for me. They had all signed it, left wee messages…and I was very surprised that they put their email addresses on it. And I thought oh my god you know, because normally they don't really keep in touch with people…I was quite taken aback you know, because I thought bloody hell…they've gone and put their names and addresses on, you know…I mean…I didn't expect that whatsoever. (Amy, interview)

Doug, reflects on how volunteering for a project supporting vulnerable older people, leaves him feeling positive and valued:

> …..well it makes you that way because you can't really be negative with someone whose 91 with early dementia and they are desperate to get out. You can't turn your back on someone like that. It's good. People like helping people don't they? It makes you feel good yourself...You cannot deny that at the end of the day if you've done something, you know, you've done something worthwhile for somebody, it makes you feel good. (Doug, group 1)

Here, Pete reflects on how feeling valued through volunteering is in stark contrast to how he was feeling previously:

> …..it gives me a bit of confidence, makes me feel valued and makes me feel that I am worthwhile, that I am contributing something…That was always an issue in the time when I was really quite profoundly ill and I wasn't able to do much. It does play on your mind, you know, I'm wasting my time, I'm a waste of space, I'm not contributing anything, I'm not worthwhile, I don't…you know, nobody values me for anything. Whereas with the volunteering…if I work with someone and they have a successful outcome, more often than not they'll turn round and personally thank me. That's enormously gratifying and that makes me feel valued and worthwhile. (Pete, interview)

Similarly, Miranda shares her experience of feeling valued through volunteering:

> …..since I joined the health and wellbeing team I've felt so much better about myself and feel included…And I think that does make a difference if you feel a big part of it you know…You feel like you are contributing but you feel valued and that without you, the big machine wouldn't go or it would be a lot more difficult to run. (Miranda, group 1)

Indeed, feeling valued was a central theme and participants remarked on how they were often thanked for their volunteering contribution which seemed to contrast markedly with people's experience of being in employment. As Doug explains:

> **Doug:** If you are a volunteer you can walk away at any time and I suppose they have to sort of molly-coddle you - "well done - thanks for today".
> **All:** (everyone laughs).
> **Doug:** That was what I was always told at the end of the day "Thanks for today Doug". When taken on as a paid employee, you never got "thanks for today". (Extract, group 2)

Interestingly, some participants contrasted positive volunteering experiences with not feeling valued in paid employment. Here, Pete poignantly reflects on his experience:

> …..I spent em, five years in a job where I felt I wasn't valued…and you know there's a part of my personality that I believe if I'm going to do something I do it 100% to the best of my ability and part of what contributed to my mental health crisis was, as well as the illness, the fact that I felt I was…undermined constantly and it really de-values your sense of wellbeing, your sense of self-worth…you begin to doubt whether you are actually capable of the things you thought you were capable of…you begin to question yourself in a really fundamental way…So going back and doing the volunteering…it reinforces to you…you are capable of doing this and it gives you that confidence back. (Pete, interview)

According to participants, many volunteer engaging organisations offered training as a two-way investment with availability of training impacting on high volunteer retention. Some participants saw volunteering as a stepping-stone to employment with training aiding employability. Here, Alexander describes how volunteering helped him gradually get back to employment:

> …..I think it's a great way of starting back into life. To get you to achieve working conditions, without huge pressures being on you…I mean working and making a living, there is a pressure to it. Still, it eases you into it. (Alexander, interview)

Similarly, Doug viewed volunteering as good preparation for employment:

> …..I started off as a volunteer with the CAB and found that I was very good at it to the point where they offered me a full-time post…being a volunteer got me the job...I've had a bad time recently and I'm on employment support allowance…I don't feel ready to go back into a full time job. I've got to admit that to myself…so I have to again start myself off with some voluntary work…to ease myself back into it again… (Doug, interview)

Doug's account above highlights that returning to employment is not always straightforward and that vulnerability to recurring mental illness is persistent and unpredictable. Archie reflects on the benefits of doing something, which although below his skill level, is less stressful than his previous employment:

> …..I don't think the work I'm doing is particularly essential. I mean, well I guess it's necessary to do it but I guess it's not necessary for me to do it…It may sound a bit arrogant but I don't think I'm necessarily you know, putting my experience to the best use it can be. But in a sense, it's nice to be…just going in and you know, just do stuff with spreadsheets, which is fine (laughs). In a sense it's nice…not to have to think too much (laughs). (Archie, interview)

Interestingly, positive volunteering experiences helped participants gain new perspectives on employment and specifically the concept of job satisfaction, which may previously have been elusive. Job satisfaction was also linked to positive mental wellbeing as Pete's reflections below highlight:

> …..and it made me realise that…I never really understood what it was that would be important for me in a career, what would drive me, motivate me…and through the volunteering I've realised that this concept of job satisfaction is actually a thing…So now I realise that if I was to go back into full time work, it would have to be in something I had a passion for…I never had any experience being motivated other than…a means to pay my bills. That doesn't really do anything for your psyche…if you're doing that long term…it is likely to have a grinding effect on your mental wellbeing. (Pete, interview)

Finally, the benefits to participants of volunteering were also remarked upon by family and loved ones. Volunteering appeared to normalise family life roles and expectations and strengthened self-image in a family context. Alexander, who kept himself busy being self-employed as well as volunteering in his spare time reflected on his wife's relief about him keeping occupied. The implication being that if he is busy then he is no longer drinking. Here, Amy, speaks touchingly about how her relationship with her daughter has improved since she started volunteering:

> …..if you look at it from your family's point of view, if you're out doing something and you come back you have something to talk about…My daughter would get frustrated with me because I was in the house all the time…She would be like "why don't you go out? Why don't you do this?"…I felt initially quite pressurised into doing something voluntarily…and I think in a very strange kind of way it's helped our relationship because I am going out and I am working and I am coming home and we can talk about what happened today and things like that... (Amy, interview)

This normalising of family life roles is reinforced further when Amy continues more humorously about her relationship with her daughter:

> …..there was one day she wanted me to go with her somewhere…and I said I can't I'm working in Oxfam and she said "Oh for God's sake" you know, (laughing) "I was the one who was determined for you to get the job and now I can't even get any time with you because you're working". I said, well it's your own fault (laughing). (Amy, interview)

In concluding the benefits of volunteering, participants whilst recognising that volunteering could be a less pressurised way towards personal growth and recovery also recognised that this was a matter of careful balance and one that required them to become experts in their own recovery journey. This is considered next.

7.1.4. Self-Management: A Question of Balance

Self-management was viewed as a personal matter that was integral to participants balancing not only their volunteering experience and their mental health and wellbeing in light of their potentially fluctuating mental health condition but also balancing all of the other aspects of their lives. There was no doubt that living with a long-term mental health condition was challenging and although self-management was viewed as crucial to maintaining health, there was recognition that mental illness was not always within one's personal control. Miranda was an advocate for self-management to the extent that she undergone training in the WRAP (Wellness Recovery Action Plan) and had become herself a trainer. Here she discusses unpredictable life stresses and how she manages her mental health, the importance of "wellness tools" and learning to say no:

> **…..**obviously I have dips and I've lost a few friends…to suicide, which is really difficult…so all these things that come up…like maybe being called in by the DWP…something like that is really difficult…I am really good at managing now and yes, I may have a blip but I can get back on track a lot easier. Because I've had so many episodes and so many life changing events…you do sort of get stronger…I have…a daily maintenance plan,

> which I strive to stick to…The main thing is that I'm up before 9 to take my medication…and then have a healthy breakfast and from then on I usually have something planned to go to early on so that it gets me out the house…I have my shower or whatever and walk my dog because that's important to me…If I'd stayed in my bed, everything would have gone off…I have a lot of wellness tools…I have a box and I'll have tickets from concerts. I'll have nice photographs. I've got a couple of DVDs that make me laugh…I have to look after myself and if that means having to say, "no sorry I can't do that". I could never do that before…But I do realise from experience that I need to keep my mental health and wellbeing stable and to do that I sometimes have to say no to people, and it works. (Miranda, interview)

A number of factors appeared to facilitate recovery through volunteering including supportive and understanding staff, fellow volunteers and volunteer engaging organisations; participants knowing themselves and being able to be honest with themselves and/or others about what was the right balance for them; and participants learning to prioritise and make decisions about the level and/or amount of a volunteering commitment to take on. Miranda adds:

> …..I had to prioritise in the past with the volunteering…it made me feel so good that I just [did] too much basically, and burned myself out…one organisation, I wasn't getting enough support…and it all went haywire and spiraled down. (Miranda, group 1)

Participants agreed that a lack of support, distrust of services and stress related to volunteering and finding work hindered their mental wellbeing. Amy recognised that the support of other volunteers had been invaluable in helping her deal with a difficult relationship with the manager of the charity shop where she volunteered. Despite this, she felt she could no longer continue. Here she explains how knowing what feels right is an embodied experience that has helped her become better at protecting her mental wellbeing:

> …..I can feel it in my bones…that it's time to move on…yes, I think it's just… knowing yourself really and when enough is enough…I think it could be detrimental to your wellbeing, to your health, your mental health if you stayed on when you felt like that…I've got to protect myself…and I feel that I'm not comfortable with this anymore… (Amy, interview)

Whilst findings in this chapter have highlighted a number of individual benefits of volunteering, all participants agreed that one of the precursors to effective self-management was having flexibility, choice and the means, or agency to make decisions about how best to balance volunteering responsibilities and fluctuating mental health. This will now be considered.

7.1.5. Flexibility, Choice and Agency:

All participants valued the ability to have choice and flexibility over their volunteering experience in order to balance engaging in meaningful occupation with staying mentally well and out of hospital; and having the means, or agency, to make informed decisions on their own terms. Having agency enabled participants to choose which organisations to volunteer with, how many hours to volunteer and to decide when they were ready for employment. Having agency also enabled participants to flexibly manage their commitment to volunteering in light of their fluctuating mental health. This usually occurred in one of two ways: either participants recognised that their volunteering commitment was becoming too stressful and that in order to maintain their mental wellbeing they should opt out; or participants recognised a dip in their mental health necessitating temporarily cutting back. However, this was to some extent also dependent on a degree of flexibility and understanding on the part of the volunteer engaging organisation. Pete, who was very involved in supporting other volunteers with lived experience of mental illness, shares his belief that volunteer engagers have a responsibility to recognise and understand that volunteers may not always be able to fulfil their volunteering role in light of fluctuating mental health and vulnerability and it is incumbent on them to accept this and make contingencies:

> …..we welcome people who have a lived experience or a diagnosis or an ongoing lifelong mental health condition provided they are well enough and they believe they are well enough. But we make it quite clear to them that at some point in the future if you feel that things are impairing your mental state or you feel unwell for whatever reason, there is every opportunity to say to us "I need to take a step back from this for a while, but at some point, when I feel ready I'd like to come back to it". And we do that. I myself have taken breaks from volunteering when I've not felt that I was in a place where I was able to give it everything it deserves. (Pete, group 2)

Having flexibility, choice and agency was also about participants' ability to make decisions about their readiness for employment using personal knowledge to evaluate their own health condition. As Polly states:

> …..I do have a long term mental health condition and…being able to commit within a work role, there's a requirement to be there…that hasn't always been possible for me... (Polly, interview)

Pete emphasises the importance of volunteering with a supportive organisation:

> …..it's been 10 years since I've worked full time and being honest I still don't think that at this moment in time I would be able to go back to a full time working environment. My mental health is such that I still have significant periods where I just wouldn't be capable…The fortunate thing about volunteering is the organisation understands…and they are quite accepting of that…If I don't feel that I'm able to put myself at their disposal, I can pick up the telephone and I'm confident in doing that because there's an understanding there…I wouldn't have that relationship with an employer…You can't just phone up out of the blue and say "I don't feel well, I don't know when I'm going to feel better, I'll be in touch". So, the thing about volunteering is I can do it on my terms…the fact it's a no pressure environment that's very helpful for me… (Pete, interview)

Volunteering appeared to have several advantages over paid work in that participants felt more in control of their weekly commitment and more able to be honest about their fluctuating mental health. Pete reflects on the benefits of honesty:

> …..in the past I've never felt able to do that with an employer…and that in itself actually, can help contribute to you being unwell because you feel guilty. You're self-stigmatising about the fact that you are unwell, and it probably prolongs it. It's a viscous circle. Whereas with the organisation I volunteer at, I can be honest with them and…they don't value me any less because of the fact that I sometimes am not capable of volunteering. So, it's good that I don't have that cycle of worry and self-stigmatisation and regret and then guilt. (Pete, interview)

The second key sub-theme builds on this idea of agency to consider how volunteering with lived experience of mental illness provides a sense of identity, belonging and potential to influence (Figure 8 below).

7.2. VOLUNTEERING IDENTITY, BELONGING and INFLUENCE

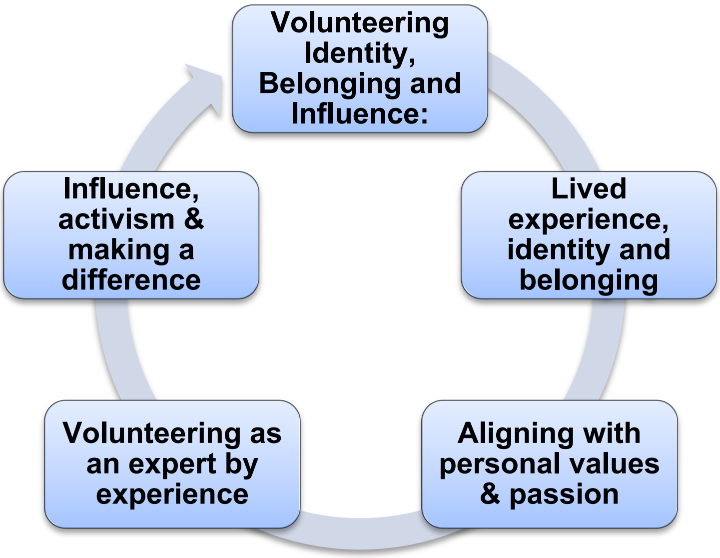

Figure 8: Volunteering Identity, Belonging and Influence: contributing elements

This sub-theme outlines how for many participants, volunteering was more than having something meaningful to do to aid recovery. Indeed, participants recognised volunteering as contributing to a strong sense of identity as a person with lived experience of mental illness, valuing that experience and reinforcing a sense of belonging specifically to the lived experience and volunteering community. Volunteering therefore facilitates community connectedness along with status as an expert by experience, enabling opportunities for influence and activism through advocacy and peer support. Examples are now explored.

7.2.1. Lived Experience, Identity and Belonging

Although lived experience of mental illness presented a number of challenges, it was also viewed positively. Many participants recognised lived experience of mental illness as a strong part of their identity giving them specific skills and knowledge and a sense of belonging to a wider lived experience community, which was useful in a volunteering capacity. Pete explains:

> …..when I first started looking at volunteering opportunities…my lived experience, was something that might actually be useful…I begun looking at opportunities in volunteering that actually related in some way, shape or form to mental health…I have more than a passing interest in mental health…I feel very strongly that if I was going to start to develop a career again, that that's possibly a field I would want to work in. (Pete, interview)

Polly explains how volunteering has contributed to her sense of identity and belonging to a wider community advocating for the rights of vulnerable people. Volunteering for her began from an early age as a means to manage her difficult early life circumstances and prevent her from becoming isolated. She explains below how volunteering has enabled her to make sense of her early experiences and how it has contributed to her identifying with and passionately advocating for women's issues and mental health charities:

> .....I think it [volunteering] has always been quite a big part of how I reconnected with things…I've always been involved in mental health charities, advocacy and…I've also had a strong interest in women's issues...I became sort of quite involved in survivor groups both in terms of mental health survivor groups and sexual abuse survivor groups and got involved in…training social workers about talking to children about abuse and informing practice at a professional level. As a young teenager when I was in hospital my experiences were really quite horrific…things were very different in those days, and I got involved in the mental patient's union and speaking out about the psychiatric system and I'm still really quite involved in that now

> and I think…it's been a big part of how I've been able to manage some of the trauma that I experienced as a young girl…having a sense of belonging to a wider community which is addressing issues for vulnerable people and trying to change systems for the better. (Polly, interview)

Indeed, participants recognised that utilising their lived experience of mental illness through volunteering enabled them to engage in meaningful work that they felt passionate about and gave them a strong sense of job satisfaction. Miranda states:

> …..I got onto recovery focused workshops, really enjoyed it…got a lot of confidence and started feeling better about myself and got training to co-facilitate the workshops. Did more recovery focused training…did peer support training…so yeah, using my own experience of mental health difficulties to help others to volunteer…I find that really rewarding…It wouldn't have been the path that I would have chosen but actually my life is much richer because of it. Yeah, I'm passionate about recovery and have found volunteering a huge part of that. (Miranda, group 1)

Noticeably, many participants used the language of "we" and "us" when referring to their volunteer organisation, denoting a commitment and sense of belonging to that organisation and endorsing its ethos and values. In addition, specific types of volunteering gave some participants a positive sense of identity. Miranda was inspired seeing older volunteers through her affiliation with the WRVS despite the age gap and stereotyped image:

> …..so I was really one of the blue rinse brigade…and I don't think there was anyone else under 70. They put me to shame. There was this old lady 92, and she would be volunteering…which was amazing. (Miranda, group 1)

Furthermore, sharing values with fellow volunteers led Miranda to feel she belonged to a wider volunteering community:

> …..you get something different from every opportunity…and in my experience all the volunteers I've met have been really nice because you've got the values you want to share…you know, help other people, so it's been a lifesaver for me really. (Miranda, group 1)

Through discussion with Doug, it became apparent that his social class and background enabled him to identify with the lives of the people he wanted to help:

> …..the thing that motivated me was…I come fae a housing estate sort of thing. I liked working in the Citizens Advice Bureau [in affluent city location] but I was fed up with people coming in asking me to help them with their self-employed accounts sort of thing and stuff like that. I wanted to work with people that really needed help. (Doug, interview)

7.2.2. Aligning with Personal Values and Passion

All participants identified with feeling passionate about volunteering, viewing their volunteering as meaningful when aligned to personal values and interests. Additional factors were that the volunteering commitment was achievable and within their control; provided opportunities for growth and development; and compared more favourably than experiences of paid employment. Volunteering for specific organisations for people with lived experience of mental illness matched personal values of social justice and social inclusion. Here Polly reinforces the importance of aligning with personal values:

> …..whilst I feel still quite vulnerable, in terms of my mental health and how things impact on that, I feel being involved with other groups and volunteering and being part of organisations that are doing things that I believe in, is an important part of keeping well. (Polly, interview)

Indeed, participants required an investment in the values of their volunteering organisation for their commitment to feel worthwhile:

> **…..**I have to believe in what the organisation is about and what it's doing. (Pete, group 1)

> …..you mostly end up volunteering for organisations that have got an ethos or an ethic that you are inclined to be attracted to like advocacy or Citizens' Advice Bureau, or an advice shop or charity, or Oxfam, something that's got some sort of ethos of helping people or helping animals. (Doug, group 1)

However, participants also acknowledged that not all volunteer roles are linked to specific values and that this depends on the volunteer, the organisation and the type of volunteering that people engage with.

7.2.3. Volunteering as an Expert by Experience

> …..as a voluntary advocacy worker…my skill set's expanded into something I never actually foresaw at the time. So, in a way it's become, this sounds horribly corporate, but the volunteering in a way has almost become a career. (Pete, interview)

Many participants recognised finding a new purpose through volunteering, specifically drawing on lived experience of mental illness to support others with lived experience through advocacy, peer support and training. Participants were often involved in educating professional groups, contributing to the development of organisational and government policy and volunteer management through committees and Boards of Trustees. For example, Miranda drew on her experience to support others going through an organ transplant, as she herself had done previously, being on the transplant list and recognising the link between kidney failure and depression. Several participants channelled their passion and values into advocacy, making a difference to the lives of marginalised people and as such viewed volunteering with lived experience of mental illness as a type of career. However, participants also recognised the importance of remaining neutral while in an advocacy role. Pete and Polly discuss this here and noteworthy is Pete's use of "we" throughout to refer to his advocacy role and organisation:

> **Pete:** We don't work in terms of best interest, we work in terms of user interest so I've invariably found myself sitting there trying to bite my tongue because I've worked with someone who is making a decision that personally I wouldn't take but that's not for me to judge or to step in or to convince them otherwise…
> **Polly:** I did used to be involved in advocacy…in the early 80s… and I became really passionate about advocacy…but also very clear that you are there to stand alongside the person and to put forward their views and not your views. But I suppose my experience of mental health services, both personally and through being involved in supporting other people…I actually began to get much stronger views about services and also about the amount of harm that mainstream services can do and so…advocacy isn't something I can do anymore…because my own views about it are actually too strong…So I am sort of like past my sell by date (all laugh)…I still think that advocacy is really important…but I recognise that I'm not in a place anymore where I can actually do that. (Extract, group 2)

What is interesting about Polly's reflection here is her recognition of having moved beyond the role of advocacy to one involving influence, change and activism. This is explored next in the final section of this theme.

7.2.4. Influence, Activism and Making a Difference:

Volunteering can harness a passion for influencing, activism and making a difference. Some participants described using their lived experience of mental illness to stir things up and challenge the system, influencing service provision for marginalised groups and educating, training and supporting future volunteers and peer support workers. Polly encapsulates this, explaining how her mental health difficulties led to volunteering and becoming an advocate for advocacy, pioneering projects that have positively influenced vulnerable people's lives:

> …..my mental health issues started when I was a child…I didn't really go to high school so I started volunteering…as a classroom assistant…for children with severe learning difficulties…and I sort of got involved in various other volunteering. One of the things that I became really passionate about was advocacy and I was actually involved in volunteering and training as a citizen's advocate in the first ever advocacy project in the UK…I became an advocate for a woman who was being resettled from one of the long stay hospitals, and I was part of a group of really passionate advocates who were…pioneers because this was the first time there had been advocacy in the UK and I sort of became a bit of an advocate for advocacy. (Polly, interview)

Interestingly, Polly describes volunteering as offering more flexibility in challenging boundaries than can be achieved through paid work:

> …..I think that paid work is just the reality of having to pay the rent (laughs)…whereas within volunteering roles, the flexibility…to be able to actually do things you couldn't really do within a paid role. For instance…it's quite empowering…getting funding for things that are more controversial…campaigning or challenging the mainstream…that's not things that the Lottery or, you know, the NHS are going to commission…If, you know, you've got an idea to do something which is going to make a difference and change things…[being] able to actually sort of challenge the system a wee bit more at times…being able to influence, em you know, organisations…Some of the things I have done as a volunteer I feel much more proud of…rather than within [paid] work. (Polly, interview)

Polly provides an example below of a successful project:

> …..one of the new projects that I set up and got funding for was an information line about mental health…The aim of the project was to provide opportunities for people who were recovering from mental health issues to become involved in the organisation and deliver our services and to volunteer and to gain confidence and skills and experience. And we very soon had quite a large group of volunteers…and then…the volunteer group…identified a gap. There weren't enough support groups especially peer-led or user-led support groups and so various support groups got set up and facilitated which became really successful. (Polly, interview)

In summary, this chapter has presented the first theme: selfish altruism: journeys of recovery through volunteering, describing the benefits of volunteering for participants and how it has contributed positively to their recovery. It has revealed how participants manage their fluctuating mental health in light of their volunteering experience and how volunteering contributes to a strengthened sense of identity by valuing lived experience of mental illness and reinforcing a sense of belonging to the lived experience and volunteering community. In this context, volunteering offers status and opportunities as an expert by experience for influence and activism in extending the boundaries of what can be done in paid work through new initiatives, advocacy and peer support. The next chapter presents the second theme: the darker side of volunteering.

CHAPTER 8: THE DARKER SIDE OF VOLUNTEERING

Figure 9: Theme 2: The Darker Side of Volunteering.

> …..so there is this other dynamic, we all looked I think at the positive last time but there is this darker side. (Julie, group 2)

This second theme, the darker side of volunteering (Figure 9) came from discussion that volunteering as well as providing a range of benefits also had a darker side. This theme describes the challenges of volunteering as experienced by the participants at an individual level within specific volunteering placements and in systems that support or hinder people with lived experience of mental illness to volunteer. It considers the wider political context and the impact of welfare reform on the volunteer experience. The two sub-themes: challenging contexts; and contradictions and Kafkaesque experiences are outlined in turn.

8.1. CHALLENGING CONTEXTS

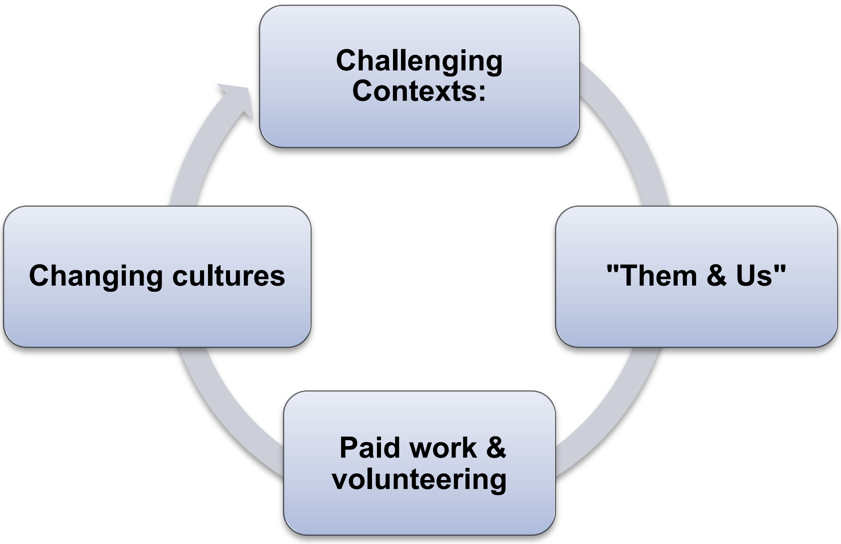

Figure 10: Challenging Contexts: contributing elements.

In contrast to the benefits reported earlier, participants recognised a number of volunteering tensions impacting on their mental health and wellbeing as a result of challenging contexts. These are highlighted in Figure 10 and include tensions of "them and us" between volunteers, volunteer engaging organisations and/or paid staff; confusion of similarities between paid work and volunteering; and perceptions of change in voluntary sector culture.

8.1.1. "Them and Us"

Tensions and challenges in volunteering were perceived as having a direct impact on participants' wellbeing and included lack of support and training opportunities; tensions in relationships between individual volunteers and staff in the organisation; as well as tensions surrounding expectations of the volunteer's role. This led to "them and us" situations with participants feeling undervalued or uncomfortable. Here, Doug explains how a lack of support from his manager impacted on the volunteers in the service:

> …..I don't think any of us got enough support (laughs)…it wasn't just me who would have been better at managing, we all would have been…All he had to do was delegate it to one of us to make sure there was enough volunteer cover but he would never do it…so it just never got done. It was a stressful job. It could have been made less stressful by making sure there were available volunteers to man the reception for instance, to answer the phones etc. (Doug, interview)

Despite organisations heavily relying on volunteers and investing in training and support, misunderstandings in expectations and a negative culture led to volunteers feeling undervalued:

> …..sometimes it is like the "them and us" sort of thing. They are happy for you to do stuff but there's stuff that you can't get involved with…I see that there has to be with some things but sometimes you just don't feel part of it…My friend was… a peer support [volunteer] and they had her making the beds. (Miranda, group1)

> …..there wasn't anything to do…and I wanted to have company and I wanted to do something to make me feel good…[the manager] said if you wanted to you could get the hoover out…and I thought hmm if I felt like hoovering…I would be doing it at home. (Megan, interview)

> …..there was a culture…I think they probably thought the volunteers where just there as skivvies and you know, the professionals, there was a bit of a them and us. (Alexander, interview)

8.1.2. Paid Work and Volunteering

> …..there's a lack of understanding about what volunteering is…work and volunteering are not synonymous. (Pete, group 5)

There was some confusion surrounding differences and similarities between volunteering and paid work. Unsurprisingly, a major drawback to volunteering was that it was not paid. Often participants used the terms “working” and “volunteering” synonymously, indicating that volunteering was similar to working, despite being unpaid. Viewing volunteering as a stepping-stone to employment where the work element was central to both reinforced this position. Participants also raised concerns that volunteering was replacing paid work opportunities. Interestingly, some participants had experienced volunteering and being employed to do the same job and whilst the roles were the same, the psychological pressure felt different. Here, Doug reflects on the similarities and differences in doing the same job as a volunteer and in an employed capacity. He uses the word “same” throughout emphasising his point:

> …..I was a volunteer before and then I was a paid employee and…it’s the same job although one is voluntary unpaid and the other one is paid. It’s exactly the same job. You're still advising on the same things you're still filling in the same forms, you're still phoning up the same power companies for people sort of thing, but I found that the two experiences, even though it was exactly the same work, were eh, psychologically different…I found myself…under a hell of a lot more pressure as a paid employee…I can only assume it’s because your status is different…I was quite pleased to become a paid employee because I felt, well people thought well of you, they want to pay you for it. They want you to stay sort of thing. But…I immediately felt pressure. (Doug, interview)

Although the tasks were identical, Doug appeared to feel more pressure having the status of an employee, recognising changing expectations:

> …..I think when you're a volunteer you're sort of applauded for volunteering to do certain things…but once you're paid it’s more or less expected…it was a good wage…but I didn’t enjoy it half as much...I felt far more pressured…Being a volunteer…if things get too much you can walk away from it, whereas if you're a paid employee, you canny do that. (Doug, interview)

Doug raised the difference between being paid and volunteering several times:

> **Doug:** I think it’s because volunteers in a strange way are more valued because the organisation relies on them as free labour but also free expertise, free experience, but as you become paid staff…it’s like becoming part of something different…You tend to get more respect as a volunteer in some ways than you did as paid staff. You would think it would work the other way round…
> **Pete:** Do you think any aspect of that is down to the fact that as a volunteer

> you quite often have a bit of leeway and choice about how to do things whereas as a paid employee you don't?
> **Doug:** …it's quite a change of emphasis, aye…it's not as if you would just ethically walk away because you are a volunteer because things got a bit tough or something like that, but leeway's a good word for it…But when you're paid staff that is your job. You're going to have to get on with it. For someone who's suffered from stress in the past, it was more stressful being paid staff than it was being a volunteer. (Extract, group 1)

This led Pete and Polly to reflect from a service user perspective, on the different perceptions of a paid versus volunteer advocacy worker:

> **Pete:** One of the things that is quite significant is the service user's view. They know the volunteers are just…peers whereas the salaried officer is a company man, if you like, and quite frequently people will view someone who is salaried as…saying what they think the organisation would want them to say. Whereas with the volunteer there is no ulterior motive. And quite often you get more of a trusting relationship with the service user than you will with a salaried officer…The service users recognise the fact that the volunteers are there of their own free will and don't have any other interest or agenda…
> **Polly:** …advocates that are paid and are working in the hospital full time…they have to have more interaction with the…nursing staff and the psychiatrist and sometimes it is really quite difficult for them…to be seen as totally independent…People who are using the service…are more likely to see them as part of the system that is detaining them or giving them treatment they don't want. (Extract, group 1)

Volunteers sometimes experienced the same pressures as paid staff and believed there was little distinction in expectations. There was also concern that volunteers may be replacing funded posts when funding was cut due to austerity measures. Doug explains that when funding ended for his paid adviser post, he was asked to continue in a voluntary capacity as a way of replacing his previously funded post. Although the organisation was under pressure Doug decided not to volunteer due to the level of stress the role entailed

> …..I'm not going back to volunteer there, not after having been a paid employee there because it's a very stressful job, especially somebody with difficulties that I've got. Sometimes things become overpowering for me. I don't want to go back into welfare rights or benefits or things like that…these days it's very, very hostile and…confrontational. (Doug, interview)

In relation to paid work, some participants recognised that they were perhaps more employable by virtue of having a mental health label and protected by equal opportunities legislation:

> .....having a diagnosis fundamentally changes your rights in terms of employment…If I choose to state my disability at various points through the application process, I am protected by law in a way that I am not if I don't disclose it...I suspect that I am now far more employable as a result of having a label. (Pete, group 2)

8.1.3. Changing Cultures

Participants recognised the changing context of health and social care delivery brought about by austerity measures and neoliberalism with reorganisation involving significant funding cuts to services and competitive markets. Participants were vocal about the changing role of the voluntary sector with charities competing to be commissioned by the NHS and Local Authority to deliver health and social care services in line with service-led agreements. This was viewed as a significant shift from the autonomy of an independent sector to becoming a commissioned service. In addition, participants recognised that charities had been forced to adopt business models in order to survive in times of austerity. With a vested interest in the voluntary sector, Polly reflects on these changes, repeating the word suddenly to reinforce the suddenness of change:

> …..I've seen such a big change in the way that the voluntary sector works and operates…One of the big changes I saw…was in the 1990s, when the move to community care included the idea that services were going to be commissioned from the third sector and a lot of services which were traditionally provided through…social services and NHS…like support services and day services and supporting people at home…suddenly, that was opened up for voluntary organisations. Suddenly, in order to survive they had to really change. Suddenly, they were working to service level agreements…as commissioned services…and it did really change emphasis and impact…It was very clear that charities were there because they were working for people who were experiencing mental ill health…and that was what drove their work…Charities now have a much more business model and they have to…plan a business strategy, but also their…clients, are now their commissioners…When I'm working within the voluntary sector I often feel the roles I'm working in are linked in and tied to services that have been commissioned and we're meeting the targets which have been set by the NHS or local authority…rather than our focus being our service users driving our work…In the old days you were…really able to challenge things that were happening in the local authority, and do things, because you weren't actually being funded by them. (Polly, interview)

Rather than viewing this shift as disappointing, Polly shares how she is responding:

> …..it is still a sector which is very ripe and quite clever…There's a lot of new organisations based around social enterprise and other ways of working…but I've also found that a lot of my volunteering now is outside the

> more formal charitable sector and more within community groups or groups which are sort of involved in supporting people outside of that formal commissioned servicing. (Polly, interview)

Interestingly, Polly has chosen to position herself outside formal voluntary sector commissioned services which reinforces having agency and fits with the growth in independent advocacy services and the rise in community groups driven by the user movement, to empower user voices. Amy also recognises charities as business orientated through volunteering in a charity shop:

> …..I guess they're there to make money…It's a bit like a business really you know. They're trying to make targets…it's a hostile environment…everything's speeded up. Everything's fast and has to be done quickly. (Amy, interview)

To some extent Amy's view was that these target driven pressures were the same for everyone and that there was no distinction between paid staff and volunteers as discussed earlier. Doug, highlights the contradictions some charities face in relation to funding when their service goal is empowerment, but their funding is reliant on people being to some extent dependent:

> …..people talk about empowerment and it's important to get people to be able do these things for themselves…but because you're a charity and because you depend on funding, you don't want people to do if for themselves (laughs) It's contradictory…Community development it's a double-edged coin really...you canny say oh we've got a lot less clients. That would mean you're successful, but you'd be out of business. (Doug, interview)

Unsurprisingly, participants recognised that austerity was affecting NHS mental health service provision and that services were less available including crisis services:

> …..I think the NHS can't cope with the number of people with mental health problems…They're overwhelmed and they totally don't have time to deal with depression. I was sent away... (Megan, group 4)

Finally, in recognition of changing contexts participants shared different perceptions of what constituted volunteering. These ranged from notions of "fancy volunteering" to caring for a loved one, to just "helping out." Participants recognised that stereotyped views of volunteering persisted despite the range of volunteering opportunities. Alexander defined volunteering broadly and included people with caring responsibilities. He recognised a degree of privilege in his freedom to choose his volunteering and walk away:

> …..there's wives looking after their husbands, or husbands looking after wives…The person's probably exhausted with it. That's why I'm saying it's a fancy volunteering that I do. None of this nuts and bolts day, in day out. (Alexander, interview)

For Julie, volunteering was just helping out. Whilst for Polly, Pete, Miranda and Jess, volunteering was strongly associated with advocacy and was defined as such. For Polly volunteering had a strong association with activism. Also, as mentioned previously participants sometimes used the terms working and volunteering synonymously. Despite changing contexts, it seemed that stereotyped attitudes to volunteering continued:

> …..I think in general, the wider public perception of volunteering is still a bit off base. When you say to people I volunteer, quite often they jump to the conclusion that you must be standing in a charity shop somewhere. (Pete, interview)

In terms of types of people who volunteer and where, Doug believed that social class, age and professional background were significant. Here, he reflects that retired professionals are unlikely to volunteer in deprived urban areas:

> …..If you work for the Citizens Advice Bureau as a volunteer, it's highly likely that you've been previously a professional…in their 60s maybe they've been like solicitors or something. They're far more qualified than you anyway and they're only doing it like a morning or two mornings a week. You wouldnay get people who worked as volunteers in the Citizens Advice Bureau in [an affluent area] volunteering in [a deprived area] (laughs). They wouldnay touch it with a bargepole like, because you're talking about real, you know, front-line stuff like, you know, heavy-duty drug-users and people with you know, cuts all over themselves because self-harming seems to be a big thing at the moment. It's terrible. They [volunteers in deprived areas] tended to be more local people. They didn't live in big houses or anything like that. (Doug, interview)

From experience, Doug reflects with descriptive clarity and insight on the harrowing challenges of volunteering in a deprived urban locality:

> …..you get these idealistic sort of notions…and then two and a half years later you come out a frazzled mess (laughs)…The guy that I took over from when he was leaving, he'd been there 5 years, I asked him how would you sum it up? And he said "harrowing"...That's the word he used and it is because you're dealing with very damaged people and very cunning people

> as well, because damaged people can be very cunning. They know how to use the system. They know how to get you to help them. There's certain faces that you see coming towards the door which made you wish there was a back door, which there wasn't…Because you know for the next two, three hours life is going to be a nightmare because this person is just tantrum happy and she wants the Scottish welfare fund community care grant for a new…and some of them use some very child-like methods like tantrums and cutting themselves…just making a general nuisance of themselves. The tactic being that you would do anything to get rid of them. It is harrowing, aye. (Doug, interview)

The challenges and changes in this first sub-theme were in addition to significant challenges to recovery faced by participants from government welfare reform and stigma which will now be considered.

8.2. CONTRADICTIONS and KAFKAESQUE EXPERIENCES

This sub-theme outlines the contradictions surrounding volunteering with lived experience of mental illness, specifically negative experiences of welfare reform and benefits sanctions; challenges around "fitness for work"; and a sense of falling through the gaps as a result of stigma and self-stigma fuelled by media attention of being an out-of-work benefits claimant living with mental illness (see Figure 11):

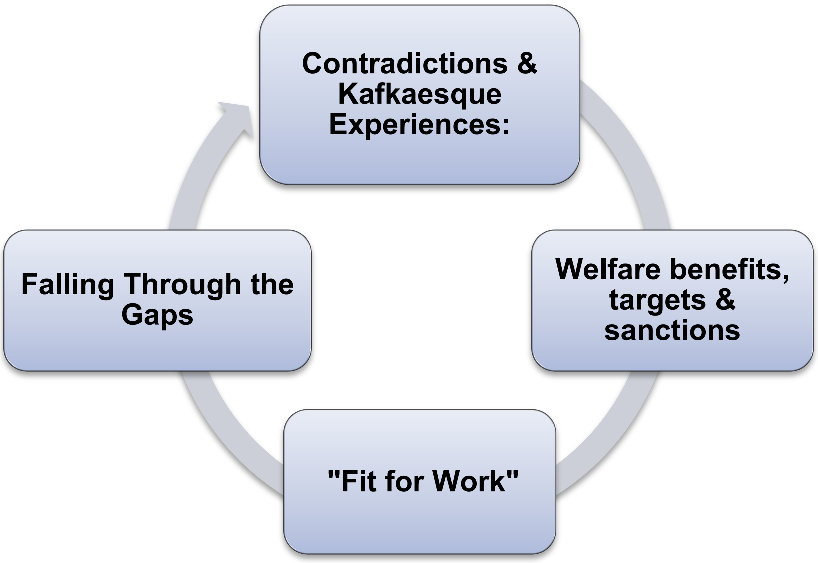

Figure 11: Contradictions and Kafkaesque Experiences: contributing elements.

The Kafkaesque in the title arose during supervision whilst reflecting on the themes emerging from group 4.

> …..it is like a mouse on a wheel. If you stop volunteering, you lose your benefits. There is no flexibility. You could lose everything. There are targets to meet. It's the stuff of madness. Kafkaesque. A punitive game. A loss of

> control. Working hard and doing what you enjoy, and someone can change it to meet their targets. (Extract from reflexive journal)

Indeed, several examples from participant experiences appeared contradictory and were reminiscent of a Kafkaesque situation, revealing the qualities of a nightmarish, absurd and oppressive world resonant with Franz Kafka's fiction. This was represented by national and political drivers impacting on individual volunteering experiences, and related to government reforms, employment targets and negative media representations of welfare claimants, which directly challenged participants' mental wellbeing and recovery. These findings were compelling.

8.2.1. Welfare Benefits, Targets and Sanctions

> …..part of the problem about volunteering now is that people are perpetually being assessed by the benefits system. (Polly, group 1)

Participants raised significant concern about the welfare benefits system and how this was at odds with a recovery culture and was undermining their health and wellbeing. Participants found the benefit system confusing and ever changing, feeling at times misinformed and subjected to perpetual assessment and form filling that was stressful. They commented on the arbitrary nature of how people are categorised and reported a lack of trust and cynicism with the welfare benefits system. In addition, they recognised that any form filling tended to focus on their deficits rather than assets, which contrasted with the philosophy of self-management, recovery and resilience. Here, Megan and Polly discuss their distrust of the welfare benefit system and the impact on volunteering:

> **Polly:** I mean it's just…really different now in terms of the hoops that people have to jump through to get their benefits.
> **Megan:** It's almost like they have trick questions as well and if you answer one thing and if they don't like it then that's it. It's jeopardized. They pull the plug on you.
> **Polly:** I think it is having a really negative impact on various aspects of volunteering…and I think there is misinformation and people aren't clear. (Extract, group 4)

Indeed, there was agreement amongst participants that the benefit system was confusing regarding what benefits they should be receiving and whether they were in the JSA (Job Seekers Allowance) category and expected to seek work, or in the ESA (Employment Support Allowance) group and deemed currently unable to work due to their mental health. Pete explains:

> …..and because I didn't know any better…I walked in and I said I need to make an application for benefits because I'm out of work and they put me through the JSA process and it was only after I'd been involved in that for about 2-3 months that when they asked me why I hadn't done anything to find work, I confessed that it was because I didn't believe I was capable of work…and they put me into the ESA process. (Pete, interview)

Here, Doug outlines the different categories of benefit:

> …..employment support allowance has two elements. One is work related activity groups…and the other…is a support group…You get a work capability assessment and there's three outcomes, either to declare you fit for work and you have to go and claim job seekers allowance, or if they declare that you have got a disability but it's not severe then you're supposed to be in the work related activity group because then you can take part in a little bit of work related activity for the future. If you're on the support group then you're deemed to be a threat to yourself or others, which is either physical threat or to do with your mental health. They're the severe group. (Doug, group 3)

There was agreement that being subject to constant assessment and form filling was stressful particularly when this focused on what participants were incapable of doing rather than their strengths and assets.

> …..it's a very precarious position getting your benefits right and then there's all these re- assessments…and you don't want anything to jeopardise it. (Doug, interview)

> …..that process made me so ill and every time it came up for renewal I would get ill again. Having to fill in forms and gather all the evidence, and you have to focus on the negative…it's also the way that the forms themselves are often designed to give a yes/no computer friendly answer, on/ off, black/white… (Julie, group 3)

> **Polly:** In terms of assessments…people have to disclose some really difficult [information]…you know, they struggle to cope but in order to be able to carry on they just have to keep persuading myself I can cope…I can do this.
> **Doug:** But that's not the way to get the benefit though…Many clients like that who had that personal pride element who said: I can't cope very well but I find ways of overcoming it somehow, they didn't get it [the welfare benefit]…Tell yourself but don't tell the DWP…The system forces you to exaggerate your condition in order to get what it is you need. (Extract, group 3)

Participants were concerned that the welfare system put volunteering and their mental health at risk. They explained that the benefit system viewed volunteering as a work preparation activity that claimants were required to undertake to prove they were actively preparing for work. This disregarded the volunteering they were currently doing, regardless of whether this benefitted their wellbeing, in favour of volunteering that might lead to paid work. In this way, volunteering had become mandatory and people were unable to choose the volunteering they engaged in. As Polly explains:

> .....part of the problem about volunteering now is that people are…required to take on various activities towards getting ready to work in the future. But quite often…they get allocated fairly arbitrarily to one of the work programme providers, and they'll be required to do training & learning activities & maybe volunteering, which is…allocated to them...So, somebody who may already be volunteering, they might be told "no you can't do that anymore, we're expecting you to go and work in this charity shop"…The reason for that is that if somebody gets a bit of experience in retail, they are more likely to get a job working in a shop or a supermarket than they would providing advocacy or advice to somebody. But it means that somebody who's trained up to do something they're passionate about, are able to feel that they are contributing something useful that gives self-esteem because they are using their knowledge & skills to help other people suddenly being told…"you just need to go and work in the shop & sort out old clothes in the back room", or something that they have no passion for. (Polly, group 1)

> …..it's not actually volunteering is it? If you're being made to do something, you're not volunteering to do it. (Miranda, group 4)

Participants viewed the DWP's railroad approach as intent on meeting targets to get people into work regardless of any detrimental effects on the person's mental health and wellbeing. Current welfare benefit systems were reported to remove choice, purpose and meaning in volunteering; to prevent flexibility in the number of hours volunteered as a person's mental health allowed; and ultimately to disregard the fluctuating nature of mental health thus disempowering participants who have worked hard to build expertise in knowing what works to keep them well. Although participants showed a degree of cynicism and distrust of the welfare system, they were also aware that many decisions about what benefits they should receive were somewhat arbitrary and depended on quotas and targets. Benefit sanctions were a real concern as voiced by participants below:

> …..it's in this economic climate…that they are actively looking to sanction people with any excuse that they can find. (Doug, interview)

> …..they are always trying to trip people up…to catch you out just to be able to suspend people from their benefits. (Megan, group 4)

> …..they've got quotas and they've got targets…if you sign on later in the week you're more likely to be sanctioned because they're trying to meet the targets. (Doug, group 3)

Polly reflects on the claimant's commitment:

> …..you're expected to do so much each week…you have to apply for so many jobs, you have to do so many job searches…you can do things…like…gaining skills, preparation for work, getting experience. So you can say, I've got an opportunity to do volunteering…one day a week, and you can put that forward to go into your claimant's commitment…There is then a problem with that, because once it's in your claimant's commitment, if you're not able to do it one week, then you can end up losing your benefits. (Polly, group 4)

Benefit sanctions placed people in major financial difficulty as Doug explains below:

> …..if it's your first offence you might lose two weeks…four weeks job seekers allowance…You can be ineligible for benefits for three years…Sanctions have been going on since 2010 but they've been badly reported. They've gone under the radar and it has shoved a lot of people into difficult positions. (Doug, group 3)

Further, the poor reputation of the welfare benefit assessors adds to Doug and Julie's distrust of the system:

> **Doug:** But the work capability assessment is key. You know, when ATOS were doing it, but they gave it up but now it's…
> **Julie:** CAPITA?
> **Doug**: Maximus…this American company who have been done for fraud in the States.
> **Julie:** Yes, they're not allowed to practice.
> **Doug:** So they've taken it over…and there's been whistleblowers and people on the TV that have admitted that ATOS and now Maximus do have targets and quotas…when I was a welfare adviser, that's the growth industry. Housing associations are employing welfare advisers…because their clients are getting into difficulty with their benefits. (Extract, group 3)

8.2.2. "Fit for Work"

Being assessed and re-assessed for fitness to work was a six-monthly process and according to participants depended on which benefit they received and was at the whim of the Job Centre. Participants were alarmed and cynical about this process:

> …..so many people now, even with quite serious health conditions…have been [categorised] fit for work. (Polly, group 4)

> …..your legs are supposed to grow back in that time if you've lost them. (Julie, group 3)

Participants reported anxiety that their own mental health would suffer when the pressure to find work became too much ultimately leading to a crisis situation with loss of benefits and potential self-harm. Indeed, substantial gains from volunteering could be undermined by anxiety about work. The participants stated that it was short-sighted of the government as there was a significant cost associated with servicing mental health crisis and managing people's deteriorating mental health. Moreover, there was concern that the DWP had a perception that if you are able to volunteer then you are fit for work. Doug explains:

> …..I went for a job interview and even though I wanted it, I was terrified of getting it because for me I get very stressed, very preoccupied with it… and things become bigger than they are…Someone in [my] situation can offer the community good voluntary work but stresses and becomes ill if they have to go into a paid environment…I miss the money. I miss my colleagues and there are some aspects of the [paid] job I miss but I don't miss the sort of bleak anxiety over it. I ended up on beta-blockers to try and defeat it, to try and get through…I don't miss…wakening up in the middle of the night thinking about cases. (Doug, group 3)

Participants shared their anxiety about the impact on their mental health of the pressure to take up paid work or face benefit sanctions:

> …..I've just been invited to apply for a post and it was very flattering to be invited and you'll laugh because it's seven hours a week for twelve weeks, and I realised I couldn't cope with that pressure. (Julie, group 3)

> …..at the Crisis Centre we've often had people who have ended up taking overdoses because they've lost their benefit. (Polly, group 4)

> …..it's so blind of the government, you know, it's counterproductive. So it's probably going to cost them more money to look after people who are in crisis and need to go into hospital…(Miranda, group 4)

> …..I know cases where they've…said they were fit for work when they were dying of cancer. (Megan, group 4)

> …..if you mention that you do X hours of volunteering, there's no scope for expansion. There's no scope to explain that the volunteering keeps you well enough to continue volunteering and that you can always opt out of it [unlike in a paid job]. (Pete, group 5)

Participants also discussed whether the job market was viable:

> **Doug:** …there isn't really a viable job market out there…they say things like there's a million private sector jobs, but you'd have to analyse what the validity of those jobs are like, zero-hour contracts, part-time jobs.
> **Julie:** I was just going to say that…part-time and you're supposed to work a

> certain number of hours now to qualify for benefits in work, and you could be told that you're not working hard enough, you need to go and get another job…
> **Doug:** All it's done is give employers an excuse to pay low wages…because they know that the tax credits will top it up. (Extract, group 3)

Participants recognised that requiring people to work for 30 hours to retain their benefits, was a form of cheap labour, resulting in less jobs being available:

> …..if organisations can get people to come and work for 30 hours and they don't have to pay them…it's actually going to reduce the number of jobs because they're saying oh well we can ask the Job Centre to send along six people to do this work. (Polly, group 4)

Further, participants raised concern that people may be prevented from volunteering who could benefit, due to worries about being viewed as fit for work and then subjected to benefit sanctions by the government.

> …..some people are worried about taking on voluntary work because they worry about it being seen as an indication that they are fit for work and they'll lose their benefit…doing voluntary work one or two days a week…people are going to think you know, I'll be assessed as being capable for work, and I think that's really affecting people's ability to volunteer or their aspirations to volunteer. There are so many people with long term mental health issues who are…really worried about…being forced to…find work because they have experience of knowing that that is actually going to lead to a deterioration in their mental health because the pressure will be too much. (Polly, group 4)
>
> .....it worries me…that people are loathe to do voluntary work because they think that that might affect their benefits. You know, it's a constant…ironic sort of thing…Voluntary work could be a device to get you back into the idea of work, but it could also show that you are capable of work which…can be off putting for folk which is a real shame because it would really benefit people, excuse the pun…if they could do a bit of voluntary work. (Doug, interview)

It is interesting to note how Doug uses the term "device" which can be used for both good and bad, depending on who is using it. Doug recognises this as a particular problem since volunteering has become so important for him. He adds:

> …..if you could get the DWP to say categorically we will not penalise people for volunteering, that would be a great thing and that would maybe get people saying I want to volunteer then. I want to be able to do something. But if that's keeping them back at all, it's awful. (Doug, interview)

Stigma and discrimination were important themes that arose through discussion and these will be discussed in the final section.

8.2.3. Falling Through the Gaps

> …..of course there's supposed to be no discrimination but we all know in the real world that it operates all the time. (Julie, group 3)

Finally, participants were concerned with issues of stigma and discrimination and specifically, that the effects of current welfare systems and the reporting of these in the media contributed to the polarisation of people with lived experience of mental illness into stereotypes of either benefit scroungers or violent, psychotic individuals. Somewhere in the middle was as Julie (group 3) explains: "the mess that is ordinary living for most of us" and a sense of falling through the gaps. Participants explained this using the terms "fakey" and "stabby" and illustrated this with props (Image 3):

> **Doug:** If you took a poll and gave everybody a truth drug in this country, an awful lot of people would say that they think a lot of people are pretending to be mentally ill…just to get money.
> **Polly:** So this idea that people with mental illness are…fakey and there is nothing wrong with them really and they are just scroungers and they don't want to work and they just want benefits or, they are stabby because they go around stabbing people…If you've got a mental health diagnosis you fit into one of these categories. (Extract, group 2)

Image 3: The "fakey", the "stabby" and falling through the gaps.

> **Polly:** So there's two ends of…negative stereotypes…either you can have your difficulties completely disregarded or you can be affected at the other end and you are a dangerous person.
> **Julie:** That's a really good point because you've got your (laughs) flakey, shakey, fakey ones there [points to one bowl of biscuits] and you've got your stabby ones there [points to the opposite bowl] and in-between you've got all these permutations, haven't you? [balances a tray between each bowl of biscuits].
> **Heather:** …all the dots…it's all the people?
> **Julie:** Yes, and there's so many more [people] in-between those two [bowls]…

> **Polly:** And they have nothing to do with that [points to the fakey end] and nothing to do with that [points to the stabby end].
> **Julie:** And everything to do with the mess that is ordinary living for most of us [points to the tray in the middle]. (Extract, group 3)

Interestingly participants recognised that the majority of people like themselves were falling through the gap between two polarised positions and to get what you need you had to fit into one or other stereotype:

> **Doug**: Where I worked before, I could identify them. They normally admit to it. It's part of being a cheeky-chappie, Jack the Lad, and they would be the ones that would insist that you represent them to get the higher component… But…the trouble is that one size doesnay fit all…people have to go through appeals, tribunals, and reconsiderations and all the bureaucratic processes are trying to turn over what was an unfair decision. Those are the ones that are more robust and able to do it [points to the fakey, Jack the Lad category] and those are the people who often haven't got the mental or physical robustness or energy [the majority in the middle]…So they'll [Jack the lads] win their appeal. They'll go for it.
> **Julie:** Think of that as a sieve now [the tray] and all the people [in the middle] are falling through the gaps.
> **Doug:** That's what's been happening...
> **Polly:** …I think these people here [pointing to the severe "stabby" end] they do get…access to a lot of support and services and they do need it as well. But it's also the fact that…people here [the middle] are worried about being seen [as fakey or stabby], or that some of that rubs off on them.
> **Julie:** …it's the middle ground which needs the help and most of all it's the ones who have fallen through.
> **Polly:** Yeah. There's also some of these people, actually have very severe mental health distress...But because they are not a risk to others they are less likely to get the help they need…In order to get what you need, somehow you need to tick one of these stereotypes. (Extract, group 3)

Polly continues this theme of discrimination and stereotypes:

> …..there used to be a lot of, especially in the tabloid media,…really negative stuff about people with mental health issues and it used to be all about…we were dangerous and we went around stabbing people or setting things alight…But now it's moved over to all these people with…non-existent disabilities, people who claim to be depressed or anxious…it's all about actually not wanting to get out and do a job…if you're not dangerous…you're just trying to get out of work or trying to get something out the system. (Polly, group 4)

Participants recognised that people could fall through the gaps following stressful benefit appeals and tribunals, which could lead to people becoming unwell:

> **Doug:** The worst thing I ever saw at a Tribunal was when there was three males. There was the doctor, the DWP and another professional. There was

> a male representative, there was a male observer sitting behind the client, who was this female who was shaking. She had terrible drug dependency problems. She was completely surrounded by men.
> **Julie:** In suits.
> **Doug**: For it to be set aside just because the very fact that the environment she was in was making her [worse]. But then again, the way the system works is that you go for an assessment…and the worst state you're in the more likely you are to get the benefit…Oh I've seen some Oscar winning performances, I felt like standing up and applauding after some of them but eh, the genuine ones are people who are really, it's difficult to actually get them to that stage of a Tribunal because it's making their condition much worse. (Extract, group 3)

According to participants, discrimination against people living with mental illness featured within the government; media portrayals of people on benefits; public perceptions of mental illness being less deserving than physical impairment; from prospective employers; and even amongst mental health professionals and GPs. There was also a concern that people who had experienced mental health problems themselves could be less sympathetic. The following quotes encompass some of these views:

> …..it's very clever how it's done, because it's brought about a…benefit bashing agenda. Benefits by the sea. All this kind of stuff. (Julie, group 3)

> …..there was a clip on the news last night of a para-olympion who has just had lifesaving surgery and he's trying to fight his way back upright and the praise that was being heaped on him for his struggle to get well in order to be able to compete. But you would never see or hear that applied to someone with a mental health condition. Oh look at them aren't they doing well, isn't it fantastic! You never see that. (Julie, group 3)

> …..you're not supposed to by law, be further disabled by your employer not putting things in place to allow you to do the job…[but] when it asks on the application form do you consider yourself to have a disability? I'm tempted to tick no just to get through that thing, but I shouldn't have to…it's just…you don't think you'll get it otherwise. (Doug, group 3)

Pete describes witnessing discrimination in his advocacy role from mental health professionals who did not know about his lived experience of mental illness:

> …..when the service user has been perhaps not particularly paying attention or has been out the room, I've been given a knowing nod or a wink by the professionals that they are saying it's quite clear that this person is not well. And I sit there thinking, do you realise that I actually qualify as a service user myself, you know and it's not a case of us and them. (Pete, group 2)

Polly recounts her concerns that even GPs whose role is to support vulnerable people, are capable of discrimination. This seems to exemplify the theme of contradictions and Kafkaesque experiences:

> …..my last role…was supporting people…when their benefits were stopped or sanctioned…We were trying to…make it easier for people to access medical evidence…One of the things that GPs were doing was actually charging people…up to £100 for…evidence for a PIP application. We got this letter back emphasising how busy the GPs were and how much time this takes when…[GPs] need to work with people who are actually ill…So within that, they are saying the reverse of what they are saying. People who are…coming to [GPs] for [mental health] things, are not actually ill…People are faced with those sorts of attitudes from their family doctor. (Polly, group 2)

Additionally, participants had witnessed discrimination towards people with mental health problems in emergency triage:

> …..that's one of the reasons why I volunteer with Choose Life...people with personality disorder who might be self-harming…and they're thrown out quite often, "no don't waste our time, you did this to yourself now go away". (Julie, group 2)

Pete reminds us that advocacy exists because stigma exists and that there continues to be a lack of understanding of the needs of people living with mental illness:

> …..stigma…doesn't come out of nastiness and vindictiveness. It's a form of assumptions made about people because of a mental health condition…more often than not…it's ignorance…rather than nastiness. (Pete, group 2)

Another type of stigma was self-stigmatisation, characterised by self-depreciation and self-doubt:

> …I'm self-stigmatised. I've thought, oh I'm not capable of doing that, or as soon as they find out about such and such they are just going to say "I'm not interested"…I would imagine that that is as much a bar to people being involved in volunteering as any form of third party stigmatisation… (Pete, group 2)

> …quite often it is as a result of having years and years and years of people…putting you down or saying "oh no you couldn't do that"…you actually take it on board… (Polly, group 2)

> …..yes, you kind of stigmatise yourself…You're judged by that label… and then you start feeling that yourself…When I'm not being great then I think I can't do this because I have bi-polar…whereas when I'm well and I'm in

> control, it’s a different matter altogether. (Miranda, group 4)

In a later group Polly reveals how her life was beset with messages from others that she would mess things up to the extent that she began to believe it. In the following excerpt, she poignantly explains how she spent her early years in an “asylum”, which especially shocks Miranda:

> **Polly:** It made me reflect back…of not being allowed to do certain tasks because I was going to mess it up…and so that became sort of ingrained…I sort of got excluded from school when I was about 12. I managed primary school just about and then secondary school it was all a bit… “you’re not really bright enough to be in school so perhaps you need to go to a special school”…So I ended up just going into the asylum instead.
> **Miranda**: Woah.
> **Polly:** So that had a really big impact…about 10 years later I ended up going to University but then…because I had it in my head that I had learning difficulties and I wasn't as bright as anybody else…when it came to taking the first lot of exams I just completely panicked and thought I won’t be able to do these…it was so ingrained that I couldn’t do things. (Extract, group 4)

Another important discussion was around whether diagnostic labels are ever useful and how as a result of the Mad Pride movement, people are claiming their labels and identifying with them in a more positive way. As Polly explains:

> …..I have a few reservations about the whole medical model of…mental illness, so that the labels that the system gave to me…I find them very stigmatising…But in terms of using the term “mad”…the Mad Pride movement was based on people taking labels that in the past were seen as quite derogatory…A lot of people with experience of mental health issues are now actually grabbing a label that they are now feeling more comfortable with and saying there are aspects of me to do with my experiences…that I feel this is part of me, but it doesn’t make me a lesser person. So, I see it [“mad”] as a much more positive label than some of the labels that the doctor gave me. (Polly, group 2)

However, there was recognition that a mental health label provided access to services:

> **Polly:** …some people in a way feel that if you get the label, it’s an access to services and support and benefits whereas if you are outside of that…
> **Doug:** I had a client…he was almost overjoyed that he had been told that he was schizophrenic because it moved him on to another level and the first thing he said was “I can get the higher component now”. It’s not that he's a scrounger or any of these things that the Tories will call him. It’s an economic reality. (Extract, group 2)

Finally, for Megan and Pete a diagnostic label helped to make sense of their experience:

> …..when you get a diagnosis…you finally think, oh so that's why. (Megan, group 4)

> …..the label can be very empowering for an individual simply because you can put things in context. I went for years being dysfunctional and not really being able to explain to people why I maybe couldn't participate in certain things. Why I disappointed or let people down. Why my behaviour was quite odd and I couldn't explain it to them...But now with a diagnosis, I can say to people, this is what happens to me. If you want to know a bit more, you can read about this. I can explain it to you, and it gives me the means to think now I know what is going on. I can think about the means to address it and I can think about what I need to do to stay well…But when you don't have that context…I felt that I was just drifting in a sea, fighting against a tide. (Pete, group 2)

In summary, this chapter has presented the second theme: The Darker side of Volunteering, describing the tensions and challenges of volunteering as experienced by participants at both an individual and systems level. It has considered the wider political context including the impact of changes in the voluntary sector and the influence from welfare reform on the volunteer experience. It has outlined the contradictions and challenges of volunteering with lived experience of mental illness highlighting challenges of benefit sanctions, fitness for work, and stigma and discrimination. The next chapter presents the final theme, Reflection and Action: Keeping Volunteering Voluntary.

CHAPTER 9: REFLECTION AND ACTION: “KEEPING VOLUNTEERING VOLUNTARY”

Figure 12: Theme 3: Reflection and Action: Keeping Volunteering Voluntary.

This chapter explores the final theme, Reflection and Action: Keeping Volunteering Voluntary (Figure 12). It begins by considering reflection and action before investigating findings from the first sub-theme: room for change: ambition, agreement and influence. This sub-theme considers the challenge of initiating ideas about action during the participatory process and includes what action was considered, the extent of agreement and what influenced decision-making. This is followed by the second sub-theme: putting the “action” into participatory action research, which describes what was finally agreed by participants during group 5. Lastly, the notion of Keeping Volunteering Voluntary, which was raised in the previous chapter, is revisited in relation to the impetus for action, thus completing the cycle of this theme. The scope of this theme is depicted in Figure 13 below.

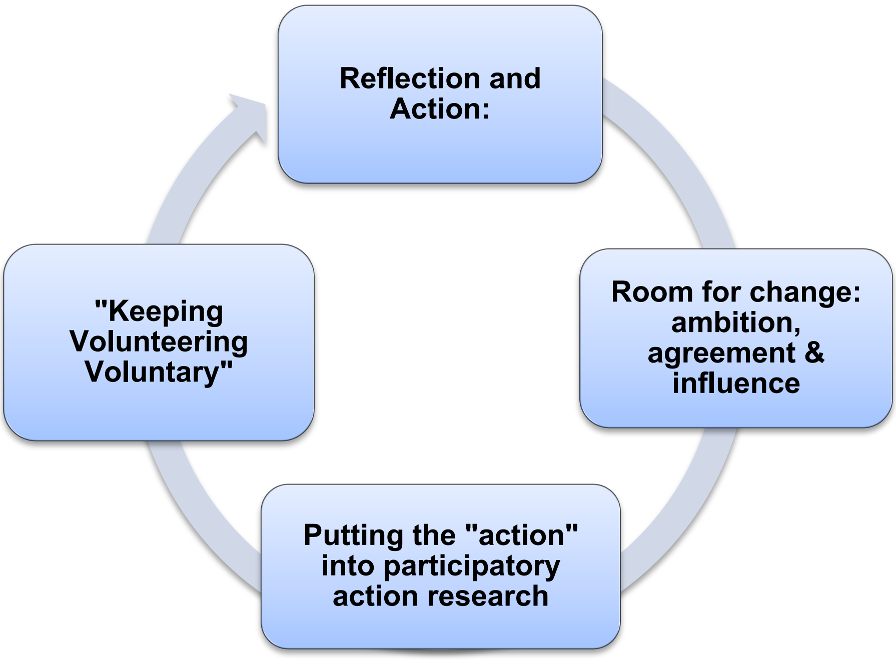

Figure 13: Reflection and Action: Keeping Volunteering Voluntary and contributing elements

9.1. Reflection and Action

Action as an outcome was raised with participants, and by participants, as an expectation from the outset of this project and featured in the recruitment material as well as in individual interview and PAR group discussion. Participants understood the project intention of producing something that would be of value to participants, and/ or the wider volunteering community. Listening to each other's views and experiences and reflecting on these as emerging themes, was central to achieving an idea of what that action might be. Suggestions for action came later in the process and discussions on action and outputs became more focussed in groups 4 and 5. However, the idea of contributing in some way to change was apparent as early as group 2 with Polly and Julie reflecting on the opportunity to change things for the better:

> **Polly:** …the idea of a project to look at how we can support positive developments…in terms of practice guidance or ideas about how things could change for the better…the idea of us identifying things which don't always work well are…a good sort of baseline of things where there is room for improvement or you know, change.
> **Julie:** I think it is very helpful to look at things that don't work because out of discomfort comes progress in my experience. Usually…it can energise you when you realise something is not right and if you…know how to direct it so that you can move it forward…then I think that is an empowering thing. What isn't is when you feel trapped or ground down or don't have the energy, mental, emotional, physical to do anything about it and you are just in the situation or observing a situation. You can either be active or passive…Is it generalist to say that if people are volunteering then perhaps they are more on the proactive side of life…Would we be more likely to say "oh this isn't working quite so well…could we make this better so that we can get better results or something?...Instead of just saying "oh God"…and moan. (Extract, Group 2)

However, some of the discussions around action were akin to stumbling around in the dark:

> **Polly:** …it would be good to get some sort of inkling as to what exactly it is that we are here to do.
> **All:** laugh. (Extract, Group 2)

This feeling appeared to persist and indeed, discussion on action was sometimes avoided because it felt overwhelming and difficult to achieve any consensus. In considering the potential for action, the participants began to think about where there might be room for change.

9.2. Room for change: ambition, agreement and influence

Familiar question throughout group discussions were “what will we do?”; “where are we going?”; “have we made a plan?”. Indeed, I found that I was constantly thinking about action, reflecting on what was being raised by participants and trying to strike a balance between being facilitative and not taking over:

> **Heather:** Do you think we could start thinking about that next week… identifying gaps or things that could be done differently or better…if we had a magic wand what might we want to change in relation to volunteering? (Extract, group 2)

Although a few ideas were proposed, there was no consensus around these and this contributed to a sense of indecision in the group:

> …..I think this is always…hanging over us…Where are we going from here? And what might we be achieving together in this project? (Heather, group 4)

And later in the same group,

> **Heather:** We’ve got just over 15 minutes left [laughs]. What are we going to do? I mean, what do we want to do as a group?...Because we talked last time about maybe doing a briefing paper? But what are your views?
> **Megan:** I don’t know what you want. What are you aiming for?
> **Heather:** Whatever you would like [laughs]. (Extract, group 4)

The above extract highlights an issue around ownership and who is leading whom. It seemed that participants wanted me to tell them what to do, which I consciously resisted, trusting that we would eventually reach some consensus through the participatory process. Producing a briefing paper was proposed by Polly as an opportunity to document how welfare reform was putting volunteering at risk. This was a key theme in the group and Polly saw a briefing paper as an important lobbying tool and was familiar with this in line with her political and activist background. Discussion focused on how best to lobby given that the main benefits, namely Employment Support Allowance and Job Seekers Allowance came under the control of Westminster. There was knowledge of devolved powers to the Scottish Government in reviewing social security disability benefits and the group recognised an opportunity to share their experience:

> **Heather:** So just bringing us back to this idea of the briefing paper, are you thinking…that something that we might want to do is to put some kind of paper together that we could share with?
> **Polly:** Yeah. MSPs…it could be the Cross-Party Groups and there’s one,

> there's a Mental Health Cross Party Group. There's also Cross-Party Groups for volunteering, I think. (Extract, group 4)

There was also recognition that peer volunteering in mental health was a topic worthy of further development. However, participants were unclear how they might contribute to this. Returning to the idea of a briefing paper and discussing the scope of what it might look like, revealed that not all participants were onboard with this idea. Miranda shared her concerns and suggesting that developing an information pack for volunteers could be more useful:

> **Miranda:** My only concern is that a lot of these things are being done already or they have been done and…it's repetition…Personally I kind of think having something that will benefit volunteers. So…a report or…coming up with a list of things that from our experience…what volunteers can do to keep themselves well or how to, you know, I don't know…information to sort of help.
> **Polly:** Information for potential volunteers that's about volunteering, what's in it for me? Like maybe, an information pack with different aspects?
> **Miranda**: Yeah. (Extract, group 4)

Despite participants acknowledging that they did not want duplication or tokenism it was difficult to reach agreement and felt as if we were going around in circles. Participants attributed this to a lack of consistent attendance and a clear vision about where to be going. Towards the end of group 4, there was another attempt to think about an information pack:

> **Polly:** …well for people who are wanting to volunteer and in particular people who are having mental health issues and who are looking into volunteering…a sheet about how it might benefit, you know what are the benefits, what might be the pitfalls, how it might affect my benefits?
> **Megan:** I think that's vital because you don't want somebody taking on voluntary work and losing all their benefits. Because there's issues when you're suspended.
> **Polly:** Things like rights and I was thinking about equality and…things like expenses and support.
> **Megan**: It depends on the organisation, because they all offer different things. There are a few that don't give you any expenses and others that do…
> **Megan:** We already have some of that that says what you can expect when you are volunteering and you should have a named person for example that you can go to…something like that exists, but we'd have to maybe alter it or expand it to deal with the specific mental health issues…
> **Polly:** That's the other thing that could be really helpful in terms of an information pack for organisations who use volunteers…what they should be offering in terms of support.
> **Miranda:** Support, yeah, definitely. That's the most important thing, I think.

> **Heather:** Does that exist already?
> **Miranda:** In most places I think it does. (Extract, group 4)

However, despite some enthusiasm for producing an information pack, there was acknowledgment of repeating what has already been done. Regarding the scope of ambition, the following extract from group 5, summarises the range of potential actions proposed by participants:

> …..one idea was around seeing welfare reform as something that is imminent with the Scottish Government…and maybe there's an opportunity to lobby MSPs about the benefits of volunteering for people with lived experience, the challenges that the current welfare system raises and em, just helping them to get a better understanding of what people's experiences are of volunteering. Another idea was about doing some kind of information pack for future volunteers with lived experience and signposting people to where they can get support or information about various things. Another idea was about people sharing their stories and although that's already been done on the website for Volunteer Edinburgh, it was about trying to look at different ways of sharing stories and one of the options was maybe about doing a photo-voice thing. (Heather, group 5)

Somewhat surprisingly, participants were reluctant to go with the idea of a photo-voice exhibition and this was dismissed fairly quickly. In fact, as an observation, the group generally were not so keen on using any creative arts-based materials, tending to prefer more verbal and written means of communication. There was awareness that leaflets and information about volunteering for potential volunteers already existed; and that organisations such as Volunteer Edinburgh, had a range of volunteer case stories on their website; and so these ideas would involve some duplication. An idea that arose during discussion between myself and Volunteer Edinburgh, was to host a breakfast meeting for local MSPs with a view to sharing the benefits and challenges of volunteering and raise their awareness of issues around volunteering and welfare reform. Alongside, was potential for words and quotes from participants to be visually displayed on posters in the room. I put this, alongside some other suggestions to participants:

> …..I did have some other ideas of things we might do. Have people heard of Asylum magazine? …We could write something from our experience…We could create a poster…about this group's experience and share…things we've said in terms of the benefits, the challenges, what we think needs to change…We could do all of those things. We could do one of those things. We could do none of those things… I also thought the taking stock conference…I don't know if people are familiar with that Sense of Belonging [Lothian mental health strategy stakeholders' annual conference]. I know

> Jess, you've been before and…maybe for next year we could do something collectively. We could do a workshop, or we could do a poster, or we could ask for some space on the stage to share our experience. (Heather, group 5)

The next section discusses the action that was finally agreed.

9.3. Putting the "Action" into Participatory Action Research

This section reports on the action agreed by participants to convey the impact of welfare reform on volunteering and to highlight the need to keep volunteering voluntary. Reaching a decision on action required a rethink on my part as to whether action was actually necessary or whether participation in the group meetings themselves could be viewed as participatory action. Indeed, as time progressed and coming to a consensus appeared at times illusory, I realised that perhaps my constant focus on action as an outcome was unhelpful and out with the scope of what participants felt able to contribute. I raised this with participants in group 5:

> …..although I'm saying there ought to be some outcome for the project, if people don't want…an outcome…other than maybe writing the project up in some way to share what we've done to so far, you know, finding a way to make this a little bit more formal, or disseminate this [group summaries] then that's fine. I feel like I've got this whip out. We've got to produce something…in fact we are producing things. We're producing lots of information from our experience. (Heather, group 5)

This was a helpful acknowledgement that participants had already produced something through group discussion, transcriptions and identifying key themes; and that this in itself was useful and could be reproduced to suit any audience of the group's choosing. During group 5, participants debated the idea of the MSP breakfast further to see if it was a feasible idea. Generally, there seemed to be agreement that it was worth pursuing as the following conversation demonstrates:

> **Megan:** I'm thinking about the MSP thing, the meeting. What powers do they have?
> **Polly:** As far as I'm aware it's disability welfare that's going to be devolved but how much actual control they'll have to vary it from what's gone on in the rest of the UK, I'm really skeptical…if it is fully devolved…the policy is actually decided by MSPs, then I would imagine having them in here and talking to them could potentially have quite a significant impact on that…it seems to make sense to me more than producing something that is geared up to potential volunteers…
> **Heather: …**Volunteer Edinburgh would be very happy to support it…financially to buy breakfast and things [laughs] and they would give us the space and help us with any organisation…
> **Megan:** It's positive.

> **Pete:** I think there's certainly potential there for that not just to be a one off event. I imagine that when MSPs are formulating policy there's going to be a consultation period…and quite often one of the things the Scottish Parliament is good at is involving ordinary members of the public…obviously people who have a lived experience of volunteering…Establishing contact with MSPs at this stage is potentially going to open up the avenue for discussion with them about other areas of what it's like to live with a mental health diagnosis and how that could potentially impact the policy they are going to be formulating. So, there's maybe room there to take something forward beyond this project. (Extract, group 5)

There was discussion that although others might contribute, our group was unique in being a small project with a lot of experience that had thought much around these issues. The proposal was to invite a small group of local MSP for an informal conversation. However, there was concern that MSPs might not come:

> **Heather:** …even if only one comes, just to have that opportunity to share, you know, our experiences and stories. If we can change…one person's perception, I think that's a win for us…
> **Megan:** I don't know how they work…would they be freer in the morning?...
> **Pete:** I think it's got legs beyond actually producing something for volunteers because as I say that seems to be quite well catered for already.
> **Jess**: I think it's a great idea…When you were saying what the options were that was the one that immediately I thought, yeah speaking to the MSPs would be. Because yeah, you don't want to duplicate what's already been done but it just feels that that's where the most impact could be made. You know, writers of policy…I love the idea of a breakfast because it's quite quirky and there's something unique about it and quite informal and…all the stuff here that you've been discussing just looks like really rich material in terms of giving them information. So, I think as well as spoken bits and maybe you know things we would do on the day, I think for you [Heather] to write up a document for them to take away that incorporates what everyone has said…would be great. (Extract, group 5)

However, despite this overall enthusiasm, it became clear that some participants were uncomfortable adopting what they viewed as a political or activist stance. Indeed, bringing things into a political sphere felt a little unsafe. Julie raises feeling out of her depth, whilst Pete is concerned about who might attend and from which political party:

> **Julie:** What time is breakfast? I can't function till 11am. What about Brunch? Does everyone need to be there? I feel out of my depth.
> **Pete:** I'd like to know who's coming before I make that decision. (Extract, group 5)

Despite expressions of discomfort, it seemed still worth pursuing and group 5 ended with discussion on the merits of the theme "keeping volunteering voluntary" which appealed to all participants as relevant and worthwhile. This will be considered in the next and final section.

9.4. “Keeping Volunteering Voluntary”

> …..there’s a big campaign in the voluntary sector about keeping volunteering voluntary. (Polly, group 4)

This section completes this theme and revisits the idea of keeping volunteering voluntary which was first raised in chapter eight when discussing the impact of welfare reform on volunteering, with volunteering becoming mandatory for some welfare claimants to demonstrate their readiness for work. In the following extract, Jess and Pete support informing MSPs about their concern in being compelled to volunteer:

> **Jess**: That’s the nub of the matter. In communicating to the MSPs we need to show them why if you have a mental health problem, being compelled [to volunteer] is unhelpful…If you have a mental health issue, it can exacerbate your mental health if compelled. Conversely if you do something that you have control over it gives you flexibility…I’ve sometimes pressured myself and it’s not worked out well. It’s better if it comes from the heart. Lots of work has been done on the benefits of volunteering but what this group could do is boil down that message that voluntary work has to be voluntary and that being compelled to volunteer is harmful. People talk about the benefits trap, but what about being in a job you hate with colleagues who are toxic…
> **Pete:** …how does volunteering relate to what these people [MSPs] are? They are the ones who will formulate policy for welfare benefits.
> **Jess**: I agree we should be targeting them directly. We need a mixture of personal stories and written things.
> **Pete:** It’s appropriate that there are negative things too. We are not all singing from the same tune.
> **Jess**: People’s health changes and fluctuates. Volunteering has to be individualised and voluntary.
> **Pete:** Yes, people buy into that. (Extract, group 5)

There was an energy and enthusiasm about the idea of a breakfast meeting with MSPs to promote the message of keeping volunteering voluntary. The finer details required to be considered and participants began to think about timescale; invitations; how long the event might last; how tasks should be delegated; whether a presentation was required; or a more informal event enabling MSPs to ask participants questions.

In summary, this chapter has presented the third theme: Reflection and Action: Keeping Volunteering Voluntary and has described the process and challenge of putting the "action" into participatory action research. More specifically, it has considered how participants came to a consensus on action based on their concern about the impact on volunteering from the UK government and Department for Work and Pensions' reform of welfare benefits that has deemed volunteering to be mandatory for some claimants in order to prove their fitness for work or face benefit sanctions. This chapter completes the three chapters devoted to the findings from the research process. A final conclusion is presented below.

9.5. FINDINGS CONCLUSION

Chapters 6, 7, 8 and 9 have presented the findings from this project from the data analysis process. Exploring participants' experiences of volunteering has highlighted the benefits and challenges of volunteering at a personal and individual level for people with lived experience of mental illness; whilst also highlighting the positives and negatives of socio-political and welfare systems that support people with lived experience of mental illness to volunteer. Furthermore, the findings demonstrate how participants reached a consensus on "action" that would benefit the group and the wider volunteering community. The themes arising from these findings will be revisited and explored more fully in the following discussion chapter in light of the research question and the literature previously reviewed.

CHAPTER 10: DISCUSSION

Chapter 10 offers a discussion of the findings from the previous three chapters, including reflections on the experience of PAR and the research process. It looks back to offer an evaluation of the literature in light of the findings and the research experience and points forward to Chapter 11 with suggestions and recommendations for the future. It begins by revisiting the research intention and exploring to what extent the research aim and objectives were realised. It then reflects on the significance and implications of the findings before considering the strengths and limitations of the research process, identifying what has been learned and what new questions have been raised.

10.1. Revisiting the Research Intention

The aim of this study was to hear about the benefits and challenges of volunteering, as well as to explore the positives and negatives of socio-political and welfare systems that support people with lived experience of mental illness to volunteer, with a view to producing something through action that would be of benefit to the group and/or the wider community. In revisiting the research intention, the research aims, and objectives were explored to consider to what extent they were realised in light of the findings and the research experience. Whilst this original aim remained unchanged, the initial objectives were shaped as a result of the literature review (adding objectives 7 and 8) and the findings (adding objective 6). Furthermore, the objective to explore the views of volunteering involving organisations was removed as a result of the participatory process with participants stating that they did not consider this desirable or necessary. These changes did not substantially alter the research focus or intention and the final objectives are presented below:

1. To explore the experience of engaging in voluntary work for people with lived experience of mental illness.
2. To explore the benefits and challenges from the volunteer perspective.
3. To engage and empower participants through the participatory action research process to collaboratively identify strengths and weaknesses of socio-political and welfare systems that support people to volunteer and explore the potential for change based on the experience of volunteering.

4. To generate knowledge through a process of reflection and action by formulating an action plan to consider how best to address, present and disseminate the data gathered for example, through the production of something of benefit to the group and/or wider community.
5. To reflect on how change has been brought about at an individual, group and wider community level through generating the product and by participating in the research project.
6. To explore the experience of volunteering with lived experience of mental illness in the current socio-economic climate in the UK.
7. To reflect on the usefulness of occupational therapy literature in conceptualising volunteering for people with lived experience of mental illness.
8. To reflect on the extent that the study findings fill a gap and extend the literature on volunteering with lived experience of mental illness.

In evaluating to what extent the study aim and objectives were met, findings from both the individual interviews and the PAR groups revealed a number of benefits and challenges of volunteering pointing to factors that support and hinder a positive volunteering experience including the strengths and weaknesses of wider systems and specifically the impact of welfare reform on the volunteering experience in the UK. Through participatory action research groups, participants explored the potential for change based on their knowledge and experience. Thus objectives 1, 2, 3 and 6, were achieved. The significance of these findings is considered in the next section. Objective 4 was arguably also achieved in terms of producing something through action that was of benefit to the group and the wider community, through the group's joint submission with Volunteer Edinburgh to the Social Security Committee in response to the Scottish Government's process of consultation on the Social Security (Scotland) Bill. Objective 5, which emphasises continuing action cycles, reflecting on how change was brought about and deciding on further action that could be self-sustaining was difficult to achieve in full. This was due to an interruption in the final stage of the PAR groups, which led to the project becoming difficult to sustain. Objectives 4 and 5 will be revisited when considering issues arising during the research process and research limitations. Objectives 7 and 8, the usefulness of occupational therapy literature; and the extent to which the study fills a gap and extends the literature will be addressed when reflecting on the findings.

10.2. Reflecting on the findings

This chapter now turns to reflect on the findings and the literature. It begins by considering the benefits of volunteering for participants in this project and proposes an original theory of five conditions that are necessary to support a positive volunteering experience with the potential to reinforce wellbeing and recovery for people with lived experience of mental illness. It then discusses the challenges experienced by participants and specifically the systems that hindered participants' volunteering experiences and recovery namely, the impact of welfare reform and conditionality, before reflecting on the hegemony of paid work and the usefulness of occupational therapy literature in conceptualising volunteering. Thus, the themes identified in the previous chapters of selfish altruism: journeys of recovery through volunteering; and volunteering as multi-faceted including that of a dark side are further explored and extended to consider the hegemony of paid work.

10.2.1. Selfish altruism: journeys of recovery through volunteering

> …..it's been very good for me, I'm telling you. It's been a lifesaver. (Doug, interview)

Volunteering was recognised by participants as playing a significant role in supporting their mental health and wellbeing. This is consistent with evidence that volunteering has the potential to offer a range of personal, social and community benefits that can have positive effects on people's mental health and wellbeing (Musick et al. 1999; Brown et al. 2003; Borgonovi 2008; Casiday et al. 2008; United Nations 2011; Wu 2011; United Health Group 2013; Tabassum et al. 2016; Smith 2017; Kamerade and Bennett 2018). Indeed, participants reported a range of wellbeing benefits in harmony with the literature including: improved mood, confidence, self-worth; a sense of purpose, accomplishment and social connectedness (Musick and Wilson 2003; Baines and Hardill 2008; Wu 2011; Brown et al. 2012; Binder and Freytag 2013; Kamerade and Bennett 2015; 2018); a sense of belonging with opportunities to contribute to others (Ellis Paine et al. 2010; Paylor 2011; Wu 2011; Harper 2015); and opportunities to remain occupied, active and independent whilst gaining new skills (Department of Health 2011; Wu 2011; United Health Group 2013; Kamerade and Bennett 2018). Further, participants recognised volunteering as providing a useful step to employability, reinforcing a worker identity, offering training and introducing them to career options that they had not previously considered (Baines and Hardill 2008; Department of Health 2011; Wu 2011; United

Health Group 2013). However, whilst the literature suggests that there is no robust evidence that volunteering increases chances of securing and retaining paid employment or advancing earning progression (Ellis Paine et al. 2013; Kamerade and Ellis Paine 2014), several participants believed that volunteering had been crucial in supporting their readiness for employment in offering them the opportunity to test out their capabilities in a supported work environment. Further, Smith's (2017) study of the benefits of volunteering for asylum seekers concords with benefits in this project such as: having purpose, meaning and structure to the day; feeling productive, valued and having worth; helping rather than being helped; having opportunities to learn new skills and use existing ones; and having the perception that these benefits contribute to improved mental wellbeing.

Nevertheless, Jenkinson et al. (2013) caution that because volunteering is often described in heterogeneous terms, future research needs to understand the type, frequency and amount of volunteering required for optimal health benefits as well as the motivating and sustaining factors for individuals before determining volunteering as health promoting. Whilst this study can lay no claims to quantitative outcomes, findings have revealed five qualitative conditions that according to participants are necessary in determining whether volunteering with lived experience of mental illness has the potential to realise positive wellbeing and recovery and provide optimal health benefits. These conditions, outlined in Figure 14 below, are each discussed in turn:

Figure 14: Five conditions for successful volunteering.

1. Readiness and support to volunteer

> …..I primarily started volunteering when I had quite a bit of a breakdown with depression, so when I was feeling able I started with one voluntary job and it's been over eleven years now and I'm still volunteering. (Megan, group 5)

The first condition is readiness on the part of the volunteer alongside the availability of support to volunteer. Readiness can be described as a transition from having sufficient time to recover from the acute stages of mental illness, highlighting the temporal aspect of recovery and the need for internal healing (Gould et al. 2005). Indeed, time is viewed as crucial in aiding recovery from mental illness and in helping people to find their voice (Deegan 1996). The participants in Gould et al.'s (2005, p. 470) study described this period of healing as "coasting", a time to be still, which could last for several years, where little else appeared to be happening that was perceptible. Indeed, for the young men recovering from psychosis (Gould et al. 2005) this stage of recovery was portrayed as an experience of lost dreams and a sense of anguish akin to losing their lives where simple everyday occupations became onerous or impossible. In this project, Miranda (interview) vividly describes this stage in her recovery as spending "several years being in the wilderness and not doing much really with my life".

According to participants, breaking away from coasting to reach a stage of readiness could stem from internal recognition of a growing need to do something, or could be initiated by others recognising that doing something at this time would be beneficial for the individual. This could be a supportive mental health professional who recognised the individual was approaching a stage of readiness in their recovery journey. However, this was also dependent on the availability of meaningful occupation-based opportunities to interrupt "patterns of social isolation, limited physical activity and lack of occupational engagement" (Gould et al. 2005, p. 467); and as Pete poignantly conveys, courage was an important factor in his readiness to volunteer following his significantly debilitating mental illness.

Although the concept of readiness is not well reported in recovery literature, consumer/survivor Deegan's (1988, p. 14) recovery narrative is helpful in elucidating a sense of readiness when she describes going through a process from denial, despair and anguish where simple tasks are impossible due to hopelessness and paralysis, to reaching a period of slow, gradual rebuilding of herself where she discovered the ability to do. This fits my understanding of what participants described as readiness and mirrors participants' accounts of reaching a stage of wanting something to do, as they came to realise that having nothing to do was impacting negatively on their mood and their mental health. Indeed, participants often referred to this as needing a purpose, a structure and a reason to get out of bed. Interestingly, Deegan's (1988) account appears to refer to an initial deeply personal and internal process rather than one that was externally influenced by support from others. However, her reference to this stage being precipitated by "the birth of hope called forth by the possibility of being loved" (Deegan 1988, p.14) potentially suggests the beginnings of taking notice of herself in relation to others in a positive way. This period of coasting and feeling stuck highlights the importance of taking time to reconfigure experience as a pre-cursor to doing, before being able to move on to rebuild some form of occupational life in a process of recovery (Gould et al. 2005; Fieldhouse 2012a; 2012b). For Gould et al.'s (2005) participants this was a time for renegotiating themselves and their possibilities in what was a gradual process of re-engaging in activities and envisioning goals, often aided by support from family and friends. Gould et al. (2005) conclude that transitioning from coasting to participating in meaningful occupation, or from being to doing is an individual process that is also dependent on external factors such as opportunity and support.

The value of having support to negotiate the transition to volunteering was evident from participants' descriptions particularly in the initial stages. Although volunteering could be something that people negotiated themselves, and acknowledging the need for support can be difficult and a turning point in itself (Gould et al. 2005), participants more commonly relied on the encouragement and support of others, initially through a mental health professional and then someone for example, Volunteer Edinburgh's health and wellbeing team who could match the volunteer with a suitable volunteering experience and offer on-going support throughout the volunteering experience. Matching involves attention to a range of factors including level of skill, preference, influence, interest, monotony and pressure (Fegan and Cook 2014).

Megan's (interview) reflection that volunteering can accommodate a range of readiness abilities and fluctuations in mental health whilst still promoting recovery because it can be graded in terms of degree of challenge starting with "baby steps…something that's not too taxing" suggests that support and flexibility are implicit in negotiating suitable volunteering opportunities. Indeed, flexibility through graded exposure, providing incremental opportunities for engagement in occupation is essential in supporting people from “coasting to reconfiguring their map”; where decisions about “what, when and how much” can be individually negotiated (Gould et al 2005, p. 472). With regard to volunteering, this might include the number of hours volunteered or the level of responsibility or degree of exposure to the general public. The crucial element here is that this can be negotiated and discussed in a supportive environment from an attitude of understanding, rather than something imposed.

Finding a suitable volunteering experience might happen from the outset or might be more a process of trial and error. This has resonance with Amy returning to Volunteer Edinburgh to consider other volunteering options following her decision to leave the charity shop. According to Fieldhouse (2012a; 2012b), through a co-constructed process of scaffolding, support can be initiated and then gradually reduced as people begin to adapt to their environment and utilise naturally occurring community resources and peer supports to reduce their social exclusion and feel connected. Indeed, Fegan and Cook (2012; 2014) recognise that when additional support is offered to ensure the appropriate level of challenge, volunteering has more potential to enhance recovery, foster positive risk taking and provide a valued identity that can integrate mental health experience for people living with fluctuating and severe and enduring mental illness as well as provide a pathway to employment if desired. In her interview, Miranda acknowledged how ongoing support is crucial to volunteering, describing how a lack of support precipitated her becoming mentally unwell, requiring admission to hospital.

Alongside support is understanding. Potential stigma and negative attitudes from volunteer engaging organisations reflect societal stigma and discrimination and pose a significant barrier to successful volunteering for people in recovery (Farrell and Bryant 2009a). Participants in this study recognised stigma at a societal level and had witnessed local examples of stigmatising comments and attitudes from health professionals; and had experienced stigmatising comments from paid workers in the organisation where they volunteered. Indeed, Amy recounted when she was required to remain in the back shop of a cafe and not allowed to serve customers. This she believed was due to stigma associated with her lived experience of mental illness rather than a lack of specific skills. Such everyday disabling social encounters reflect the “micro-aggressions” and “invalidations” proposed by Cameron (2015, p. 118) that reinforce disabling social relations and require to be brought to critical awareness and challenged in the fight for emancipation and social change. Indeed, this is reflected in Cameron’s (2015) definition of disability where the role of being mad, different and therefore not socially acceptable is assigned in this case to volunteers recovering from mental illness with the requirement to remain hidden from the general public. There is also resonance here with the concept of occupational injustice and specifically occupational marginalisation (Townsend and Wilcock 2004) an invisible form of occupational deprivation where people are not offered opportunities to participate in specific occupations and are thus excluded due to unseen societal norms and expectations for example individual, societal and institutional perceptions of impairment or ability (Townsend and Wilcock 2004; Durocher 2017).

Interestingly, participants chose not to interview volunteer engaging organisations, originating from Farrell and Bryant’s (2009a) finding, as they did not consider this to desirable or necessary. Indeed, participants appeared stoic about the existence of stigma and it was Polly and Pete, both keen supporters of advocacy who reminded the group that advocacy exists because stigma exists and that stigma stems from assumptions and ignorance rather than “out of nastiness and vindictiveness” (Pete, group 2). On reflection their stoicism was not so much about tolerating stigma but more about justifying and validating their conviction for the continuing need for advocacy services, perhaps reinforcing their sense of belonging to the advocacy community. This has resonance with Baumberg’s (2016) view that stigma may not lead to shame when there is a strong personal identity and when devaluation from others can be disputed. This strong personal identity also has resonance with the “proud, angry and strong” disability culture mantra espoused by Swain and French (2000, p. 569) in support of their affirmation model to signify a positive social identity both individually and collectively that validates disability and the experience of disabled people and stands in opposition to a personal tragedy model of disability.

For the participants in this study, volunteering was their doing of choice. However, Aldrich and Dickie (2013, p. 13) caution that being out-of-work creates conditions that limit occupational possibilities such as lack of money and unpredictable waiting times at welfare agencies, that “prevent the establishment of functional routines, which then prevents engagement in the sorts of productive occupations that society values”, for example volunteering, because people are “too busy making ends meet”. Whilst a lack of opportunity to volunteer was not raised by participants, perhaps because of the wide ranging volunteering possibilities that an urban environment offers and the existence of Volunteering Edinburgh as a supportive broker organisation, it is important to be mindful that proposing volunteering as an occupational possibility without fully understanding the daily challenges of living with long-term unemployment and mental illness may inadvertently perpetuate inappropriate societal expectations and occupational injustice (Aldrich and Dickie 2013). This reinforces the importance of autonomy and choice in decision-making whilst also questioning opportunity and accessibility and whether volunteering is indeed open to everyone.

Whilst volunteering has a broad scope and can be classified as formal or informal and according to the type of activity and the intensity of involvement (Ellis Paine et al. 2010), volunteering for a formal organisation is privileged in definitions of volunteering raising a further question about whether independent volunteering is more prevalent in working class communities. Indeed, the literature suggests that there are disparities in opportunity to volunteer, with being asked to volunteer for many low-income individuals having a direct bearing on participation (Brodie et al. 2011; Benenson and Stagg 2016). Interestingly, evidence surrounding protective factors for mortality suggests that volunteering independent from a formal organisation has optimal benefits (Ayalon 2008). Many participants in this project had been involved in formal and informal volunteering and admitted confusion about what actually constituted volunteering and frustration with the stereotyped image of working in a charity shop usually associated with formal volunteering. Indeed, only one participant was volunteering in a charity shop at the time of the study although many had had previous experience of this. Some participants believed that social class, age and professional background were significant in determining who volunteered and where, with the Citizens’ Advice Bureau (CAB) viewed as more likely to attract retired professionals compared to local advice centres in areas of significant deprivation. Indeed, anecdotal evidence suggests that historically, people living with mental illness did not fit the volunteer profile of the time and arguably volunteering has become more inclusive in terms of age, race, social class and disability. However, alongside mental health stigma, competition for volunteer placements with school leavers, students and those seeking opportunities to improve their CV was raised as a potential barrier to accessing volunteering opportunities of choice. Indeed, choice and more specifically synergy between the volunteer, their background and values, and the volunteering experience to support meaning was recognised as an important condition for the success of the volunteering experience and will now be discussed.

2. Synergy

> .....you mostly end up volunteering for organisations that have got an ethos or an ethic that you are inclined to be attracted to. (Doug, group 1)

The second condition is the importance of synergy or ease of fit between the volunteer and the experience to ensure that volunteering is meaningful. The value of engaging in meaningful occupation as a mechanism for health and wellbeing is central to occupational therapy and is well recognised in the occupational science literature as the concepts of doing, being, becoming and belonging (Reilly 1962; Wilcock 1998b; 1999; 2007; Reed et al. 2010; Wilcock and Hocking 2015; Hammell 2017). Indeed, Wilcock's (1998b; 1999; 2007) concept of doing recognises that engagement in occupation must be meaningful, purposeful and pleasurable; and provide structure, social interaction and societal development to be health giving. However, for people living with mental illness, participation in meaningful occupations is often conditional or denied with significant life disruption leading to deterioration in participation in occupation over time (Roy et al. 2013; Hamer et al. 2017); and restricted opportunities for social relationships, self-expression and access to community resources (Gould et al. 2005; Fieldhouse 2012a). Volunteering is regularly advocated by occupational therapists for people recovering from mental illness as a means to give purpose and structure to the day; develop a range of valuable and transferable skills; contribute to the wider community; and reclaim a valued social identity (Rebeiro and Allen 1998; Farrell and Bryant 2009a; Farrell and Bryant 2009b; Aldrich et al. 2014; Fegan and Cook 2014). However, volunteering although recognised as having the potential to offer a range of personal and social benefits can only do so when viewed as meaningful by the volunteer (Black and Living 2004; Fegan and Cook 2014). Teasing out the range of internal and external values of what constitutes meaning can be complex (Reed et al. 2010). Therefore, getting the right fit between volunteer and volunteering experience is crucial for volunteering to be successful in supporting recovery (Fegan and Cook 2014).

According to participants meaningful volunteering depended on finding synergy between their values, interests, passion, experience, abilities and aspirations, which are individual and deeply personal; alongside the values and objectives of the charity, the type and scope of the volunteering role on offer and the level of support and training available. Literature asserts that valued occupations tend to be those that offer structure, routine, accessibility, acceptance and meaning in life through interests and values (Eklund et al. 2012; Hitch et al. 2013; Aldrich et al. 2014). For participants in this study, having a structure and routine was certainly valued. Interestingly, many participants chose to volunteer with organisations supporting people with lived experience of mental illness. This was in synergy with their own illness experience, reflecting a desire to give back and perhaps also higher levels of empathy and social justice (Feigin et al. 2014). Many participants also believed that mental health charities would be more understanding of their lived experience of mental illness and so there may also be a protective element in choosing this line of volunteering. The desire to give back to an organisation supporting mental health and to make a difference to the community and to the lives of marginalised and vulnerable people through for example, peer support and advocacy has resonance with Robotham et al.'s (2012, p.13) notion of "reciprocal altruism" explaining how gratitude for being supported by services results in a desire or duty to reciprocate. In addition, participants appeared to need to be invested in the values of their volunteering organisation for their commitment to feel worthwhile. For Amy, working in a charity shop had synergy with her values of servicing the community alongside her experience of being a mum buying clothes for her family on a tight budget. For Doug, volunteering in an advisory capacity with people in a less affluent city location had synergy with his social class and political background and his aspiration to build skills for future employability. Archie (interview) whilst recognising his volunteering was not specifically challenging or "on the cutting edge" according to his abilities, found synergy and meaning through investing in giving something back to a mental health charity whilst challenging himself to a regular routine that could build his stamina in readiness for paid work.

This also resonates with Smith's (2017, pp. 6-7) exploration of the motivation for altruistic occupations for example, "kinship" which prizes connectedness, community and a sense of belonging through being needed and feeling valued; "empathy" with the desire to help through an emotional connection with the hardship of others and give something back whilst distracting from personal circumstances; and "moral principles" associated with having a strong moral compass and conscience where the needs of others are placed before oneself and where kindness and "being good and doing good" are valued (Smith 2017, pp. 6-7). Arguably these were evident throughout the project as examples of participant motivation to volunteer. This is reminiscent of Wilcock's (2007) occupational science concepts of doing, being, becoming and more specifically belonging and the importance of social relationships in sustaining positive health and wellbeing where a sense of connectedness to people and communities is reinforced through kinship; and supports a connection between becoming and belonging where participants in meeting their personal goals through volunteering also experience a strong sense of being connected to others (Hitch et al. 2014b). Surprisingly, although the term altruism was rarely mentioned with the exception of Pete's phrase "selfish altruism" to communicate that although volunteering offered him an altruistic opportunity to contribute to others, he volunteered primarily for his own benefit, in hindsight its presence was evident throughout. Pete recognised the significant benefits to his mental wellbeing that he received through volunteering and emphasised the importance for him of keeping busy. This seems to accord with Smith's (2017, pp. 6-7) notion of "empathy" as referred to earlier and giving something back whilst being distracted from personal circumstances. Interestingly, Pete also noted a sense of job satisfaction that had previously been elusive to him through paid work, perhaps alluding to the benefits of being needed and feeling valued as in "kinship" with the work of his advocacy organisation where moral principles of doing good were valued (Smith 2017, p. 8).

Indeed, the range of personal benefits from this two-way process of giving and receiving were recognised by all participants and were deemed substantial and central to staying well and keeping out of hospital. Whilst there is general agreement that the fundamental principle of altruism is an act that is carried out voluntarily with the goal of benefitting another (Feigin et al. 2014; Wilson 2015), it could be argued that any motivation to volunteer will contain some selfish component in terms of social and/or personal reward. Indeed, in this project there was evidence of co-occurring motives underpinning participants' altruistic behaviour (Smith 2017) including acting for one's own benefits as recognised by Pete and other participants under the term "selfish altruism" and acting for the benefit of another person or particular community in the case of advocacy work (Pete, Polly,) peer support (Megan, Miranda, Jess, Julie, Alexander) volunteering in an advisory capacity (Doug); benefitting the community through charity shop volunteering (Amy) and fundraising for a mental health charity (Archie). Motivation to volunteer for the participants in this study was therefore wide ranging including identifying with a shared experience; giving something back; adjusting following a significant life event; gaining skills towards employability; and enacting political attitudes and values with causes that have meaning and significance (Bekkers 2005; Baines and Hardill 2008; Brodie et al. 2011). This reflects the "multi-lens approach" in understanding motivation to volunteer as advocated by Ellis Paine et al. (2010, pp. 25-31) alongside the range of altruistic drivers identified by Smith (2017).

Further, meaningful occupation is often linked through synergy with past experiences and familiarity (Reed et al, 2010; Eklund et al. 2012; Hitch et al. 2013). Smith's (2017, p. 8) concept of "occupational constancy" is useful here in understanding the motivation for altruistic occupations which is often embedded in cultural and personal needs and values as well as previous occupational choices thus enabling a re-connection or sense of continuity during transition with a previous sense of self, occupations, passion and interests. Occupational constancy was clearly evident in this study with the majority of participants making volunteering choices based on a range of personal needs and values and previous occupations and passions. Findings from this study revealed a rich diversity of volunteering experience and suggested that for some participants volunteering pre-dated their illness and for many, there was synergy between employment history, educational background and the type of volunteering chosen. Additionally, many participants were engaged in formal volunteering with a charitable organisation and through governance and/or advocacy or campaigning for improved services through organisations with a mental health focus and as previously stated there was a strong link between participants' lived experience of mental illness and supporting people with lived experience of mental illness suggesting more than a continuity of interest in mental health issues through lived experience. This will be revisited when discussing the condition of opportunity for influence and activism.

Regardless of motivation, participants recognised that the volunteering commitment had to be achievable and within their control, provide opportunities for growth and development and compare more favourably than negative experiences of paid work. Indeed, Polly stated that she preferred volunteering to paid work because it gave her more scope to make a difference in supporting marginalised groups and individuals; and she willingly experienced a personal loss in terms of monetary reward for altruistic reasons. Indeed, all participants appeared passionate about volunteering, viewing their volunteering as aligning with personal values and interests providing meaning, which in turn they perceived as having a positive effect on their wellbeing. Conversely, participants provided examples of when volunteering lacked synergy with their abilities or values and how this led to an unrewarding and potentially stressful experience through lack of challenge, monotony or too much pressure (Fegan and Cook 2014). Lack of synergy with values was evident for Amy who was responsible for organising and displaying children's clothes in her charity shop. When this space was reduced due to changes in organisational priorities, Amy believed that her altruistic value of servicing the community for families with limited income was compromised due to business priorities. She described feeling undervalued and became so upset that she terminated her volunteering position. Amy identified with families on low income and believed she was making a difference in supporting them with a community service. When this was not valued by the charitable organisation, there was no longer synergy between her values and her volunteering experience. Engaging in meaningful occupation that has personal significance resonates with the concept of recovery (Deegan 2002). It aligns with Csikszentmihalyi's (1975) concept of flow where people become so absorbed in their doing, that it becomes an intrinsically rewarding experience. However, whilst having synergy and engaging in meaningful occupation has resonance with wellbeing, this may not be sufficient to maintain wellbeing. According to participants in this study there also requires to be flexibility during the volunteering experience to enable volunteers to manage their mental health and to support them in staying well. This is discussed next.

3. Flexibility to stay well

> …..I don't want to take something on that's going to give me too much responsibility because I can't handle that. I don't handle that well, not any more anyway. I used to but not now. (Amy, interview)

The third condition is that volunteering offers sufficient flexibility to enable participants to tailor their fluctuating mental health to their volunteering commitment and/or to curtail the volunteering experience if it is proving too stressful. Remaining mentally well was an on-going and underlying preoccupation for participants who in acknowledging their fluctuating mental health also recognised their fragility and vulnerability. Whilst participants agreed that volunteering had the potential to support them in staying mentally well, this required careful self-management and monitoring of their mental health and wellbeing alongside flexibility on the part of the volunteering engaging organisation to accommodate their fluctuating mental health needs. Indeed, all participants valued the ability to have choice and flexibility over their volunteering experience in order to balance engaging in meaningful occupation with staying mentally well and out of hospital.

There is growing evidence that providing social support to others through volunteering is associated with better mental health outcomes for volunteers through a process of stress-regulation, although understanding of the neurobiological mechanisms involved in this research is still in its infancy (Brown and Brown 2017). Nevertheless, current evidence suggests that the psychosocial benefits of social connectedness can predict health and longevity; and that prosocial helping behaviours ameliorate the impact of stress on major health outcomes including mortality (Poulin et al. 2013; Roth et al. 2018). More significantly, supporting others through volunteering is a better predictor of wellbeing than being in receipt of social support with gains stemming from having a sense of meaning, feeling valued and having the opportunity to contribute something (Poulin et al. 2013; Brown and Brown 2017). Within this project, feeling valued through volunteering was a central theme and participants remarked on how they were often thanked for their volunteering contribution which they recognised as contributing to feeling good about oneself.

For some participants flexibility to stay well involved actively choosing volunteering over paid work because of the experience of feeling valued which was often in marked contrast with people's experience of paid employment as exemplified here by Doug:

> …..if you are a volunteer you can walk away at any time…I was always told at the end of the day "thanks for today Doug". When taken on as a paid employee, you never got "thanks for today". (Doug, group 2)

Indeed, the emerging field of compassionate neurobiology has arisen because of recognised health consequences of compassion namely that people who help others are healthier and live longer than those who do not, when helping behaviours are inherently other focused in terms of motivation (Poulin et al. 2013; Brown and Brown 2017). Brown and Brown (2017, p. 163) refer to this as a “social bond” where people are invested in helping others in need over the long term and contrast this with evidence that social isolation has significantly poorer health outcomes. Models of compassionate neurobiology highlight the importance of social relationships, social connection, feelings of acceptance and making a contribution to others where stress relief hormones are released at a physiological level and which have the potential to regulate psychological stress and potentially “improve an individual’s resilience to stressful life events and internal states that may give rise to mental health problems” (Brown and Brown 2017, p. 175).

Poignantly, all participants in this project recognised the fragility of their mental health and their susceptibility to stress, significant change and loss of control in contrast to wellness, which they associated with meaning, choice, flexibility and autonomy. In addition, participants recognised the current strain that the NHS was under and the lack of available support for mental health crisis. This added to concerns about becoming unwell again and reinforced the need to stay as well as possible rather than risk tipping over into illness and a potentially long journey of recovery back to relative health. Recovery is recognised as a deeply personal process (Anthony 1993; Leamy et al. 2011) that is more about liberation than cure (Bonney and Stickley 2008; Harper and Speed 2012). Meaningful occupations can support a desire to take control and monitor health and wellbeing when “coming to terms” with fluctuating mental health is a difficult but necessary step towards recovery (Hitch et al. 2013, p. 81). There is resonance here with the occupational science concept of being which involves self-reflection and the need to be true to oneself with the ability to express choice and agency when investing personal creativity or fulfilling an occupational role (Wilcock 1999; Hitch et al. 2014a). However, according to Hitch et al. (2014a) this may not always be achievable. Through volunteering, participants in this study felt more in control of their lives and felt that their fluctuating mental health could be spoken about, understood and contingencies could be made where necessary. This contrasted with experiences of paid work where they felt less able to be honest and less likely to be understood.

Indeed, this also resonates with criticisms of the social model of disability in its denial of the complexity of disability and the disabling aspects of impairment on people's bodies and in this case minds (Shakespeare and Watson 2010; Shakespeare 2013); and adds weight to counter the argument that disadvantage has nothing to do with individual impairment (Shakespeare and Watson 2010). Participants in experiencing fluctuating mental health problems recognised a combination of disadvantage from their intrinsic impairment and the social environments and attitudes that limited their participation (Shakespeare and Watson 2010; Shakespeare 2013). Participants valued having agency to use their personal knowledge to evaluate their mental health to make decisions about readiness for paid work or take on more responsibility through volunteering. Indeed, wellness was associated with meaning, choice, flexibility and autonomy. All participants recognised becoming more adept at managing their mental health. They were sometimes cautious and at other times able to take bold steps to change their situation to one that supported recovery and wellbeing however this required feeling empowered with a degree of flexibility and control.

Empowerment is a central component in Leamy et al.'s (2011) CHIME (Connectedness, Hope, Identity, Meaning and Empowerment) recovery acronym, where having personal responsibility and a sense of control over one's life is recognised as a crucial element of recovery. Research evidence suggests that the impact of stress on people's health and wellbeing can be mitigated when people have high levels of social support and/ or self-esteem and a sense of mastery over their situation (Thoits 2010). Participants in this study echoed the importance of empowerment through flexibility, choice and having the means, or agency, to make informed decisions on their own terms. This included choosing the organisation and the number of hours they volunteered; and managing their mental health condition with the flexibility to alter their volunteering commitment according to their variable mental health either by temporarily or permanently cutting back or opting out when things became too stressful. However, this was also dependent on a degree of flexibility and understanding on the part of the volunteer engaging organisation. Pete understood the responsibility of volunteer engagers to recognise when volunteers with lived experience of mental illness may not always be able to fulfil their role in light of fluctuating mental health and vulnerability and that this should be accepted, and contingencies made without question.

Balancing and adapting their volunteering commitment alongside living with a long term and fluctuating mental health condition and other life commitments was a careful process of self-management in a range of personal coping strategies that participants used to stay mentally well. For Miranda it was her “wellness toolbox” and learning to say no. For Amy, it was the support of other volunteers that helped her to cope during a stressful volunteering experience. Interestingly for Amy, recognition that things were becoming stressful was an embodied experience where she described during her interview as being able to feel it in her bones when things got too much, recognising that she needed to protect herself. For Amy, knowing herself and having flexibility to act on that knowledge, was critical to maintaining her mental wellbeing.

However, Harper and Speed (2012) caution that emphasising self-management of the mental illness experience as a personal tool for change transfers the onus of responsibility to the individual rather than society for managing the impact on wellbeing from wider conditions including unemployment, poverty and other social determinants of health. Indeed, individualising what are inherently social problems conceals the structural causes of mental distress and prevents these from being explored from a more political and collective perspective (Onken et al. 2007; Harper and Speed 2012). This accords with a social model of disability perspective where the experience of social exclusion and restrictions on participation are due to social and physical barriers enforced by society that require to be challenged and removed through collective action (Shakespeare 2013). Over-emphasising individual responsibility in recovery where the person is expected to confront their negative attitudes and cognitions to bring about change within their personal life endorses a political and neo-liberal approach of responsible consumers where distress is individualised, and any collective identity is denied (Harper and Speed 2012). This raises an important question about the extent to which people feel responsible for their mental health and the extent of agency, choice and control people actually have in managing their situation. The negative impact of wider systems was a significant finding in this project and will be revisited later when considering the challenges of volunteering.
The next condition to be discussed is that volunteering offers the opportunity to meet needs of identity and connectedness.

4. Meeting needs for identity and connectedness

> …..since…[volunteering] I've felt so much better about myself and feel included…and I think that does make a difference if you feel a big part of it you know…you feel like you are contributing but you feel valued and that without you, the big machine wouldn't go or it would be a lot more difficult to run. (Miranda, group 1)

The fourth condition of successful volunteering for people with lived experience of mental illness is that it offers the potential to meet needs for identity and connectedness. Occupational therapy literature advocates that engaging in meaningful occupation enables possibilities through its transformative potential that can be linked to identity formation and the rebuilding of an occupational life motivated by passion and human connectedness (Gould et al. 2005; Reed et al. 2010; Fieldhouse 2012a; 2012b). In other words, having something meaningful to do contributes to a deeply personal sense of identity that connects us to society through occupational status, recognition or standing (Blank et al. 2015). Indeed, there is consensus within the occupational therapy literature that for people recovering from mental illness, paid employment is an important means to moderate the impact of their illness, gain a sense of worth and construct a positive worker identity within a valued social context (Van Niekerk 2009; Hitch et al. 2013; Fegan and Cook 2014). However, findings from this project concur with Blank et al.'s (2015) study that although having the identity of a mental health service user may be experienced as unhelpful, paid work often holds ambivalence for people recovering from mental illness. In Blank et al.'s (2015) study, the onset of mental illness coincided with participants having to give up work and therefore their ambivalence of returning to paid employment was arguably based on a realistic perception of what paid work entailed. This was also the case for the majority of participants in this project who in making a judgement about their best interests, actively chose volunteering over paid work because it appeared to better support their mental wellbeing and recovery.

Similarly, in Blank et al.'s (2015) study, participants experiencing mental illness valued the construction of a new identity moving from patient status to becoming an expert through lived experience of mental illness as a means of confirming their existence to self and others. For some of Blank et al.'s (2015) participants, volunteering became important in achieving a sense of identity and belonging. Although Blank et al. (2015, p. 205) do not explore volunteering in any depth they suggest that supporting people to “craft an occupational identity” is an important recovery task. According to Fegan (2014) and Fegan and Cook (2012; 2014) supported volunteering enhances mental health recovery by endorsing a valued identity that integrates and cherishes mental health experience. However, Fegan’s (2014, p. 174) theory “emerging as a worker through volunteering” confirms her focus on vocational readiness for paid work and the importance of constructing a worker identity for the volunteers in her study.

Taking a broader view, participants in this study were indeed “crafting an occupational identity” (Blank et al. 2015, p.205) through volunteering. Indeed anecdotally, volunteering in Edinburgh has a history of offering people in recovery the opportunity to move beyond the identity of service user or patient to identify as someone who can make a valuable contribution and become more than their illness. According to Leamy et al. (2011) identity, a core element of the CHIME (Connectedness, Hope, Identity, Meaning and Empowerment) recovery acronym, discussed in the literature review, involves overcoming stigma to redefine or rebuild identity. Having a strong personal identity can mitigate against feelings of shame arising from personal and societal stigma (Baumberg 2016). Indeed, Guibernau (2013) reflects that identity has changed from traditionally being assigned to others according to gender, status and religion to being an outcome of individual choice and influenced by a reflexive interpretation of the attitudes, views and expectations of others towards the public image projected by the self. Thus, a sense of self is fluid and is constructed through interaction with significant others. Construction of self-identity and collective identity is realised through group membership and influenced through both belonging and exclusion. The construction of a positive disabled identity is arguably the cornerstone of the affirmative model of disability (Swain and French 2000; Cameron 2014; 2015) where living with an impairment can be experienced by disabled people as valuable and satisfying, thus validating a positive identity of being impaired, rejecting the dominant value of normality, and demonstrating how disabled people can take ownership of their impairment, their bodies and arguably their minds.

For example, identification with mental illness associated with shame for some people is being overturned by movements such as Mad Pride in advocating for people living with mental illness to take pride in their mad identity and reclaim pejorative language of madness as positive (Lewis 2013). This was particularly evident in this project in the discussions between Polly and Pete. Indeed, participants recognised that their lived experience of mental illness had become a strong, positive part of their identity as an expert by experience which was valuable in a volunteering capacity in sharing their knowledge, skills and experience. Thus, participants in recognising that living with mental illness presented a number of challenges also viewed it as an important and positive part of their identity. This supports Shakespeare and Watson's (2002; 2010) and Shakespeare's (2013) criticism of the social model of disability in recognising impairment as a valued embodied experience in the lives of disabled people. The majority of participants recognised finding a new purpose by drawing on their lived experience of mental illness to support others with lived experience of mental illness through volunteering that involved some form of advocacy, advice, peer support and training. Further, participants engaged in advocacy roles recognised the ethical requirement of remaining neutral whilst drawing on their experience, but not imposing it on the people they were advocating for. Participants who were passionate about advocacy appeared committed to making a difference to the lives of other marginalised people and as such viewed volunteering akin to that of career or a calling that offered them status, recognised their talents, supported their wellbeing and was preferable to paid work or other volunteering options.

For Polly, advocating for women's issues and the rights of vulnerable people through mental health charities had become her identity from an early age and was intrinsic to her making sense of her own mental health experience, connecting with others and making a difference. Participants in drawing on their lived experience of mental illness through volunteering were able to engage in meaningful occupation that channelled their passion and gave them a strong sense of job satisfaction. Miranda in acknowledging the recovery focused and peer support training she had completed in addition to her own lived experience of mental illness was able to recognise the reward in helping others but also the change in direction from her previous paid work pathway stating: “it wouldn't have been the path that I would have chosen but actually my life is much richer because of it” (Miranda, group 1). For Pete, volunteering as an expert by experience offered him his first experience of job satisfaction and feeling valued. This was closely linked to an experience of connectedness and belonging which contrasted to previous experiences of paid work where many participants recognised not feeling valued or experiencing any form of job satisfaction, connectedness or belonging.

Therefore, crafting a volunteering identity was not only at an individual level but directly related to developing a collective identity for example, being affiliated with and endorsing the ethos and values of a charitable organisation or particular service and thus experiencing a sense of belonging to that organisation which was noted in their language of “we” and “us”; being connected to and accepted by a community of people with lived experience of mental illness through advocacy and campaigning work; and sharing values with fellow volunteers which also gave the experience of belonging to and being accepted by a wider volunteering community with opportunities to develop new relationships. This aligns with belonging from an occupational science perspective reinforcing the importance of social relationships in sustaining positive health and wellbeing (Wilcock 2007) and the value in having a sense of connectedness to people, places and communities where belonging relationships are characterised by reciprocity, sharing and mutuality (Hitch et al. 2014a). Guibernau (2013) contends that the need to belong to a group or community is a persistent and enduring aspect of modern social life. She argues that the power of belonging comes from the possibility of generating an emotional attachment capable of fostering a shared identity, loyalty and solidarity among members of a given community and it is this attachment that has the potential to activate political movement as well as the power to foster collective passion (Guibernau 2013). Thus, belonging involves more than just identifying with a particular group, it entails being accepted by others as an integral part of a community or society (Cohen 1982 in May 2013, p.83). This has resonance with Cameron’s (2014, p. 29) reflection on whether aspects of the affirmation model are implicit in the social model where he notes that “access is not the same as inclusion…there is still a gap between being able to be there and being valued there”. Poignantly, Amy described her complete surprise that people would want to keep in touch with her once she had decided to leave, seeming not to recognise the extent of her positive impact on others. Miranda valued her connectedness to others, which had the potential to extend beyond volunteering. This also accords with Leamy et al.’s (2011) view that connectedness in encompassing supportive relationships and connections to the community is a core element of recovery.

Interestingly, volunteering also contributed positively to home life offering a productive role external to the home thus normalising family life roles and affirming identity and connectedness. Indeed, relationships with family, friends and the broader community who value the person as an individual are crucial in providing a sense of connectedness (Eklund et al. 2012; Fieldhouse 2012a; Hitch et al. 2013, p.82). For Amy and Alexander, volunteering offered the opportunity to regulate family life roles and expectations and improve family relationships and provided topics for conversation. Specifically, volunteering in offering a productive role external to the home environment strengthened participants' self-image providing a renewed sense of identity which appeared to be supported and valued by family members. Alexander's wife's relief that he was keeping busy potentially reveals the anxiety that family members may have when their loved ones appear housebound and un-occupied. Moreover, Amy was able to laugh at her new status of being temporarily unavailable to her daughter due to her new volunteering routine, again emphasising the normalcy of family life.

According to Hammell (2017), meaningful occupational engagement is central to meeting wellbeing needs for recovery for people with lived experience of mental illness and includes having the need for belonging and social connectedness to family, friends and communities; contributing to the wellbeing of others alongside feeling valued and having a positive sense of self-worth and identity; being able to experience and express pleasure and having purpose and meaning through roles that are individually and/ or collectively valued; and having the ability and opportunity to express and experience hope, choice, control and empowerment. Arguably, these needs can be met through volunteering and were evident in this project. Volunteering in facilitating community connectedness and status as an expert by experience also enabled significant opportunities for influence and activism though advocacy and peer support and this will now be explored.

5. Opportunity for influence and activism

> .....if…you've got an idea to do something which is going to make a difference and change things…[being] able to actually sort of challenge the system a wee bit more at times…being able to influence, em you know, organisations…some of the things I have done as a volunteer I feel much more proud of…rather than within [paid] work. (Polly, interview)

A key finding from this study is that volunteering offers participants with lived experience of mental illness not only the opportunity to contribute as experts by experience but also the potential to be influencers and activists. The fifth and final condition therefore is that volunteering offers the potential to support volunteers with lived experience of mental illness to be empowered through agency, free choice and control to act independently and/or collectively to influence and to make a difference through activism. Many participants described how knowledge gained through lived experience of mental illness harnessed their passion to make a difference through volunteering and enabled them to stir things up and challenge the system by influencing service provision for marginalised groups and educating, training and supporting future volunteer advocacy and peer support workers. This was encapsulated by Polly when she explained how her mental health difficulties had led to her volunteering and becoming an advocate for advocacy and pioneering projects that had positively influenced vulnerable people’s lives including setting up a volunteer helpline and a range of support groups. In addition, several participants in this study were involved in positions of decision making and influence through volunteering as: committee members on boards of trustees and governance; volunteer ambassadors promoting volunteering to others; facilitators of peer support forums; as educators of professional groups; trainers of future volunteers; pioneers of new developments in peer support and advocacy; and as developers of volunteering policy and management at an organisational level including recruiting, training and supporting future volunteers.

Taking a “multi-lens approach” to volunteering according to Ellis Paine et al. (2010, pp.25-31) encompasses the opportunity to challenge the state through “activism”, thus locating volunteering as a socio-political activity in the local community through for example, mutual aid and advocacy, where benefits are reciprocal based on principles of solidarity, collaboration and altruism and volunteers become the organisation. Activism also has synergy with co-occurring motives underpinning human altruism when having high levels of empathy, social justice and responsibility (Feigin et al. 2014); having a commitment to “collectivism” and “principlism” such as acting for the benefit of a particular community and in response to a moral principle (Smith 2017, p.3); and in enacting political attitudes and values with causes that have meaning and significance (Bekkers 2005; Baines and Hardill 2008; Brodie et al. 2011). This is exemplified by Polly when she reveals how she gathered together a large group of volunteers to set up a helpline and how the group then in recognising a lack of peer led and user led support groups more generally, worked collectively to successfully set these up to meet a gap in current service provision.

Indeed, influence and activism in volunteering aligns with a social model of disability focusing on full participation in society and specifically emancipation where disabled people have the power to challenge negative perceptions and by way of a collective identity, are in the best position to influence and manage services and organisations (Shakespeare 2013). In her interview, Polly states how through volunteering she had become: “part of a group of really passionate advocates who were…pioneers because this was the first time there had been advocacy in the UK”, thus concurring with Harper and Speed’s (2012) and Shakespeare’s (2013) views that having a collective identity, in this case as a group of volunteer advocacy workers, is an important pre-cursor to emancipation, influence and change for marginalised groups, and in Polly’s example, influenced the beginning of an advocacy movement in the UK, a movement that has since become significant in changing service delivery, policy and legislation for people living with mental illness.

However, Polly also recognises the limitations of an advocacy role when she states in group 2: “I became really passionate about advocacy…but also very clear that you are there to stand alongside the person and to put forward their views and not your views.” Through personal experience of using mental health services and supporting others, she adds:

> …..I actually began to get much stronger views about services and also about the amount of harm that mainstream services can do and so…advocacy isn’t something I can do anymore…because my own views about it are actually too strong. (Polly, extract group 2)

What Polly is indicating here is that advocacy is not always sufficient, and that activism is necessary for change to be realised. Indeed, activism has the potential to expose disabling societal structures that continue to marginalise disabled people (Oliver 1992) and to disrupt the hegemony of professional services by giving control to disabled people for disabled people through disabled organisations (Oliver 1992; Stone and Priestly 1996; Oliver 2002). Influence and activism enable people with lived experience of mental illness to pay closer attention to power relationships where debates can be challenged on behalf of survivor movements campaigning for a radical rethink of what forms of knowledge are privileged, how mental health is conceptualised and how services are delivered (Bracken et al. 2012; Kinderman et al 2013; Timimi 2013; Wright 2014). Further, influence and activism reflect a critical-emancipatory paradigm that seeks to expose inequality, exploitation and injustice and give voice to excluded and marginalised groups to help clarify oppression in order to precipitate social change (Henn et al. 2009). There is also clear resonance here with Freire's (1970) pursuit of emancipatory action and social justice through a model of social transformation as previously discussed in relation to participatory action research through systems of participatory governance, education, dialogue and finding collective solutions in recognition of the power struggles that support or challenge change (Schugurensky 2014).

Interestingly, volunteering within the voluntary sector offered participants more flexibility to challenge boundaries than could reasonably be achieved through paid work. In Polly's interview she alluded to examples of receiving funding for projects that were more controversial and that challenged mainstream services and thus would not normally be supported by Lottery funding or NHS service commissioning. In this way, volunteering has the potential to offer more of an opportunity to influence organisations and try out new ideas that are going to make a difference than can reasonably be achieved from within statutory services. This is an important point that was also reflected in participants' views of the changing context of health and social care delivery initially brought about by the move to community care in the 1990s and closely followed by neoliberalism and austerity measures with reorganisation involving significant funding cuts to services and competitive markets. Participants were vocal about the changing role of the voluntary sector with charities competing to be commissioned by the NHS and Local Authority to deliver health and social care services in line with service led agreements. This was viewed as a significant shift from the autonomy of an independent sector working to meet the needs and rights of vulnerable societal groups to becoming a commissioned service with the client becoming the commissioner. In addition, participants recognised that charities had been forced to adopt business models in order to survive in times of austerity. Polly nostalgically states: "in the old days you were…really able to challenge things that were happening in the local authority, and do things, because you weren't actually being funded by them". However, rather than viewing these shifts as discouraging, Polly remained optimistic about other ways of volunteering describing the voluntary sector as “still a sector which is very ripe and quite clever”. Indeed, Polly had chosen to position herself outside formal charitable sector commissioned services within community groups, recognising the value of social enterprises. This aligns with Wilcock’s (1998b; 1999) concept of becoming from an occupational science perspective which considers how our actions influence the future and have the potential for personal growth and transformation through realising hopes and ambitions. Arguably, Polly’s narrative supports a view of becoming through volunteering which offers her the potential for recovery, growth, transformation and human flourishing.

Additionally, this reinforces the importance of having agency and fits with the growth in independent advocacy services and the rise in community groups driven by the user movement, to empower user voices. Having agency, influence and the potential for activism also aligns with the top three rungs of Arnstein’s (1969; 2011, p. 5) ladder of citizen participation representing “citizen power” with increasing decision making authority from enabling negotiation through “partnership” to full managerial power associated with “citizen control” (Arnstein 1969; 2011, p. 5). Arguably findings from this study also reflect Kotus and Sowada’s (2017, p. 79) extension to Arnstein’s (1969) ladder of citizen “awakening” with the beginning of engagement in discussion and the potential for radical action to protest against coercion and manipulation to combat declining rights for disabled people. In adopting an emancipatory approach, Mad Pride advocate for alternative possibilities for recovery including full participation in decision-making and organisational governance as “consumer/survivors” (Lewis 2013, p.121; Timimi 2013). However, despite recognising some improvement in user participation in health and social care agendas Beresford (2019) cautions that continuing inconsistencies through competing ideological and neoliberal political agendas between service users and the state include a lack of funding opportunities for user-led organisations to remain sustainable.

Finally, whilst there appears to be general agreement amongst occupational therapists of the importance of valuing people as individuals and recognising their role as agents of change in their recovery (McKay 2010; Hitch et al. 2013, p. 85); and recognition that supporting people to flourish and take charge of their own lives through friendships and mental health activism (McKay 2010) is important, there is limited evidence in the literature of how meaningful occupational engagement supports activism. One exception is Bryant et al. (2019) who recognise the value of and potential for activism to raise issues that can change services for the better, as a developmental outcome of participatory and inclusive research involving mental health service users. Interestingly, Bryant et al. (2019, p.21) recognise that whilst activism may not be perceived as such by those involved due to its militant associations, direct experiences can positively “direct and disrupt processes” and as such, the potential for activism should be embraced wherever people are.

This section has highlighted the benefits of volunteering from the findings and the literature proposing an original theory of five conditions for successful volunteering with lived experience of mental illness to support recovery. Interestingly, these conditions have synergy with occupational therapy theory where meaningful occupation is a central mechanism for health and wellbeing through a process of doing, being, becoming and belonging (Wilcock 1998b; 1999; 2007; Wilcock and Hocking 2015). The conditions also have synergy with the principles underlining the Scottish Government’s (2019b) national framework for volunteering which includes opportunities for inclusive, flexible, meaningful volunteering, where people feel valued, supported, enabled, and connected. However, findings also revealed a darker side to volunteering with participants experiencing interference and disempowerment associated with control exerted by a range of systems, policies & legislation affecting out-of-work disabled benefits claimants and ultimately negatively impacting on participants’ mental health and wellbeing. These will now be explored.

10.2.2. Volunteering as multi-faceted including that of a dark side

> …..so there is this other dynamic, we all looked I think at the positive last time but there is this darker side. (Julie, group 2)

The dark side theme came from participant discussion that volunteering despite providing a range of advantages also contained a number of tensions, challenges and contradictions, which were experienced at both an individual and systems levels. The most pressing of these according to participants were concerns about national and political drivers related to the current socio-political context of government welfare reform and how this was impacting negatively on their volunteering experience and ultimately undermining their mental health and wellbeing. Findings revealed challenges around employment targets and welfare benefit sanctions; concerns about unfair assessments of fitness to work; a sense of falling through the gaps as a result of experiences of stigma and discrimination fuelled by negative media representations of being an out-of-work benefits claimant living with mental illness; and blurred boundaries between what is paid work and voluntary work. These finding were compelling and for some participants, had taken on a surreal or Kafkaesque quality imbued with contradiction and uncertainty revealing the qualities of a nightmarish, absurd and oppressive world resonant with Franz Kafka's fiction. This section considers the challenges that hindered participants in their recovery through volunteering. It begins by discussing the impact of welfare reform and conditionality, driven by an agenda other than recovery. It then explores how this policy context, in reinforcing stigma and discrimination of out-of-work disabled people, is experienced by the participants in this study. Finally, it questions the hegemony of paid work, the blurring of boundaries between volunteering and paid work and highlights potential challenges for occupational therapists.

In order to fully understand human occupation, the political, sociocultural and historical context in which it is experienced needs to be more critically investigated. Whilst the title of this theme sounds similar to occupational therapy literature referring to the dark side of occupation (Twinley 2013) it would be misguided to see these as comparable. Whilst Twinley's (2013) definition refers to people finding meaning in deviant or harmful occupations considered antisocial and health compromising, the dark side of volunteering in this study critically reflects how the current UK socio-cultural and political context is having a negative impact on people's experience of volunteering and potentially jeopardising benefits to participants' mental wellbeing. This is arguably more an issue of occupational injustice (Townsend and Wilcock 2004). These findings warrant further discussion.

1. Impact of welfare reform and conditionality

> …..they've got quotas and they've got targets…if you sign on later in the week you're more likely to be sanctioned because they're trying to meet the targets. (Doug, group 3)

Welfare reform and austerity measures in the UK have had a significant impact on the context of volunteering for people with lived experience of mental illness in this project. Indeed, the Conservative government's Department for Work and Pensions (DWP) continues to emphasise the centrality of work through successive legislation in relation to welfare reform, redefining the agreement between the state and the citizen as to what is provided in terms of welfare support and what is mandatory in return (Patrick 2017). Welfare reform was based on the government's view that out-of-work claimants including disabled people, had become too dependent on benefits rather than obtaining paid employment; and that this was promoting a culture of dependency and irresponsibility which was in marked contrast to responsible citizens who were in work; thus defining from the outset the difference between the "deserving" and the "undeserving" (Patrick 2017, p.2). The impact on participants of this stigma and discrimination will be revisited. Indeed, there is cross-party agreement that the solution to minimising poverty is through welfare reform, getting people into work, without any critical consideration of the experience of low pay and poor working conditions (Jensen 2014). Participants recognised that paid work was privileged over volunteering and felt stigmatised by virtue of being a disabled out-of-work benefits claimant. Findings from this study concur with evidence suggesting that the goal of facilitating people from out-of-work benefits into work, with reduced levels of financial support and a narrowing of entitlement (Patrick 2017) has resulted in a number of ethical, financial and social wellbeing issues for people with lived experience of mental illness (Grover and Piggott 2010). Furthermore, participants raised concern that the welfare benefits system appeared at odds with a recovery culture and was putting volunteering and their mental health and wellbeing at risk. These finding will now be explored.

Participants distrusted the benefit system and were confused about what benefits they should receive and whether they should be seeking work or be deemed unable to work due to their mental health; and believed that they were often misinformed. Being subjected to constant assessment and form filling was stressful particularly when this focused on their deficits rather than their assets, which was in marked contrast with the philosophy of self-management and recovery. Paradoxically, taking personal pride in coping could be misinterpreted resulting in them being perceived as more capable than they were, which could lead to losing benefits they were entitled to. Participants reported a lack of trust and cynicism with the system. They commented on the arbitrary nature of categorisation outcomes that depended on quotas and targets. Benefit sanctions were feared, placing people in financial difficulty. Participants felt they were in a precarious position and worried that they might inadvertently do something to jeopardise their benefits. Further, the poor reputation of welfare benefit assessors added to their distrust of the system. Jensen (2014, p.2) recognises how "social security has been corroded under neoliberalism and replaced with a more punitive and limited model of welfare, littered with sanctions and restrictions and characterized by conditions to be satisfied, rather than by universal entitlements". This punitive regime is disempowering and contrasts with the ability and opportunity to express and experience hope, choice, control and empowerment associated with wellbeing and recovery (Hammell 2017). It negates opportunities for transformation, growth and human flourishing as agents of change (McKay 2010; Hitch et al. 2013); and is removed from calls for emancipation and full participation in decision-making as espoused by disabled activist groups supporting a social model of disability (Lewis 2013, p.121; Timimi 2013). Further, it is a matter of occupational injustice when socio-political conditions trigger stressful occupational experiences (Townsend and Wilcock 2004); and where opportunities to engage in healthy occupations that support people to use their abilities, develop positive identities and contribute to society become jeopardised (Durocher 2017).

Being assessed and re-assessed for fitness to work was alarming and participants were anxious that the pressure to take up paid work or face benefit sanctions was negatively impacting on their mental health, ultimately leading to a crisis situation with loss of benefits, acute mental illness and potential self-harm. Participants recognised that this was exacerbated when facing benefit appeals and tribunals. This concurs with evidence that six-monthly re-assessments of disabled people were responsible for a significant increase in the number of suicides, self-reported mental health concerns and higher rates of anti-depressant prescribing (Barr et al. 2015). Indeed, people with mental health problems may be hit hardest in the re-assessment process as psychological issues are rarely considered and people may appear capable at the assessment but may have hidden support needs (Watts 2017). Further the tick box structure of the work capability assessment (WCA) is noted to be unable to cope with gradations of complex health problems failing to recognise the fluctuating nature of chronic illness meaning that many people are classified as fit-for-work despite medical evidence to the contrary (Gentleman 2011b; Gillberg 2016). There are numerous personal reports of unfair assessment outcomes in the media (Gentleman 2011b; Goodley et al. 2014; Gillberg 2016; Moore 2017; Petrie 2017). Participants' distrust and cynicism is perhaps justified considering the number of successful appeals, reflected by The Independent's (Moore's 2017, online) strapline "It's funny that there are so many successful appeals against disability assessments – it's as if there is something wrong with the system". Whilst the title is humorous the message is sobering in reminding us of the waste of tax-payers money in a flawed system; and the stress endured by people with lived experience of mental illness navigating the appeals process (Moore 2017). Furthermore, participants reported that once recognised as capable of volunteering, they were perceived as capable of paid employment. Volunteering and paid work become conflated, disregarding participants as still in recovery and failing to recognise the value of flexibility in volunteering to manage fluctuating mental health. Indeed, participants were concerned that substantial gains from volunteering would be undermined by anxiety about paid work and recognised the government as short-sighted due to potential costs in managing mental health crises. This is exemplified by Doug (group 3):

> …..I went for a job interview and even though I wanted it, I was terrified of getting it because I get very stressed, very preoccupied with it…and things become bigger than they are…Someone in [my] situation can offer the community good voluntary work but stresses and becomes ill if they have to go into a paid environment.

Interestingly, any social capital gains or contribution to the global economy in offering the community "good voluntary work" appear undervalued in a neoliberal society with a government intent on reducing welfare benefit costs. Participants also reported concern that people with lived experience of mental illness may be prevented from volunteering because it would signal being "fit for work". Interestingly Doug uses the term "device" in the following quote, which can be used for both good and bad, depending on who is using it:

> .....it's an ironic sort of thing…voluntary work could be a device to get you back into the idea of work, but it could also show that you are capable of work which…can be off putting for folk which is a real shame because it would really benefit people. (Doug, interview)

Unsurprisingly, benefit sanctions linked to the principal of conditionality were a further source of concern for participants. The claimants commitment (DWP 2014), an agreed, personalised contract with expectations of adhering to job seeking and training to secure paid employment or face benefit sanctions (Gauke 2017), occurs when people are assessed as fit for work and must undertake work preparation activities for 30 hours per week to retain their benefits. Not complying with conditionality carries severe consequences that can lead to suspension of benefits from anything between four weeks and three years (Newman 2011; Jayanetti 2017). Sanctions and compulsion to find work have a negative impact on self-esteem and mental health leading to further social exclusion including significant debt and hardship for an already marginalised and vulnerable population (Newman 2011). Significantly, the threat of benefit sanctions changes the power dynamic between the out-of-work claimant and employment support services from one of support, co-ownership and empowerment to one based on punitive measures of conditionality (Newman 2011). Indeed workfare, the government's mandatory work activity process of working for your benefits, is contentious and has been criticised for undermining working conditions by replacing jobs and undercutting the minimum wage (Clark 2013; Friedli and Stearn 2015). Perhaps unsurprisingly, a large-scale longitudinal study found that welfare conditionality is ineffective in helping people including disabled people into sustained paid work with findings suggesting that periods of short-term employment and unemployment are routine; and that negative effects of conditionality include increased poverty, disengagement and a worsening in physical and mental health conditions, making paid work more difficult to achieve (WelCond 2018). WelCond's (2018) recommendations include a more effective, ethical, voluntary and individualised approach to employment support for disabled people. Participants in this project were uncomfortable being compelled to work and believed this violated their right to choose work freely in relation to their fluctuating mental health. This is a matter of occupational injustice and more specifically occupational deprivation characterised by marginalisation and denial of opportunity to participate fully in society due to socio-economic and political factors including policies and regulations that are imposed and are beyond the immediate control of the individual (Whiteford 2000; 2011; Whiteford and Townsend 2011; Wilcock and Hocking 2015). Additionally, Paz-Fuchs and Eleveld (2016) suggest workfare programmes offer less employment law protection than that given to paid employees despite similarities in role and expectation.

Participants were concerned that volunteering had become a work preparation activity that claimants were required to undertake to prove that they were actively preparing for work. Controversially, this disregarded the volunteering they were currently doing, regardless of whether this benefitted their wellbeing, in favour of volunteering that was deemed to provide skills that were more likely to lead to paid work opportunities. Therefore, participants were compelled by the DWP work programme providers to volunteer in an area that was more likely to lead to paid employment. Thus, volunteering became mandatory and people could no longer choose the volunteering they engaged in. This views volunteering through a work lens where paid work is positioned hierarchically and volunteering is perceived as a means to employment in a type of “investment model”, rather than an end in itself (Ellis Paine et al. 2010; Ellis Paine et al. 2013, p.18). Indeed, the UK government in setting targets for volunteer organisations to get people into paid employment through volunteering further reinforces this hierarchy and the relentless drive towards paid work. Jones (2013) agrees that mandatory volunteering contradicts the essence of volunteering and potentially damages its reputation. It can be perceived as punishment for unemployment and prevents people from having time to do things they find more meaningful including volunteering through personal choice (Coote 2014; Moore 2014). Whilst charities have a strong history in supporting people back into employment through community connections and offering people valuable opportunities to develop skills and support causes about which people feel passionate, mandatory volunteering contradicts the ethos of volunteering as mutually beneficial and puts charitable organisations into the position of enforcers of DWP schemes that involve benefit sanctions for people who do not participate (Bubb 2013). Jones (2013) urges charitable organisations to protect the notion that volunteering is time given freely rather than allowing it to become conflated with a different type of engagement. Indeed, Baines and Hardill (2008, p.315; p.308) caution against volunteering becoming “rebranded in ways that privilege its association with employment, and that marginalize notions of altruism and caring” recognising that volunteering can offer “spaces of hope” to those excluded from paid employment through labour market failure. Given that many people who volunteer do so as an “alternative to employment”, this should become the focus, where volunteering viewed through an alternative lens emphasises more valuable outcomes (Ellis Paine et al. 2013, p.19), including arguably, the opportunity to recover.

Indeed, mandatory volunteering lacks any understanding of volunteering as a mechanism for recovery and is at odds with the conditions supporting recovery as identified at the beginning of this chapter. It negates the importance of synergy to ensure that volunteering is meaningful. It prevents opportunities for flexibility to enable participants to tailor their fluctuating mental health to their volunteering commitment. It denies participants the potential to meet needs for identity and connectedness; and disregards the principles of recovery and those of the social model of disability in supporting full participation for people with lived experience of mental illness to be empowered through agency, free choice and control to influence and make a difference through activism. Further, it confirms Cameron's (2015) definition of disability as a social role that:

> simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal. (Cameron 2015, p.118)

Moreover, this oxymoronic position reflects the surreal or Kafkaesque quality experienced by participants imbued with contradiction and uncertainty revealing the qualities of a nightmarish, absurd and oppressive world resonant with Franz Kafka's fiction as referred to earlier. From an occupational justice perspective, mandatory volunteering typifies the concept of occupational alienation characterised by estrangement from self and society and disempowerment due to institutional forces that prevent individual occupational potential being realised (Wilcock and Hocking 2015); and arises when there is a loss of purpose through an imposition to engage in occupations that are neither meaningful nor health promoting, and may be manifest through obligation or force and institutional structures causing potential detriment to the person's identity and development (Townsend and Wilcock 2004; Durocher 2017).

Participants viewed the government's railroad approach of getting people into work as intent on meeting employment and welfare spending targets regardless of any detrimental effects to their mental health and wellbeing, removing choice, purpose and meaning in volunteering; preventing flexibility in the number of hours volunteered as a person's mental health allowed; and ultimately disregarding the fluctuating nature of mental illness thus disempowering participants who had expertise in knowing what worked to keep them well. As Polly passionately states:

> …..so, somebody who may already be volunteering [in advocacy], they might be told no you can't do that anymore…go and work in this charity shop…But it means that…somebody who's…passionate about…using their knowledge & skills to help other people suddenly being told…you just need to go and

> work in the [charity] shop & sort out old clothes in the back room, or something that they have no passion for. (Polly, group 1)

Whilst the government could be commended for attempting to support disabled people into work, welfare reform policies namely, conditionality and workfare, remain contentious. These individualise social issues, redefine workability and fail to recognise wider socio-economic difficulties in the labour market, thus further marginalising and socially excluding disabled people. Volunteering becomes mandatory and getting people back to work becomes conflated with getting people off benefits which obscures what is really happening. People with lived experience of mental illness are being disabled by welfare systems and forced into situations they find stressful risking becoming mentally unwell due to government pressure. This is at odds with the recovery culture & undermines people's ability to self-manage their own health & wellbeing.

Interestingly, through euphemism, language is used to conceal different objectives. For example, volunteering as part of their recovery journey has become hijacked by the DWP who say that if you are able to volunteer then you are able to work; and to prepare for work you must volunteer in an area chosen by them or face benefit sanctions. Labour in changing the name from the Department for Social Security (DSS) to the Department for Work and Pensions (DWP), shifted the focus from the language of security to one where work is deemed the best way for people to secure their own personal welfare and where concerns about welfare dependency have continued to pre-occupy successive UK governments (Lister 2016). According to Beresford (2016, p.2) the term welfare has become contentious yet "is essentially concerned with how we take care of each other as human beings". Indeed, the government's focus on achieving independence from the welfare state is interesting as arguably in a society where inter-dependence exists, it is difficult to conceive of people being wholly independent from social and welfare support (Beresford 2016; Patrick 2017). Furthermore, whilst welfare in the UK in relation to the welfare state was viewed as positive in supporting people "to fare well from cradle to grave", the phrase "welfare dependency" from the USA signifies a negative, limited and stigmatised view which denies dependency as part of being human (Lister 2016, p.xi). What is needed is a system where social security relieves as well as prevents poverty and provides everyone with genuine protection and support at difficult times (Lister 2016); and a society that reminds us that unpredictable life circumstances can affect everyone where “there is no “them and us”- just us” (John Hills 2015, cited in Lister 2016, p. xii). Indeed, stigma and discrimination was an important theme from the findings and will now be considered.

2. Experiences of stigma and discrimination

> …..if you took a poll and gave everybody a truth drug in this country, an awful lot of people would say that they think a lot of people are pretending to be mentally ill…just to get money. (Doug, group 2)

Findings from this project revealed participants’ experiences of stigma and discrimination and their concerns that the effects of the current welfare system and the reporting of this in the media contributed to the polarisation of people with lived experience of mental illness into stereotypes of either benefit scroungers or dangerous, psychotic individuals. Somewhere in the middle was as Julie (group 3) explains: “the mess that is ordinary living for most of us” and a sense of falling through the gaps. Indeed, according to participants, discrimination against people living with mental illness was widespread and featured within the government; media portrayals of people on benefits; public perceptions of the experience of mental illness being less deserving than physical impairment; attitudes of prospective employers; and even amongst mental health professionals, emergency hospital services and GPs whose role participants believed was to support vulnerable people. The latter again seems to reinforce the theme of contradictions and Kafkaesque experiences referred to earlier.

Literature confirms a rise in public support for stigmatising media coverage where people receiving welfare benefits are objectified for the gratification of others (Jensen 2014; Patrick 2017). Indeed, politicians and sections of the media regularly reinforce derogatory judgemental attitudes and make moral judgements about deservingness (Briant et al. 2013; Jensen 2014; Patrick 2017). According to Jensen (2014, p. 2) a punitive model of welfare incorporating a derogatory welfare discourse has become legitimatised through the media suggesting that people claiming benefits don’t want to work and are happy to be rewarded by the welfare system for not working. People are represented by simplistic binary positions such as passive versus hard working; dependent on welfare versus independent and employed; responsible versus irresponsible (Jensen 2014). More importantly, there is a lack of critical engagement with the wider socio-political context including the serious challenge of paid employment in a neoliberal economy (Jensen 2014); and that many people are forced into a cycle of moving between low paid work and unemployment due to the insecurity of available work and reliance on benefits for those in poorly paid work (Lister 2016). Indeed, social issues have become individualised denying systemic causes of poverty, viewing people as problematic and relying on media support and political action to redress the balance (Patrick 2015).

More significantly, the stigmatisation and shaming of disabled claimants is also well reported in the literature (Garthwaite 2011; Newman 2011; Briant et al. 2013; Garthwaite et al 2013; Coote 2014; Garthwaite 2015; Baumberg 2016; Beresford 2016; Patrick 2016; Patrick 2017; Gedalof 2018) with disabled people traditionally regarded as deserving now perceived as “undeserving claimants” and “workshy” needing continuous medical assessment to prove their eligibility for welfare support (Patrick 2017, p.6). Thus, the term skiver as a person of social loathing has been roused by wilful and premeditated media attention to denote welfare trickery and fraud; and by inventing anxieties about the fraudulent activities of people entitled to welfare support; such entitlements can be more easily challenged (Jensen 2014). Gedalof’s (2018, p. 83) research on the changing narratives of disabled people has particular resonance with participants, specifically the shift in the discourse around disabled people as vulnerable individuals deserving of charity to that of “benefit scrounger”; the reframing of the social model of disabilities’ recognition of the rights and language of independence and autonomy to one where disabled people require state intervention, surveillance and discipline; and a view supporting all disabled people as “work-able”, conferring status through their relationship to paid work. This resonates with Cameron’s (2015) affirmative model definition of disability which includes the roles that people are required to adopt in relation to their impairment whether one of personal tragedy or denial of difference in response to the dominant societal discourse of what is considered normal (Cameron 2015). It also reinforces the social model of disability’s position that disabled people can and should work as all that is needed is some form of environmental adaptation (Shakespeare 2013). Concerningly, there is no opportunity to consider the complexities surrounding the lived experience of mental illness (Gedalof 2018) or to recognise the complex interplay between disadvantage and individual impairment (Shakespeare and Watson 2010). Indeed, evidence exists for a growing lack of compassion towards disabled people including those living with mental illness (Briant et al. 2013). Whilst, disabled people with a physical or sensory impairment are viewed as having “triumphed over adversity” and considered deserving in line with the dominant and presumptive personal tragedy and abnormality view of disability and impairment (Swain and French 2000), people with more invisible impairments such as mental illness, chronic pain or depression are viewed as potentially faking their symptoms (Briant et al. 2013, p. 884). This appears far removed from Cameron’s (2015, p. 118) preferred definition of impairment where “difference divergent from culturally valued norms of embodiment” can be “expected and respected” in a diverse society.

Interestingly, participants themselves adopted binary labels to illustrate discrimination of mental illness, using the terms “fakey” and “stabby”. Fakey, were people who faked mental illness to avoid work and claim additional benefits and were viewed by participants as chancers of the system. This is reflected in Doug’s quote at the beginning of this section. Stabby, referred to people living with mental illness as dangerous psychotic killers. Participants claimed that the majority of people like themselves were falling through the gap between these two polarised positions. It appeared to them that the fakey people were actually quite robust in getting what they wanted, a type of “Jack the lad” who according to Polly (group 4) were people with “non-existent disabilities, people who claim to be depressed or anxious”, whereas the stabby group, were genuinely people living with severe mental illness who were a significant risk to themselves and/or others and needed additional support. What troubled participants as the group in the middle, was that they were also coping with mental illness, but because they were not viewed as a risk to others, they were less likely to receive the help that they needed. Participants concluded that in order to get help, you had to conform to one or other of those stereotypes. The government’s reclassification of disability categories, evident in the fitness for work assessment has elevated thresholds of ability to consider those previously categorised as disabled now fit-for-work, thus reclassifying “disabled people as non-disabled people who are pretending to be disabled” (Briant et al. 2013, p. 885). Therefore, this notion of being seen as faking mental illness has to some extent been triggered by the government. Being forced to conform to a stereotype is interesting and supports Cameron’s (2014; 2015) proposal that the affirmation model should be used as a tool to reveal the conflicts experienced by disabled people in creating positive identities in everyday encounters where self-image and understanding are formed by both structural inequity and individual experience; and to expose how negative assumptions about disability continue to affect the social relations encountered by disabled people in their everyday living.

Acknowledging people as fakey chancers claiming to have mental illness, aligns with Patrick's (2017, p. 168) process of "defensive othering", a response used to cope with the shame of being a disabled out-of-work benefits claimant where stigma is deflected onto those that are perceived as less deserving than themselves in order to strengthen their own sense of deservingness and protect their self-identity. This also has resonance with Pemberton et al.'s (2016) study where participants were keen to deny any identification with worklessness, which they attributed to others. However, as previously noted this unwittingly colludes with and supports the dominant narrative already espoused by politicians and the media as a form of social control and dilutes any potential collective challenge of solidarity to the current situation (Tyler 2013; Pemberton et al. 2016; Patrick 2017). Findings from this study add support to Baumberg's (2016) recommendations for reducing benefits stigma by calling politicians and the media to account for their continuing role in propagating stigma against disabled benefit claimants; by making the process of claiming benefits more respectful; and by changing the structure of the benefits system to be more universal, more generous and less conditional. The findings also support Lister's (2016) call for a social security system that provides us all with genuine protection and support at difficult times in our lives and is a poignant reminder that "there is no "them and us"- just us" (John Hills 2015, cited in Lister 2016, p. xii) as previously stated.

This section has discussed findings arising from the tensions and challenges of volunteering as experienced by participants at both an individual and systems level in light of the wider political context and the influence of the UK government's welfare reform on the volunteer experience. It has discussed the contradictions and challenges surrounding volunteering for people recovering from mental illness including the impact of benefit sanctions and conditionality; tensions surrounding mandatory volunteering; and experiences of stigma and discrimination. This chapter now turns to consider the hegemony of paid work, the blurring of boundaries between volunteering and paid work, and the challenges for occupational therapists.

10.2.3. The hegemony of paid work

Hegemony is usually attributed to Antonio Gramsci (1891-1937), the Italian communist politician and Marxist philosopher to describe a system whereby the ruling capitalist class:

> …..provide philosophy and ideology for the masses…to exercise “hegemony” by supplying the system of belief accepted by ordinary people so that they do not question the actions of their rulers. (Joll, 1977, p. 90)

Such ideology relies on assumptions about reality that gain traction through dominant social forces to become what Gramsci called “common sense” (Hoare and Smith 1971, p. 322). These “common sense” values denote an uncritical and taken for granted view of the world that continues without question thus maintaining social order and consent (Hoare and Smith 1971, p. 322). This has resonance with Pierre Bourdieu’s (1972, in Jensen 2014, p. 2) notion of “doxa” meaning “that which goes without saying because it comes without saying” thus reinforcing how critical analysis and debate become denied; the perceived order of the social world becomes viewed as self-evident and legitimised (Jensen 2014); and people internalise and embody often oppressive parameters regarding a sense of their place in life (Kielhofner et al. 2011). According to Jensen (2014) common sense welfare discourses suggest that paid employment is the only way to escape poverty and that total employment is possible in neoliberal times of austerity. This section draws on the findings to explore the hegemony of paid work, espoused by the government through welfare reform; accepted within UK culture as a mark of the dutiful tax-paying citizen; and arguably endorsed by the occupational therapy profession’s emphasis on achieving paid employment outcomes for disabled people through vocational rehabilitation. It considers blurred boundaries between volunteering and paid work, before exploring alternative positions.

The current UK context of welfare reform, austerity and neoliberalism is driven by the hegemony of paid work. This raises several tensions. Firstly, paid work is viewed as central to defining the dutiful citizen in a “contractual form of citizenship” where people are expected to work for their benefit payments or face sanctions (Patrick 2017, p. 23). This includes coercive training programmes geared towards building skills and modifying attitudes to become more employable through a process of reactivation, often experienced as pointless and humiliating (Briant et al.

2013; Friedli and Stearn 2015). The language of reactivating out-of-work disabled benefit claimants into a working life reinforces the power dynamic where disabled people are arguably passive within a paternalistic and punitive system, which appears at odds with the recovery language of agency and emancipation. In terms of agency, participants believed they were making a significant contribution to their community through volunteering but continued to be labelled and stigmatised as out-of-work disabled benefit claimants.

Secondly, the focus on work reinforces an able-ist agenda where everyone is viewed as capable of employment given the right support. Arguably, this supports the social model of disability’s call for full participation in society where disabled people can and should work because all that needs to be done is to adapt the environment whilst denying the lived experience of disability and disregarding impairment as a problem (Shakespeare 2013). Whilst the attraction of support into paid work for some disabled people cannot be disputed, experience suggests that many disabled people face further exclusion, marginalisation and poverty (Newman 2011; Grover 2017). Interestingly, Gedalof (2018) examines how the selective appropriation of the disability rights movement’s language of independence and being more than a label is specifically linked by the government to work, thus supporting an able-ist agenda where a person’s worth is measured by their workability which is regularly re-assessed with any lack of progress punishable through benefit sanctions. Participants in this study did not feel work-able despite the fact that they were volunteering. Furthermore, many participants had made a conscious choice to volunteer as an alternative to work due to the positive impact volunteering was having on their wellbeing. Despite the offer of the right support into work, many did not believe that paid work could offer the same wellbeing effects. Drawing on classic economic theory where the main purpose of work is viewed as generating income, O’Halloran et al. (2018) recognise a disconnect between the espoused benefits of getting work and the actual experience of being in work. Indeed, whilst evidence suggests that being unemployed has a negative impact on mental health, up to 30% of paid work increases the risk of mental illness and fails to lift people out of poverty (NHS Scotland 2016). Indeed, for people living with fluctuating mental illness, NHS Scotland (2016) recommends focusing on improving and/or managing the condition before considering employability. Applying a critical occupational lens in a study of the experience of long-term unemployment in government activation programmes during neoliberal times of austerity, Rudman and Aldrich (2016, pp. 6-7) describe a tension between people "doing all the right things" to become re-employed including volunteering to enhance work options whilst experiencing being "activated but stuck" where people's lives are "on hold" as they cycle between unemployment and precarious paid work. Feelings of uncertainty were pervasive leaving people stuck "in survival mode, in financial dependency, in having less access to healthy food, in the life course, in housing, in relationships, and in options for leisure" often leading to depression, isolation, negative self-worth and disillusionment about the future thus demonstrating the wider implications and negative consequences of unemployment for health than solely having a lack of work (Rudman and Aldrich 2016, p. 7). Similarly, Hamer et al.'s (2017, p. 80) qualitative studies of people recovering from mental illness described them as "citizens in waiting" often excluded from the occupations enjoyed by others including paid work due to the stigma and discrimination associated with having a mental health label.

Finally, paid work is viewed as unproblematic and endowed with transformative properties as the only way to beat poverty despite the reality that paid work is often poorly paid, precarious and potentially demeaning (Hamer et al. 2017; Patrick 2017, p.28; Bloodworth 2018; Gedalof 2018). This individualises the problem away from wider issues such as "market failure, precarity, the rise of in-work poverty, the cost of living crisis and the scale of income inequalities" (Friedli and Stearn 2015, p.45; Wright 2016). Indeed, precarity has given rise to a rapidly emerging group of people named the Precariat, characterised by insecurity and angry disillusionment from unstable living and unstable labour in short-term, temporary and often meaningless paid work, with no rights or specific occupational identity or sense of becoming (Standing 2011). Hamer et al. (2017) suggest that this is also the experience of people recovering from mental illness who are viewed like the Precariat as dangerous, underserving and not to be trusted. Further, Standing (2011) recognises the Precariat as the first social class in history whose level of education is above that of the level of work they are expected to obtain. Indeed, paid work is often elusive and transitory (WelCond 2018). Job growth in the UK since 1995, arguably influenced by increasing reliance on automation and technology, is now characterised by temporary, part-time and freelance positions (Harris 2016) leading to a growing "gig economy" (Wilson 2017). Whilst offering flexibility in employment hours, the gig economy is also considered exploitative, offering no employment protection in terms of the national minimum wage or paid sick or annual leave (Wilson 2017). The acceptance of work insecurity has given rise to the heroic modern freelance worker as exemplified by Uber with people working up to 60 hours per week for a decent income arguably furthering the divide between the strivers and the skivers (Harris 2016). Thus, people have become commodities in search of buyers (Gollain 2018). Indeed, austerity with reduced work opportunities in the public sector and successive legislation to constrain trade union leverage regarding depressed wages, terms and conditions has paved the way for dependency on low paid private sector employment as the only alternative to extreme poverty and reliance on food banks for many people (Visentini 2018). Unsurprisingly, participants in this study acknowledged the realities of paid work:

> …..there isn't really a viable job market out there…They say things like there's a million private sector jobs but you'd have to analyse what the validity of those jobs are like, zero-hour contracts, part-time jobs. (Doug, group 3)

Harris (2016) cautions that the rhetoric of work and the worker no longer express any meaningful vision due to factors including increasing caring needs of an ageing society, the effects of automation and technology on employment, and a predicted loss of a third of jobs in the retail sector by 2025. Indeed, futurists recognise this as the dawning of a "post-work" era where automation alongside a growing population will lead to a time when people will experience episodic employment or a lifetime of unemployment (O'Halloran et al. 2018, p. 305). Employment figures are striking. Despite many people recovering from mental illness wanting to work, the percentage of adults with lived experience of mental illness in employment is significantly low (Bonsaksen et al. 2016) with only 10% of those living with mental illness in paid employment; disabled people more likely to be in low paid jobs and part-time work; and more likely to live in poverty with a third of families with a disabled person living in poverty (Low et al. 2015). Indeed, a recent House of Commons Work and Pensions Committee (2019, p. 3) report criticises the negative impact of welfare reform as not only pushing disabled people into poverty but also into "hunger and destitution"; and indicates that part-time work is not sufficient to lift people out of poverty. People with lived experience of mental illness often have more difficulty securing employment than the general population and those in mid-life are less likely to be employed (Bonsaksen et al. 2016). Furthermore, a meta-analysis of work-related risk factors for common mental health problems indicated that factors including occupational uncertainty, low job control, lack of value and respect in the workplace, role stress and low social support are associated with a greater risk of developing depression and/or anxiety (Harvey et al. 2017). Whilst it is difficult to argue that any help to work scheme that supports disabled people transition into paid employment does not have some potential benefit, it is problematic to defend a government that appears to conflate support with punitive measures and fails to recognise the contrast between the transformative potential of welfare reform on the lives of disabled people with the reality of the lived experience of welfare reform (Patrick 2017). According to participants, until the same wellbeing factors that are available through volunteering (i.e. flexibility, meaningfulness, choice, feeling accepted, valued and being able to make a difference) become conditions of paid employment, then volunteering will remain their first choice.

Reflecting on the usefulness of the occupational therapy literature in conceptualising volunteering (objective 7 of this study), the value of work appears to be a given amongst occupational therapists with paid employment viewed as providing a sense of worth through the construction of a positive worker identity within a valued social context (Van Niekerk 2009; Hitch et al. 2013; Fegan and Cook 2014); and offering security in living standards and wellbeing (Jansson 2019). Indeed, occupational therapists recognise the role of worker in western culture as pivotal in understanding perceptions and informing assumptions about an individual's socio-economic class, social and financial status thus revealing the high social value attached to work in western society (Blank et al. 2015). Paid work is recognised as highly meaningful for people recovering from mental illness in terms of self-perceived usefulness, social connectedness, income and structure (Marwaha and Johnson 2005; McKay 2010; Dominy and Hayward-Butcher 2012; Blank et al. 2015; Carmona et al. 2019). Not working is associated with feelings of social exclusion and not fitting in (Blank et al. 2015). The dominance of vocational rehabilitation programmes within the occupational therapy literature supporting people living with mental illness to access meaningful paid employment, is unsurprising given the emphasis on work and the worker identity in western culture (Aldrich and Dickie 2013). The UK government's drive to decrease the number of disabled people receiving out-of-work welfare benefits, including those recovering from mental illness is an additional push in the growth of this area for occupational therapists (DWP 2008; 2016) and emphasises how supported employment projects are enshrined in government initiatives (Talbot et al. 2018). Indeed, occupational therapy research emphasising maximising employment opportunities for people recovering from mental illness, promotes the success of implementing the individual placement and support (IPS) model, where people recovering from mental illness are placed in paid employment and supported to succeed (Dominy and Hayward-Butcher 2012; Fegan and Cook 2014; Modini et al. 2016; Schneider et al. 2016; Carmona et al. 2019). Volunteering is viewed as a pre-employment occupation for people with limited previous work experience or skills (Talbot et al. 2018). Whilst there is some recognition that paid work may hold ambivalence for people recovering from mental illness (Blank et al. 2015), with work perceived as stressful and potentially exacerbating mental illness (Marwaha and Johnson 2005), this is rarely explored within occupational therapy literature. Further, there is a significant gap in the occupational therapy literature looking beyond individual factors affecting employment outcomes for people recovering from mental illness to consider the impact of societal attitudes and work-related policies (Carmona et al. 2019). Given the current and predicted challenges of achieving paid work alongside recognition that some form of finance is needed for survival, both O'Halloran et al. (2018) and Jansson (2019) in their refreshing critiques, call for the dearth of literature surrounding an occupational perspective of unemployment to be urgently reviewed with consideration given to alternatives such as a Universal Basic Income.

Interestingly, Marwaha and Johnson's (2005) descriptive study of the views and experiences of employment for people recovering from psychosis resonates with the findings from this study despite differences in time and welfare conditions. For example, Marwaha and Johnson (2005) note that people regarded available paid work e.g. stacking shelves in a local supermarket, as lacking meaning and offering limited opportunity to feel appreciated. Respondents were concerned that such work would lead to a relapse of their mental illness, mirroring previously negative experiences of work (Marwaha and Johnson 2005). Interestingly, some respondents found meaningful alternatives to paid work leading Marwaha and Johnson (2005) to conclude that participating in social roles other than paid work e.g. caring, advocacy and volunteering provided significant benefits for people living with severe mental illness. Indeed, as previously stated, whilst some participants in this project were keen to transition into paid work from volunteering viewing it as a useful pre-employment occupation, the majority of participants were ambivalent about paid work and were actively pursuing volunteering as an alternative. Participants perceived volunteering as better supporting them to manage their enduring and fluctuating mental health condition. Volunteering compared more favourably to previous negative experiences of paid work and provided them with wide-ranging benefits that they did not believe they could achieve through paid work.

Although volunteering offers opportunities for social inclusion, it creates tension when the volunteer remains unemployed in a society where the hegemony of paid work is taken for granted. Indeed, volunteering within occupational therapy literature is predominantly regarded as a stepping-stone to employment rather than a meaningful occupation in and of itself. It is regularly advocated for people living with mental illness to recover their mental health and reclaim a valued social identity whilst offering a realistic work experience that proves readiness and competence as a worker (Fegan 2014). Whilst findings from this study concord with Fegan's (2014) findings supporting the importance of choice and meaning in volunteering alongside support to negotiate the right degree of challenge to build confidence and self-efficacy in a process of "personal, social and vocational recovery" (Fegan 2014, p. 172); they differ is in the emphasis given to paid work as an outcome. Fegan (2014, p.162) labelled people who appeared to get stuck in volunteering as "career volunteers" due to personal fears of readiness for paid work and concerns about their mental health, reflecting that perhaps participants were given less vocational goal orientated and structured support to progress further. This perceived lack of vocational progression reinforces a hierarchy where paid work is the ultimate goal. Thus, volunteering is a means to an end i.e. paid work, rather than a means in and of itself. Thus, volunteering is viewed as having less value than paid employment and "career volunteers" are viewed as potentially less than those who are capable of paid work. Volunteering becomes "othered" as an undesirable end goal. This reflects a glass ceiling view of volunteering where it is problematic in preventing people from progressing to paid work. Although Fegan (2014) acknowledges that work may not be advantageous to wellbeing for all and that the value of non-work occupations should not be misjudged, there is no expansion of this idea in relation to volunteering. In contrast, Smith (2017) recognises that volunteering can be an end in itself, and the significant value placed on volunteering in her study has concordance with findings from this study. However, Smith (2017) notes that paid work was not an option for her asylum-seeking participants, which potentially further reinforces a view that volunteering was second best in the absence of opportunities for paid work.

Wider literature reveals that volunteering has indeed a broad scope involving philanthropy and mutual aid; “governance” in decision making and political processes; “advocacy” and “campaigning” for improved services; and in fulfilling a personal passion and interest in sport, culture or the arts (Ellis Paine et al. 2010, p.22). All of which were recognised and valued by participants in this study. Somewhat surprisingly, the wider scope of volunteering as an “alternative to employment” is rarely addressed in the occupational therapy literature despite emphasising more valuable outcomes (Ellis Paine et al. 2010; Ellis Paine et al. 2013, p.19) and reflecting a number of values that occupational therapists hold dear in relation to meaningful occupation as a mechanism for wellbeing and the importance of personal choice, balance, agency and empowerment. Occupational therapy theory emphasises the notion of doing, being, becoming and belonging through meaningful occupation as a central mechanism for health and wellbeing (Wilcock 1998b; 1999; 2007; Wilcock and Hocking 2015). Being is investing meaning in life, drawing on personal characteristics and abilities to fulfil creative endeavours or occupational roles and involves self-reflection (Hitch et al. 2014a). Being is about being true to ourselves as individual human beings recognising our values and worldview and how this influences what we do (Wilcock 1999). Many participants in this study preferred volunteering to paid work as a way of being. Participants recognised that volunteering also offered them opportunities for personal growth and transformation through realising hopes and ambitions in line with Wilcock’s (1998b; 1999) concept of becoming that could not be achieved through paid work. Further, they recognised that volunteering presented opportunities for belonging where they could develop social relationships and gain a sense of connectedness to people, places and communities through reciprocity and mutuality (Wilcock 2007). Participants recognised the broader scope of volunteering where they could exercise personal choice to engage in philanthropy, governance, advocacy, campaigning and fulfilling personal passions and interests through volunteering whilst also recognising that this supported their mental wellbeing. Thus, volunteering was an active choice. Volunteering compared more favourably to their experience and perception of paid work, which although providing an income, offered fewer overall benefits to their wellbeing. Indeed, participants in this study reflected a strong volunteering worldview and appeared to view it akin to that of a career, or a calling where they were heavily invested in the ethos and outcomes of the organisation that they volunteered with.

Furthermore, viewing volunteering as preparation for paid work and forcing people into unpaid labour contradicts the spirit of volunteering (Coote 2014). It conflates volunteering and work and changes something purposeful into something perceived as potentially purposeless. As Coote (2014, online) states:

> …..people usually volunteer because they hope to find themselves in a congenial setting, doing work that is meaningful and personally fulfilling. Otherwise it is just thankless drudgery – no less demoralising and demotivating than long-term unemployment.

Coote's (2014) reference to thankless drudgery reflects participants' concerns and is reminiscent of Arendt's (1958 in Dant 2003, p.43) thinking about choice and meaning in distinguishing between labour and work, where labour is described as the necessary, on-going, grind of everyday life that "must be accepted as part of the human condition" thus indicating lack of choice. Arendt considered labour and more specifically "alienated" labour, drawing on Marx's view of loss of freedom and self-control in productivity through capitalism, as never ending (Arendt 1958, in Dant 2003, p.44); whereas work, a more creative process involves as an end point, the production of something that has permanence and utility beyond the labour process thus indicating creative fulfilment and being (Arendt 1958, in Dant 2003). It could be argued that meaningful volunteering as described by participants in this study, represents Arendt's (1958, in Dant 2003) view of work and aligns with being from an occupational perspective where personal creativity is invested in the process of doing. This compares to labour, a type of endless drudgery, perhaps exemplified by workfare programmes including mandatory volunteering where according to the participants in this study, there is a significant lack of meaning. Arendt's view of labour is also potentially represented by current demeaning forms of paid employment or zero-hour contracts where, as previously stated, workers have no control, or access to annual leave or sick pay (Bloodworth 2018; Gedalof 2018). Further, this aligns with Marxist alienation where through the process of labour workers become estranged from the products they produce (Dant 2003); and is captured by the term "occupational alienation" to indicate a process of "going through the motions" suggesting a lack of personal engagement or satisfaction in the task (Bryant 2014, in Bryant et al. 2017, p.74).

Additionally, blurred boundaries between volunteering and paid work make the link contentious. Participants voiced confusion surrounding differences and similarities between volunteering and paid work. Indeed, people often refer to volunteering as work, and volunteering has many "work like characteristics" with similarities to paid work in the time and commitment required; similar challenges of juggling family commitments as paid workers; and recognition that some of the tasks carried out may be the same as those given to paid workers (Baines and Hardill 2008, p.313). Categorising volunteering is complex because of the perception of being productive in a work like capacity whilst having choice and flexibility to do things that people enjoy doing rather than have to do (Aldrich et al. 2014). Unsurprisingly, participants in this study used the terms "working" and "volunteering" synonymously, indicating that volunteering was similar to working, despite being unpaid. Viewing volunteering as a stepping-stone to employment where the work element is central to both potentially reinforces this position. Some participants had experienced volunteering and being employed to do the same job and whilst the roles were the same, the psychological pressure felt different. Participants also described experiencing the same pressures as paid staff with no apparent difference in the organisation's expectations. In addition, participants were concerned that as volunteers, they may be replacing funded posts when funding was cut due to austerity measures. In the current economic climate, there is indeed sensitivity around job substitution, real or perceived where volunteers may be inappropriately expected to complete work that should be paid and therefore face exploitation (Naylor et al. 2013). Whilst there may be a degree of cynicism regarding volunteering being promoted as a guise for free labour (Naylor et al. 2013), it is clear that volunteering should not be about replacing paid workers (Department of Health 2011) and differences between paid employment and volunteering need to be more clearly distinguished (Naylor et al. 2013).

10.2.4. Counter-hegemony and the notion of "good sense"

Findings from this study problematise the hegemony of paid work in light of the experience of the volunteers, privileging real-world knowledge about volunteering with lived experience of mental illness. Given that being in paid work dominates government policy, defines the good citizen and influences occupational therapy practice, it is difficult to conceive of how the hegemony of paid work can ever be challenged and how volunteering might become a legitimate, viable and acceptable alternative to paid work for people with lived experience of mental illness. Whilst hegemony is undoubtedly complex, Hall (2011) recognises that:

> …..no project achieves a position of permanent “hegemony”. It is a process, not a state of being. No victories are final. Hegemony has constantly to be “worked on”, maintained, renewed and revised. Excluded social forces, whose consent has not been won, whose interests have not been taken into account, form the basis of counter-movements, resistance, alternative strategies and visions…and the struggle over a hegemonic system starts anew. (Hall, 2011, pp 727-728)

Counter-hegemony therefore refers to critically evaluating or disassembling hegemonic power in a bid to challenge dominant positions and propose moral and principled alternatives (Hall 2011). Gramsci’s notion of “good sense” is pertinent here referring to a pragmatic form of common sense based in realism rather than uncritical dogma (Hoare and Smith 1971, p. 323). In searching for good sense, this chapter now turns to consider some viable arguments and alternative positions.

Firstly, several participants reported that a major drawback to volunteering was not being paid thus raising a question that if advocacy roles are valued in supporting others with lived experience of mental illness, then perhaps all advocacy roles ought to be paid. However, notwithstanding the economic consequences it could be argued that wellbeing benefits associated with altruistic roles will be less evident through paid work. Not being paid also means not paying taxes and according to the literature and in line with the findings from this study, benefitting from taxpayers’ money through welfare payments furthers a sense of marginalisation and contradicts societal expectations of what it is to be a good citizen (Lister 2016, Patrick 2017). However, given that volunteering is recognised as making a significant contribution to the global economy (Johns Hopkins Centre for Civil Society Studies, in Wu 2011, p. 5); and in Scotland, volunteering contributes over two billion pounds to the economy (Cross Party Group on Volunteering 2016), arguably participants in this study are already making a significant economic contribution to society through volunteering. Somewhat surprisingly, this economic contribution appears to go unrecognised. Instead, workfare programmes remove meaningful volunteering from out-of-work disabled people and instigate benefit sanctions for remaining out-of-work. Further, in terms of economic contribution, it could be argued that participants by maintaining their health and wellbeing through volunteering are potentially saving the government healthcare costs associated with relapse and hospital admission. These economic arguments raise questions about whether volunteering can ever be legitimised and celebrated as a viable alternative to paid work for working aged adults with lived experience of mental illness; and, how people volunteering with lived experience of mental illness can be better recognised as valued contributors to society and the global economy.

Secondly, in recognition that welfare reform in the UK has become ineffective in tackling in-work poverty, work insecurity and unemployment (Painter 2017) there is growing support for the introduction of a Universal Basic Income (UBI) as a solution to reducing inequality and poverty resulting from the detrimental labour changing effects of technology and a flexible labour market on jobs and income (Harris 2016; Painter 2017; Standing 2017; Coote 2019; Jansson 2019). UBI is a regular cash payment given unconditionally to all individuals without means testing or any requirement to be in paid work or demonstrate willingness to work (Standing 2017; Coote 2019). In removing benefit sanctions, UBI has the potential to offer predictability, security, autonomy and greater work choice including risk taking and creativity in developing entrepreneurships (Painter 2017; Geraghty 2019). As Harris (2016, online) states:

> …..proposing that the state should meet some or all of people’s basic living costs would be an implicit acknowledgement that work alone cannot possibly deliver the collective security that the left has always seen as its basic mission, and that space has to be created for the other elements of people’s lives.

Standing (2011) agrees that UBI in building a system of security creates a good society where people have more control of their time, become more altruistic and spend time in meaningful work that is not labour, contributing to family and community. Recently trialled in Finland as an alternative to a complex social security system, 2,000 randomly selected unemployed people received approximately £475 tax free per month for two years regardless of whether they found paid work or not in an effort to encourage people into low paid employment (Standing 2017). An Indian study of UBI revealed positive emancipatory effects in decision making creating equity for women and disabled people with positive outcomes for health, housing and education (Standing 2017). Currently, the Scottish Government is carrying out a feasibility study to consider a Citizens' Basic Income (CBI) across four local authorities including Edinburgh (Standing 2017; Carnegie UK Trust 2019; Irvine 2019). Interestingly, according to O'Halloran et al. (2018) there is no evidence that UBI diminishes motivation to work, rather it has the potential to prevent people engaging in exploitative, harmful and poor quality paid work; can remove the stigma of being out-of-work; can reduce mental health hospital admissions; and can offer an alternative and socially valuable means of engaging in meaningful occupation other than paid work. Thus, in answer to the question posed earlier, UBI could legitimise volunteering as a viable alternative to paid work for working aged adults with lived experience of mental illness where they could be recognised as valued contributors to their community and wider society.

Thirdly, of relevance is the work of Andre Gorz (1985; 1989) the Austrian/ French social philosopher and political ecologist who calls for a paradigm shift from the hegemony of paid work, advocating a citizen's income in line with UBI. Gorz (1985; 1989) recognised that current working practices shaped by capitalism, commercialisation, market consumption and consumerism reinforce work for economic ends; support a relationship that consistently values profit for employers and wages for employees; and result in people becoming essentially wage dependent in a society driven by economic growth and commercial productivity (Gollain 2018). Gorz's (1985; 1989) key argument is that work in an anthropological sense i.e. work not for economic reasons that supports self-determination and human flourishing, has become subordinate to waged work resulting in personal meaning or pleasure derived from work taking second place by necessity to financial gain (Gollain 2018). Indeed, Gorz laments the loss of individual autonomy with activities once undertaken by people in their homes and communities e.g. domestic tasks becoming outsourced and commercialised resulting in low paid sources of work and a growing incapacity to look after oneself (Gollain 2018). Gorz advocated for publicly funded support rather than commercial services in caring for dependents and more crucially, that these should exist alongside support from self-organised voluntary and community systems (Gollain 2018). To realise this paradigm shift, Gorz (1985) advocated a guaranteed basic income for living; policies that support reducing time in paid employment; and spaces that support human flourishing and community capacity (Gollain 2018). He states:

> .....reduction of work time has nothing to do with emancipation if it merely leads to more time being spent on material and non-material consumption. It can be an emancipatory project only if combined with contraction of economic and market activity and expansion of activities performed for their own sake – for love, pleasure, or satisfaction, following personal passions, preferences and vocations. (Gorz 1985, p. 53)

Whilst Gorz's (1985; 1989) writings could be criticised as utopian and potentially confining women to domestic roles at home, his ideas about achieving human flourishing and self-determination through meaningful occupation, not for economic reasons, and developing community capacity have significant resonance with the views of participants in this project supporting personal choice and the right to wellbeing through meaningful volunteering (Hammell 2017). More specifically, Gorz's (1985; 1989) writings have resonance with a range of seminal occupational therapy theory. For example: advocating engagement in personally meaningful occupation for health and wellbeing (Reilly 1962; Wilcock 1998b; 1999; Hammell 2017); achieving occupational balance through participation in work and non-work occupations and between those occupations that we want to do versus those that we have to do (Wilcock et al. 1997; Aldrich et al. 2014; Wilcock and Hocking 2015; Hocking 2018); maintaining occupational constancy by connecting with passions and interests that retain a sense of self (Smith 2017); and recognising the value of interdependence, belonging, collaborating and contributing to the wellbeing of communities (Hammell 2014; Hitch et al. 2014a; 2014b; Hammell 2017). Indeed, Aldrich et al.'s (2014) qualitative study of unemployment recognised people's need to engage in purposeful occupations such as volunteering, community building and ecological sustainability in order to be socially connected to others to deliberately create and maintain a sense of community. Thus, Gorz's ideas challenge the prevailing neoliberal agenda of individualism (Gerlach 2015). Interestingly, Clouston's (2014, p.514) study of the work-life balance of occupational therapists found that wider socio-political and neoliberal drivers emphasising a market culture based on individual responsibility and accountability, pressurises staff into making "occupational compromises" investing more personal resources into the workplace in order to cope with excessive demands, whilst feeling an unending sense of responsibility and anxiety about failing to meet expectations, resulting in stress, loss of control and exhaustion. According to Clouston (2014, p.514) occupational balance and wellbeing become compromised through paid work as a socially sanctioned occupation and opportunities for more freely chosen, potentially restorative and meaningful occupations are constrained, as "…neoliberal economies have no value for activities that cannot be commodified in terms of profit". This supports Gorz's writings (1985; 1989) and resonates with Aristotle's notion of an impoverished life that is "without the freedom to undertake important activities that a person has reason to choose" (Aristotle in Sen 2000, p.4). It supports Arendt's (1958 in Dant 2003, p.43) criticism of labour as the necessary, ongoing, grind of everyday life that "must be accepted as part of the human condition" and specifically "alienated" labour, Marx's view of loss of freedom and self-control in productivity through capitalism (Arendt 1958, in Dant 2003, p.44). It is further reflected in the concept of occupational alienation describing a lack of personal engagement or satisfaction in the task (Bryant 2014, in Bryant et al. 2017, p.74). Indeed, Gorz's (1985; 1989) perspective aligns with Arendt's view of work, involving creative fulfilment and where imagination is invested in the process of doing. Interestingly, it offers support to the notion that people volunteering with lived experience of mental illness can be better recognised as valued contributors to society and the global economy.

10.2.5. Occupation is Political

Finally, whilst occupational therapy emphasises the value of crafting an occupational identity (Blank et al. 2015) and supports the notion of becoming, as a process of recovery and re-framing identity and a future self (Hitch et al. 2014a), this discussion has highlighted a tension between supporting human flourishing in neoliberal times and the privileging of paid work as a means to this end without critical scrutiny. Within occupational therapy and occupational science literature there is significant emphasis on occupational justice (Wilcock and Hocking 2015) and the right to inclusive participation in everyday occupations regardless of difference, to facilitate doing, being, becoming and belonging. However, Hammell (2017) reminds us that using a label is not sufficient and that occupational injustices need to be addressed. According to Hamer et al. (2017, pp. 83-85) people recovering from mental illness continue to be marginalised when their right to occupational justice is "interrupted, suspended or denied" through for example, limited access to paid work; and oppressed through "neoliberal constructions of work" that offer limited security. In identifying this as a human rights issue rather than a health issue, Hamer et al. (2017) argue that people would be better served by more inclusive employment practice including more reasonable workplace adjustments. However, whilst laudable, this reinforces the paid work hegemony despite recognising the negative impact of neoliberalism on the experience of work for people recovering from mental illness and the perpetuation of occupational injustice. Indeed, many occupational therapists assume that paid work will facilitate doing, being, becoming and belonging whilst ignoring the implications of austerity and neoliberal welfare policies and the futurist “post-work” narrative (O’Halloran et al. 2018 p. 305) on the viability of paid work for people with lived experience of mental illness, thus failing to critique whether paid work can indeed support significant wellbeing gains or lift people out of poverty. Arguably, occupational therapists are limiting occupational possibilities defined by Laliberte-Rudman (2010, p. 55) as “the ways or types of doing that come to be viewed as ideal or possible with [in] a specific socio-historical context, and that come to be promoted and made available within that context”. Occupational possibilities are often shaped over time by taken for granted practices and discourses situated within specific socio-cultural and political structures and can work at subtle and invisible levels where power operates to determine the right things to do (Laliberte-Rudman 2010). Indeed, there are parallels here with Foucault’s (1984) archaeological method enabling us to examine the continuities and discontinuities of how knowledge and rules of practice, in this case occupational possibilities, are influenced by power relationships where the rationale for adopting such rules of practice is often hidden, disguised or unconscious on the part of those holding power and influence. Thus, certain occupations become the norm or ideal whilst others are viewed as abnormal or less than ideal (Laliberte-Rudman 2010). Drawing on Foucault’s (1988 in Laliberte-Rudman 2010, p. 58) view that critical reflection on how things have come to be creates the possibility for change, Laliberte-Rudman (2010, p. 58) asks occupational therapists to consider the following questions:

1. What occupations do dominant discourses idealise and promote and who is able and not able to take up these occupations?
2. How do individuals take up, negotiate and resist discourses pertaining to occupations in their everyday lives?
3. What are the consequences for individuals and collectives who do not have the resources to live out the occupations constructed as ideal, natural and ethical, or who resist such constructions?

4. In what ways do occupational therapy texts and practices contribute to and/or resist marginalizing discourses?
5. How might occupational scientists work to highlight the limits and inequities of contemporary discourses that marginalize particular types of occupations and particular types of subjects?

Arguably, this project has gone some way to addressing the questions posed above in highlighting a socio-political context where paid work is valued over volunteering for working aged adults including those with lived experience of mental illness and is supported by occupational therapists who unwittingly contribute to a marginalising discourse. Indeed, Durocher (2017, p.12) reminds us that “as occupational therapists we can be instruments of occupational justice or injustice, or both, for our clients”. Findings from this study support critical voices in occupational therapy calling for the profession to attend to contradictions and to challenge taken for granted assumptions and hegemonic positions in order to consider the situated nature of occupation and how it is shaped by socio-political and cultural influences that have a tendency to individualise and homogenise solutions to being out of work, for example, through punitive and discriminatory approaches (Kronenberg et al. 2005; Hammell 2009; Laliberte-Rudman 2010; Hammell 2011; Gerlach 2015; Rudman and Aldrich 2016; Hammell 2017; Gerlach et al. 2018). Indeed, occupational therapy concepts that promote autonomy and independence and align with a neoliberal paradigm require revision in light of principles of interdependence and vulnerability that support a more equal and less oppressive societal social contract (Hammell 2014; Bullen 2017). Further, Gerlach (2015, p. 245) recommends “sharpening our critical edge” to avoid becoming complicit in disempowering practices that are shaped by normative assumptions underpinned by white, gendered, middle-class views. In order to support socially responsive practice with marginalised populations and engage in a broader discourse Gerlach (2015) calls on occupational therapists to co-construct knowledge with people who are experiencing marginalisation; to engage in critical reflexivity to expose socio-historical influences on power and privilege embedded in professional theory and practice; and to attend to broader socio-political factors including neoliberal economic policies that limit occupational choice and are beyond individual control. Arguably, this PAR project is a useful response to Gerlach’s (2015) call and demonstrates the value of co-constructing knowledge with the potential to challenge marginalisation and inequity. This will be discussed further when reflecting on the research experience. Indeed, the findings and the literature suggest that this project is timely in highlighting the wider value of volunteering for people recovering from mental illness and emphasising the importance of exploring the implications of neoliberalism, austerity and welfare reform on the occupations that people want to do to remain well and to contribute to their communities (Rudman and Aldrich 2016). It provides a useful tool to challenge the accepted wisdom within occupational therapy of the hegemony of paid work and to begin to understand how dominant societal forces and power significantly influence the current day concerns and practices of occupational therapists and the value associated with volunteering (Stevenson and Cutcliffe 2006). Pollard and Sakellariou (2014) remind us that occupation is political and call on us to challenge the perpetuation of occupational injustices that result from the divide between government and experience, to promote active citizenship and to ensure that occupational therapy remains relevant. Findings from this study remind us that as occupational therapists we need to pay attention to the political context of volunteering where it has been hijacked by governments who say that if you are able to volunteer then you are able to work. Schemes designed to support people in their recovery from mental illness are actually causing more stress with the potential for readmission to hospital and increased healthcare costs. The findings from this study therefore call on occupational therapists to recognise a broader scope of volunteering beyond one viewed solely through a work lens and to engage with the complexity of occupation from a socio-political perspective. As Durocher (2017, p.16) states:

> …..acting together as instruments of occupational justice, it is occupational therapists’ moral and ethical obligation to contribute to orchestrating towards a more occupationally just and inclusive world.

This section has questioned the hegemony of paid work proposing alternative views and highlighting potential challenges for occupational therapists supporting paid work as the sole outcome for people recovering from mental illness without critique. The next section concludes this chapter by reflecting on the research process and the experience of PAR.

10.3. Trumpets and Confessions: reflecting on the research process

This section critically reflects on the strengths and limitations of the research process by considering the quality of the research process and to what extent the project satisfies the participatory and action requirements of PAR. It concludes by considering how the project could have been approached differently.

As stated previously, the design of this project was influenced by the current drive within policy and practice to engage service users in co-producing, co-designing and co-creating services thus advocating equal reciprocal partnerships between service deliverers and service participants (Boyle and Harris 2009) as opposed to passive recipients of services designed and delivered by someone else (Needham and Carr 2009). The design has congruence with occupational therapy, valuing the importance of partnership, collaboration and action with the potential to challenge occupational injustices (Bryant et al. 2011; Kramer-Roy 2011; 2015; Bryant et al. 2017). It was also influenced by critical social research where research methodologies can remove information from their contexts involving participants as subjects and respondents rather than active participants in the research process (Baum et al. 2006) risking that personal recovery narratives become "disability tourism" rather than tools for socio-political change (Costa et al. 2012, p. 85). For these reasons, I was keen to reject research methodologies that privilege the researcher position over that of the participants and adopt a participatory action research (PAR) approach. Furthermore, given that people living with mental illness are often marginalised within society, I was keen to avoid "constructing people as vulnerable participants rather than partners, with agency" (Locock and Boaz 2019, p.8) and was influenced by a critical and emancipatory research paradigm based on exposing and seeking to challenge inequalities and oppression. Therefore, critical PAR became my methodology of choice. However, heeding Zarb's (1992) caution that increasing participation does not constitute emancipatory research until disabled people are in full control of all research decisions, the extent to which active participation was realised and socio-political inequalities have been challenged within this project, requires closer scrutiny. This chapter now turns to respond to the following questions proposed by Zarb (2002, p. 128 in Henn et al. 2009, p. 43):

1. Who controls what the research is about and how it will be carried out?
2. To what extent are disabled people involved in the research process?
3. What opportunities exist for disabled people to shape the research outputs and influence future research?
4. What happens to the research outputs?

10.3.1. Reflecting on participant control and involvement in the research process

According to Barnes (2002, p.4), a key benchmark of emancipatory disability research is “user participation and control over all aspects of the research process or a commitment to work towards this”. Whilst this project sought to fully involve participants in taking control and making decisions about the research process, it was somewhat constrained by being a self-funded doctoral study following a set of institutional guidelines in a process to achieve an outcome that is ultimately personal and academic. It was therefore difficult to envisage how this could be truly emancipatory in terms of full participant ownership, power and control of all aspects of the research process including research design, recruitment and selection procedures (Daley et al. 2010). Therefore, although my intention was to align with a critical-emancipatory paradigm, and I valued the commitment to working towards full user participation, pragmatically the ultimate control of the research process lay with myself as academic researcher with dual goals of facilitating a PAR project and completing a thesis for University scrutiny.

Rather than an emancipatory design, a participatory approach was more suited to the research process and desired outcomes of this study and served the research intention of working in “partnership” (Arnstein 1969; 2011, p. 5) through shared decision making with participants in a meaningful way. My understanding of partnership aligned with Pant’s (2014, p. 584) principles of PAR including a commitment to research that is collaborative and equitable in terms of contribution, responsibility and expertise rather than research where power is unexamined and taken for granted; and one that has a commitment to empowering participation through shared decision-making and negotiation in all stages of the research process to critically and systematically clarify and create awareness of issues, design strategies for action and then re-evaluate for impact and social change. On reflection, working in partnership in this project also aligned somewhere between Biggs’s (1989 cited in Cornwall and Jewkes 1995, p. 1669) notion of collaboration with people and researchers working together on projects designed, initiated and managed by researchers; and “collegiate” when people have control over the process and work together with researchers in a process of mutual learning.

Arguably, a key limitation due to pragmatic reasons was that participants were not involved in initiating and designing the project from the outset. Not being involved in deciding the research aim may have accounted for the group's difficulties in reaching decisions about action and outcomes. For example, if the project had begun with a clear problem or issue generated by participants from the outset, then a solution in terms of an action may have been reached more fluidly. However, the project aim was intentionally kept loose to enable flexibility with the potential for participants to influence the research process at a later stage. For example, when first meeting potential participants there was discussion as to whether the aim of the project had resonance with them and was worthy of pursuit with opportunities for participants who may have disagreed, to shape the project with their views about volunteering at that stage. Although no participants disagreed with the aim of the project, participants were vocal during the research process in rejecting one of the original objectives to interview volunteer engaging organisations, as they believed this to be neither necessary nor desirable. This arguably demonstrates the existence of partnership (Arnstein 1969; 2011) in shaping the research process through shared decision making, negotiation (Pant 2014), collaboration and mutual learning (Biggs 1989).

Participants were vocal during PAR groups about the method they preferred to support data generation and how they wanted the iterative process of data analysis to be carried out. Given that PAR literature supports using arts-based methods and visual tools such as mapping etc. as a means of enhancing and triangulating data and offering patterns for reflection (Loewenson et al. 2014; Kramer-Roy 2015), I was keen to introduce these to enrich discussion. However, participants unanimously resisted adopting alternative methods, preferring to talk rather than to write, or draw, or create. This was somewhat challenging for me as an occupational therapist, used to relying on creative materials to facilitate discussion and attracted by PAR's history in using participatory arts-based methods. I was curious about their refusal to engage in these methods given that I was aware that some of the participants had creative arts backgrounds. On reflection, many participants appeared articulate and comfortable with verbal discussion and perhaps this was about familiarity, safety and a way of maintaining control rather than being at the mercy of my "professional" facilitation skills, which were perhaps reminiscent of their experience of services or discomfort with the unfamiliar or the unknown. There was one exception with the spontaneous use of a tray and biscuits during group 3 to sculpt out and make visual the experience of stigma. This occurred naturally and was initiated by participants who seemed to enjoy positioning the items to represent their thinking.

How to “be” in the PAR groups was challenging for me. Reminded by Oliver (1992, p.111) “that researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose”, I sought comfort in Cornwall and Jewkes (1995) view that a key element in participatory research is the attitude of the researcher rather than the method, alongside continuing self-awareness and reflexivity. I realised that adhering to my presentation of self in adopting a participatory attitude was crucial to avoid the pitfall of tokenism and the potential for exploitation of power by being an academic researcher and an occupational therapist. However, this presented me with a challenge as to how to put my professional knowledge and skills at the participants’ disposal. Reminded by Schugurensky (2014) that knowledge and power are always entwined, I realised that I had a choice in preserving or transforming the social order but felt somewhat adrift as to how to do this whilst avoiding appearing authoritarian or laissez-faire. Therefore, a key tension in recognising my position of power was to neither deny it nor exploit it. Gadamer’s philosophical hermeneutics emphasising the value of conversation and practical reasoning through participating with others has resonance here with my preferred attitude throughout this project and was a helpful means of resolving my power dilemma, where neither participants nor researcher dominate, continuities are agreed and differences are settled and retained (Scott-Villiers 2014). Gadamer (1975 in Scott-Villiers 2014, p. 374) states:

> …..we may perhaps survive as humanity if we would be able to learn that we may not simply exploit our means of power and effective possibilities, but must learn to stop and respect the other as an other, whether it is nature, or the grown cultures of peoples and nations; and if we would be able to learn to experience the other and the others, as the other of our self, in order to participate with one another.

Additionally, I found solace in Habermas’s (1996 cited in Kemmis et al. 2014, p.34) notion of communicative spaces alongside Kemmis’s (2008, p.123) belief that critical PAR must work “in the conversations and communications of participants about crises and difficulties confronted by social systems and the lifeworlds in which people find meaning, solidarity and significance”. Kemmis and McTaggart (2014, p.208) suggest that identifying and reflecting on “sayings”, doings and relatings” can achieve this. On reflection, I believe this was achieved through the verbal conversations in the PAR groups in a climate where participants appeared sufficiently comfortable to openly explore and share what they thought about volunteering, what they did in their volunteering and how they related to others through their volunteering to draw on similarities and differences of experience and to come to a common understanding of the complexity of issues surrounding volunteering with lived experience of mental illness. Indeed, Bryant et al. (2017, p. 80) helpfully recognise that "…sometimes it is necessary to be on the margins of group activity and collaboration, and at other times to be in the centre". This enabled me to reflect on and be mindful of, the different ways of participating both for myself and for the other group members.

A further potential limitation was that although participatory methods were central to the research, the overall project also involved individual interviews or conversations, which were conducted prior to the PAR groups. Any dilemma surrounding the appropriateness and compatibility of conducting individual interviews alongside PAR groups was resolved when I discovered Perry and Zuber-Skerritt's (1992) model (Figure 3, methodology chapter), illustrating the difference and relationship between thesis research, core research and thesis writing. Indeed, Perry and Zuber-Skerritt's (1992) model offers a clear distinction between the contribution of the core collaborative action research project, which sits within and informs the doctoral thesis, as a form of literature; whilst the doctoral thesis is produced independently by the doctoral candidate to ensure an original contribution to knowledge (Perry and Zuber-Skerritt 1992; Zuber-Skerritt and Perry 2002; Zuber-Skerritt and Fletcher 2007; Zuber-Skerritt 2018). This served to resolve to some extent the challenge regarding control of the research process as the initial interviews or conversations with individual participants at the outset of the project were initiated by me and considered separately from the core PAR project. Indeed, data generated from the interviews was deemed confidential to the interviewee and myself and was not shared with fellow participants nor used to inform the PAR groups. My decision to do this was pragmatic and personally and academically motivated due to my desire to gather data that could be used to achieve an academic outcome that might not otherwise be guaranteed if the PAR element of the project was unable to proceed. However, it was also a useful first point of contact where ethical issues regarding consent and any issues affecting participation could be discussed. In hindsight, data generated from these initial conversations proved valuable and significant in informing the findings and was a useful method of triangulation, serving to confirm the themes arising from the PAR groups.

Finally, in terms of who controls the research it is important to acknowledge the role of any stakeholder or funding influence. Whilst a potential drawback of this study was that it was self-funded and therefore limited in the extent that participants could be truly co-researchers by receiving formal mentoring and training in research methods including PAR group moderation and data analysis (Daley et al. 2010), arguably the lack of accountability to a specific budget holder also provided a degree of freedom in the project's ability to make decisions about process and outcomes. In hindsight, the decision to locate the preliminary interviews and PAR groups in Volunteer Edinburgh's premises although pragmatic, may have compromised the neutrality of the project with the researcher perceived as having an alliance with Volunteer Edinburgh as an organisation and endorsing Volunteer Edinburgh's position rather than that of any other third sector organisation.

10.3.2. Reflecting on shaping the research outputs, challenging socio-political inequalities and influencing future research

This chapter now turns to consider the opportunities for participants to shape the research outputs, influence future research and satisfy the action requirement of PAR in challenging socio-political inequalities. More specifically, in line with Barnes's (2002, pp.4-9) core principles of emancipatory disability research, it considers whether the role of experience within this project was able to highlight disabling consequences of society and produce practical outcomes that are meaningful for participants and the wider community of people with lived experience of mental illness who are volunteering or considering volunteering in the future.

Arguably a successful element of this project was in enabling participants' voices to be heard in relation to their lived experience of both volunteering and mental illness in the current socio-economic climate. Indeed, the role of experience was paramount in shaping the output by highlighting the disabling consequences of the impact of welfare reform and conditionality on volunteering and mental health. Participants shared their experience of how this policy context, driven by an agenda other than recovery, reinforced the stigma and discrimination of being out-of-work disabled people. These experiences are reported at length in chapter 8 within "The dark side of volunteering" theme and were critically explored earlier in this chapter in relation to the literature. However, whilst the outcomes from the overall study including the proposed conditions for successful volunteering and the rich data supporting the challenges of volunteering with lived experience of mental illness within the current climate of neoliberal welfare reform have been well discussed, the opportunities for participants to shape the research outputs and the key action that was generated by this PAR project, has thus far received little critical scrutiny.

Participants understood from the outset that the project intended to produce an output or action plan that could disseminate the findings and agreed themes from the project to produce something of benefit for the group and/ or wider community. This was reinforced in the information sheet about the project, at the preliminary interviews and throughout the PAR groups. Arguably, the PAR groups provided many opportunities for critical reflection and action including discussion of the final product and potential research outputs. This is in keeping with PAR methodology and in line with objective 5 of this research project and stage 4 of the research process. However, shaping the research output into something that would be of value to participants and/ or to the wider community was challenging, raising issues of ambition, agreement and influence that at times seemed to overwhelm the group. Indeed, this stage in the PAR process was by far the most perplexing. These difficulties are documented in the findings chapter, where the theme "Putting the action into participatory action research" reflects participant discussion on how to realise the action phase of this project following refection on the themes and knowledge generated through the PAR groups.

From the outset I had anticipated that the action product or output would be formulated to address, present and disseminate the information gathered by participants and become accessible to the wider community through for example, the production of a written guide or arts based film or exhibition which could be aimed at volunteer organisations and/ or prospective volunteers with lived experience of mental illness, local government, health and social care professionals, community organisations, and friends, families and carers. Findings could also be published in a journal and/or presented at a conference. This seemed fairly straightforward. However, on reflection, I had not anticipated the difficulties on reaching a consensus on action. These difficulties are also well documented in the Findings chapter under the heading "Where is there room for change? Ambition, agreement and influence” with selected quotations illustrating challenges surrounding ownership and leadership at this stage. During group discussion, I felt that participants wanted me to take the lead in deciding on any action, whilst I attempted to resist in the hope that consensus would be reached through the participatory process. However, when I made suggestions, for example that we adopt photo-voice to represent the research themes in an exhibition, this was unanimously rejected. This reinforced my earlier observation that the group appeared to prefer verbal and written means of communication over creative arts-based methods. Participants were in agreement that they did not want duplication of something that already existed for example the production of a leaflet or information pack for prospective volunteers, nor did they want to produce something that was tokenistic. Indeed, participatory strategies that are tokenistic in involving disabled people and not confronting systems of oppression leave disabled people positioned in oppressive ways (Oliver 2002). Arguably, whilst literature recognises PAR as a systematic and cyclical action-reflection process enabling participants to prioritise the issues that are important to them; dialogue and reflect on their experiences; and plan and take actions on those issues that are meaningful and achievable in their lives (Koch and Kralik 2006; McIntyre 2008), it does not always highlight the specific challenges in achieving the final stages when “the tools fail and pathways are blocked” (Bryant et al. 2017, p. 80). Following a private conversation between Volunteer Edinburgh and myself, I suggested to the group that we could host a breakfast meeting for local MSPs to share the benefits and challenges of volunteering to raise their awareness of participant experiences around volunteering and welfare reform. After some debate, this became the front-runner for potential action. However, although it appeared to achieve a consensus, some participants were uncomfortable adopting what they viewed as a political or activist stance where bringing their experience into a political sphere felt potentially unsafe. Kemmis and McTaggart’s (2014) view of communicative action is when participants are free to participate and to reach unenforced consensus through agreement and understanding about what to do in a particular situation rather than reaching a goal that may be strategic or serve one or two individuals over others. Communicative action is guided by what is true, authentic and morally right and proper in the participants’ circumstances (Kemmis and McTaggart 2014). Indeed, participation, dialogue and emancipation are not guaranteed outcomes of the process where divergence amongst participants may make consensus on decision-making and action difficult and where many of the problems affecting communities and the potential solutions appear to be located in higher echelons of authority (Loewenson et al. 2011; Pant 2014). Many of the themes generated through difficult experiences of volunteering were political in nature reflecting the UK government's focus on neoliberalism and welfare reform. Given that not all participants were comfortable with taking what they perceived as a political and activist stance; and that attendance varied from group to group due to factors such as fluctuating interest, health and personal circumstances, I can now see the value of asking clarifying questions such as "Who are we?"; "What do we want?"; and "Who cares?" as a means to potentially reach a consensus (Bryant et al. 2019, p. 15). Further, Bryant et al.'s (2017) reflection on the importance of offering flexibility in method and valuing transitory involvement to avoid potentially alienating people from the research process, led me to realise that perhaps my constant focus on an action output was unhelpful and out with the scope of what participants felt able to manage. Reflecting on whether an action output was necessary, led me to question with the group whether themes generated through the PAR groups were sufficient in themselves to be viewed as participatory action and could be formally recorded and disseminated in some other way. Acknowledging that the information already produced by the group was valuable as an output and could be reproduced to suit any audience of the group's choosing, appeared to remove any pressure on the group to come up with other ideas for action.

A core principle of emancipatory research is that it should adhere to the social model of disability ensuring that the research focus considers the structures and processes which create disability; and that it should produce practical outcomes that are meaningful for disabled people and the wider community (Barnes 2002, pp.4-9). Arguably, this condition was met and was prompted by a timely and serendipitous opportunity that arose with a Scottish Government consultation request in preparation for devolved powers on aspects of social security. Given, that a major concern raised by participants was the requirement for volunteering to become mandatory through workfare programmes to avoid benefit sanction, this was a natural opportunity for participants to reach a consensus on an action that could convey their experience through a message about the impact of welfare reform on volunteering for people with lived experience of mental illness and highlight the need to keep volunteering voluntary. Through email communication, participants agreed to collaborate with Volunteer Edinburgh to produce a joint briefing paper summarising the key themes from the research findings including anonymous quotes from PAR group data, with the tagline "Keep Volunteering Voluntary" (Appendix 16). This output provided an opportunity to influence Scottish government decision-making and policy change. Indeed, a practical outcome from this Government consultation was that from the 1st April 2018, the Scottish Government through Fair Work Scotland removed the mandatory element of volunteering as a requirement for work preparation and therefore the link to benefit sanctions. However, there is no change in the rest of the UK. Whilst it cannot be claimed that evidence from this project was the sole reason for the Scottish Government removing the mandatory element of volunteering, it certainly contributed to the weight of evidence to support this change and was considered by participants to be a meaningful outcome. Accordingly, Kemmis and McTaggart (2014, p.211) argue that the purpose of critical PAR is not about creating academic knowledge but more about contributing to history and "transforming the work, lives and situations of people in the interest of rationality, sustainability and justice". Arguably, the output from this PAR project has done exactly that, by producing a briefing paper for the Scottish Government in response to a call for evidence to support change at policy level, thus enabling marginalised voices to be heard and contributing to positive socio-political change by resolving the problem of mandatory volunteering for participants, future volunteers and the wider Scottish community.

Koch and Kralick (2006) suggest a successful outcome of PAR is when participant groups continue contact following completion of the research element and generate action plans in a continuing cycle, which can be sustained independently by the group if they so choose. This was included as Objective 5 of this project and anticipated as Stage 5 of the research process with reflection on action being crucial to thinking about how change has been brought about at an individual, group and wider community level as a result of generating the practical outcome discussed above. Objective 5 and Stage 5 both anticipated participants critically reflecting on action and taking further action in a simultaneous, iterative, cyclical process of observation, exploration, knowledge construction and action which could be self-sustaining and where critical dialogue and collective reflection thus build a community of inquiry and change, which may result in further action (McIntyre

2008). In this way, action is evaluated and modified by participants in order to move in new directions including opportunities to influence future research.
Remaining participants offered a positive evaluation of the research process through email communication and appeared satisfied that the project had generated a useful output. However, due to a number of pragmatic reasons including my own ill health, which interrupted the flow of the project, the momentum that had been gathered could not be sustained and the project reached a natural conclusion. Arguably, a limitation of this project was in being able to sustain the continuing cycles of reflection and action, illustrated previously in Figure 4 (Loewenson et al. 2014, p.13), to facilitate participants contributing to future research. In recognising the valuable contribution made by participants in freely giving their time, energy and commitment to this project, it is important to respect that personal circumstances, mental illness, physical health, interest and motivation will change and fluctuate throughout the participatory process. This chapter now turns to reflect on measures of quality in PAR.

10.3.3. Reflecting on measures of quality in the research process

According to Hill (2014) research in practice is often complex and seldom straightforward requiring a degree of problem solving, which is rarely shared thus perpetuating a myth that the research process was unproblematic. A key feature of rigour in PAR is that it is articulated with transparency to demonstrate the richness and iterative nature of the inquiry and how understanding was reached, and decisions taken at each stage of the research process (Hill 2014). Whilst rigour is associated with positivist research, the term trustworthiness encompassing the qualities of confirmability, dependability, credibility, and transferability, is used in PAR and other qualitative methodologies to assess the qualitative rigour of the research process and knowledge outcomes (Baskerville 2014).

Confirmability requires sufficient documentation of the research process to confirm that the study was carried out properly according to PAR procedures and to enable the study to be reconstructed if so required (Baskerville 2014). It is intended that this thesis through successive chapters detailing and exploring the decisions taken in relation to methodology, data analysis, the findings and subsequent discussion and reflection on the research process including strengths and limitations has provided sufficient description and detail to fully articulate the research process rendering it transparent to the reader and thus demonstrating a commitment to ensuring the criteria are met for confirmability of the research process.

Dependability, according to Baskerville (2014) requires that the knowledge generated through iterative cycles will become a documented solution and potentially dependable theory in the future through continuing action cycles. Findings from this study have generated conditions for successful volunteering with the potential to promote mental health recovery whilst also demonstrating mitigating socio-political factors and challenges to occupational therapy practice. These findings may be the beginning of a process that could benefit from further iterative research cycles to reach a position of a dependable theory.

Credibility requires evidence that is convincing in terms of the honesty of the research process and the credibility of the findings and the action arising from the study as a solution to a potential problem alongside evidence of rich sources of data documenting the iterative nature of the process and a reflexive evaluation of the research process (Baskerville 2014). Again, documentation available in this thesis is intended to testify to the integrity of the research and the relevance of the action and outcome for people with lived experience of mental illness who are volunteering in a climate of neoliberal welfare reform where the action from this project has potentially influenced policy change addressing the problem of mandatory volunteering as a workfare requirement.

Finally, transferability draws on the requirements of credibility and requires that documentation of the research process and setting are sufficient to enable others to use the knowledge in the future to compare it to a future comparable setting or a novel setting with full awareness of the similarities and differences (Baskerville 2014). This study has hopefully sufficiently described the social setting, the participants and the methods used to enable a degree of transferability to carry out a similar project in the future whilst recognising similarities and differences.

Furthermore, Gibson (2012 in Loewenson et al. 2014, p. 81) proposes a number of questions of trustworthiness associated with each of the four criteria adapted for the purpose of measuring quality in PAR. Whilst not exactly comparable with the descriptions sourced from Baskerville (2014) above, they add another element of quality control. These are detailed in Table 10 below alongside a commentary from this project.

PAR quality criteria:	Project Response:
Confirmability: Was the process through which the community interrogated and validated the evidence well described? Were the findings reviewed after actions?	The iterative process of participatory data generation and analysis is well documented. The findings were reviewed prior to action but have not been revisited following action for pragmatic reasons.
Dependability: Was the research process participatory for all key members of the homogeneous group, was it logical and well documented?	The PAR element was as participatory as possible for all key members. The process was logical and well documented with a clear audit trail of decision-making. Limitations on full participation are explored within this chapter.
Credibility: Was the process for validating and analysing findings participatory for all key members of the homogeneous group, and did it adequately review outliers and differences?	Participants were fully engaged in an iterative process of generating, validating and analysing the PAR group findings and acknowledging differences in experience. The PAR groups were observed by a second facilitator (Loewenson et al. 2014). Findings from the interviews were analysed by the researcher following member checking of transcripts and themes to avoid misrepresentation. The research supervisor independently validated themes from interview transcript. Themes from interviews and PAR groups served as a useful form of triangulation or crystallisation confirming themes across methods and providing a richer, fuller picture of the issues (Braun and Clarke 2013; Loewenson et al. 2014).
Transferability: Do the findings generate insights or motivations for action or reflection that are transferable to other settings?	Although the findings are not generalisable, the themes, insights and new knowledge generated were so pervasive that arguably, the research captured a common aspect of the experience of out-of-work disabled people who are volunteering in their recovery from mental illness that could have broader relevance and transferability (Lincoln and Guba 1985; Braun and Clarke 2013). The findings generated a theory on conditions for successful volunteering to promote recovery, which requires further exploration for wider relevance. Similarly, the negative experience of welfare reform; conditionality and volunteering; and volunteering beyond a paid work agenda are insights that may have wider resonance. Mandatory volunteering remains in the rest of the UK and the findings from this study may help to provoke and motivate future action (Loewenson et al. 2014).

Table 10: Criteria and questions for assessing research quality in this project, adapted from Gibson (2012 in Loewenson et al. 2014, p. 81).

Finally, Loewenson et al. (2014) propose that the concept of validity, associated with ensuring that research measures what it claims to measure and accurately captures reality (Braun and Clarke 2013), can be useful in evaluating whether knowledge produced by PAR is broadly applicable and in line with PAR assumptions and goals, including a commitment to the plurality of knowing (Reason and Bradbury 2008). Indeed, a strength of this project is that it used multiple methods and was located in people's real-life experiences drawing on knowledge both collectively and individually (Loewenson et al. 2014). Arguably, using concepts common to scientific research is controversial amongst qualitative researchers however it may have value in being used to defend the quality in PAR to persuade positivists who question it (Dick 2014). Loewenson et al. (2014) propose that methods for validating PAR should be collectively debated and validated by the group according to:

> …..how relevant the community involved perceives the issues to be; how far the process and methods engage experiential knowledge without losing information; whether the research takes into account the cultural context of the community; and whether the collective process of analysis is well-facilitated and rigorous. (Loewenson et al. 2014, p. 80)

In acknowledging concerns about validity in PAR, Anderson and Herr (1999, p. 16) suggest five types of PAR validity criteria namely: democratic, outcome, process. catalytic and dialogical validity. These are presented in Table 11 below alongside a commentary from this project:

Type of Validity:	Comment:
1. Outcome validity:	The main beneficiaries are the participants and other out-of work disabled people in Scotland who are volunteering and receiving welfare benefits. This project led to action that contributed to change at policy level that resolved the problem of mandatory volunteering for participants and the wider Scottish community.
The issue of who benefits from the resolution of the problem and that action orientated outcomes lead to some form of problem resolution.	
2. Democratic validity:	Participants as relevant stakeholders participated fully and their voices and perspectives informed the action and solution, which was locally relevant. Volunteer Edinburgh as a key stakeholder did not participate fully in the project and no other perspectives were invited to take part. This was perhaps a limitation of the study.
Whether relevant stakeholders in the problem participate fully in the research and the extent to which their perspectives and needs accurately inform solutions and outcomes relevant to the context.	
3. Process validity:	This project used appropriate means

Ensuring the research methodology is appropriate and qualitative strategies enhance trustworthiness; and that the way problems are investigated allows for on-going learning and improvements and enables people to reflect on their social reality for learning.	through PAR groups to produce knowledge and relevant action. The quality of the relationships between participants created an honest and trusting environment where people disclosed positive and challenging experiences. Participants appeared to benefit from learning from each other and sharing experiences to reach a commonality of experience and a plan for action. Interview findings were analysed following member checking of transcripts and themes to avoid misrepresentation. Triangulation of interviews and PAR group data confirmed themes across methods.
4. Catalytic validity: The extent to which the research collaborators are invigorated to understand and change social reality both within and beyond the research study.	Motivation to participate was evident from attendance at PAR groups over a sustained period. Transformation through learning occurred amongst participants and myself in gaining new insights through shared experiences, although this was not formally evaluated. The project was invigorating and generated a desire to influence and change a socio-political situation that was having a detrimental effect on participants. There is potential to continue developing ideas generated and test the volunteering and recovery theory
5. Dialogical validity: Critical dialogue with peers about research findings and actions to challenge the findings for inconsistencies, biases and failure to include key stakeholders.	Achieved in part by presenting preliminary findings to peers at an international conference. Further dialogical validity can be established through formal publication and peer review and discussion with Volunteer Edinburgh and other local services and potential interested parties not originally involved.

Table 11: Five types of validity in PAR adapted from Anderson and Herr 1999, p. 16.

Loewenson et al. (2014. p. 80) suggest that methods for validating PAR are collective through an iterative process of analysis and interrogation until participants are satisfied that they have reached a point where the final themes can be validated they summarise a number of processes supporting validation including: parallel observation of the process by a second facilitator or observer; triangulation of different sources of evidence; other people from larger local group from the same community checking and correcting findings (Loewenson et al. 2014). Parallel observation of the PAR group process was carried out during this project when the research supervisor joined two of the PAR groups. Themes from interviews and PAR groups served as a useful form of triangulation or crystallisation confirming themes across methods, providing a richer, fuller picture of the issues (Braun and Clarke 2013). Additionally, the findings from the interviews were analysed by the researcher following member checking of transcripts and themes to avoid misrepresentation and the research supervisor independently validated themes from interview transcript. In retrospect, involving a larger group from the same community to check findings could have been a useful addition to ensuring validity across the community.

10.3.4. Reflecting on approaching the project differently

Reflecting on the research process with the benefit of hindsight, there are a number of things that could have been done differently.

1. Locating the project more specifically within Volunteer Edinburgh, or another existing community or advocacy service supporting people recovering from mental illness. This would have enabled the project not only to capitalise on the availability of support for recruitment and premises for meeting, but also according to Loewenson et al. (2014) participation can be better sustained by integrating the project within existing community services where networks of trust are already established. Whilst this project benefitted from the substantial and valuable support provided by Volunteer Edinburgh, it was also attempting to maintain independence from any specific organisational perspective about volunteering and recovery. This added a degree of unnecessary confusion. For example, some participants were well acquainted with Volunteer Edinburgh who supported them in their volunteering and perhaps were more motivated to take part through what they saw as Volunteer Edinburgh's endorsement of the project. However, other participants with no previous contact with Volunteer Edinburgh were more suspicious of being located within their premises wanting reassurances that the project was not being expected to tow a particular party line. Locating the project within a specific service or services would have enabled more people to be involved in supporting and facilitating the project and

given the project more of a sense of teamwork and inter-agency working rather than relying solely on an independent academic researcher.

2. Ensuring that any preliminary discussion and planning of the project involved participants from the outset and that any aims and objectives were based on issues that participants identified as worthy of further exploration. This would have enabled participants to take more control of the research design and process and to have ownership of the research experience.

3. Applying for funding to support participants to gain specific research skills and to be more empowered in the research design, data generation and data analysis as co-researchers.

4. Better supporting the participants in disseminating the findings. Firstly, by achieving the breakfast meeting with MSPs and jointly producing publicity material such as postcards or fliers summarising the key issues as identified by participants and showcasing participants' voices through a range of thought provoking quotes; and secondly, by co-producing an article or conference presentation or workshop with participants to support them in disseminating their findings to wider audiences.

10.3.5. Chapter Summary

This chapter began by revisiting the research intention to explore to what extent the research aim and objectives were realised. It reflected on the significance and implications of the findings in light of the literature and proposed five conditions for successful volunteering that are necessary in supporting recovery for people with lived experience of mental illness. In discussing the challenges, it considered the impact of welfare reform and conditionality, the issue of stigma and discrimination, and the hegemony of paid work. In looking back to offer an evaluation of the findings and the research experience in light of the literature, it also points forward with suggestions and recommendations for the future and considers the strengths and limitations of the research process, identifying what has been learned and what new questions have been raised. The next chapter concludes the thesis.

CHAPTER 11: CONCLUSION

In concluding this thesis, this chapter summarises the research intention and key themes and outcomes from the findings and highlights the potential of this study to contribute to theory, policy, practice and future research.

In summary, the aim of this study was to hear about the benefits and challenges of volunteering, as well as to explore the positives and negatives of socio-political and welfare systems that support people with lived experience of mental illness to volunteer, with a view to producing something through action that would be of benefit to the group and/or the wider community. The final objectives which were shaped by the literature review, the participatory process and the findings, were all arguably achieved and are presented below:

1. To explore the experience of engaging in voluntary work for people with lived experience of mental illness.
2. To explore the benefits and challenges from the volunteer perspective.
3. To engage and empower participants through the participatory action research process to collaboratively identify strengths and weaknesses of socio-political and welfare systems that support volunteering and explore the potential for change based on the experience of volunteering.
4. To generate knowledge through a process of reflection and action by formulating an action plan to consider how best to address, present and disseminate the data gathered for example, through the production of something of benefit to the group and/or wider community.
5. To reflect on how change has been brought about at an individual, group and wider community level through generating the product and by participating in the research project.
6. To explore the experience of volunteering with lived experience of mental illness in the current socio-economic climate in the UK.
7. To reflect on the usefulness of occupational therapy literature in conceptualising volunteering for people with lived experience of mental illness.
8. To reflect on the extent that the study findings fill a gap and extend the literature on volunteering with lived experience of mental illness.

In meeting these objectives, this project adopted a critical-emancipatory social research paradigm with participatory action research (PAR) as the methodological approach underpinning the research strategy. This project was further influenced by critical PAR, seeking to challenge conflict and oppression and bring about change (Kemmis 2008). Ten working age adults agreed to take part comprising four men and six women of white British ethnicity, predominantly Scottish and all were living in the same Scottish city. All had lived experience of mental illness and many had significant experience of volunteering. All were actively engaged at the time of the project in unpaid volunteering in the community through personal choice as part of their recovery journey. The research adopted two methods of qualitative data collection namely, preliminary individual interviews and participatory groups. The interview was designed to gather relevant background information and involved a conversation about volunteering with lived experience of mental illness whilst giving opportunities to clarify the research intention and discuss hopes and reservations about the project. Data from the interviews, although contributing to the overall findings for the thesis, was analysed by the researcher and kept separate from the participatory element of the project and the PAR group data. All participants were invited to attend a series of five PAR groups. Following consultation with participants, participatory group discussion was recorded and transcribed by the researcher after each group, with annotated first thoughts and preliminary emerging themes taken back to the next group for further discussion, analysis, critique, consolidation and validation. Data generation and analysis of the PAR groups was combined and followed Freire's (1970, p. 80; p. 104) process of "problem posing" and "conscientization" or critical consciousness raising where participants by asking critical questions about their situation recognised the potential for transformation. Data generation and analysis of the PAR groups was therefore collaborative, iterative, cumulative and co-constructed by participants through on-going discussion with themes revisited and revised by participants during and following each PAR group meeting.

Findings from the thematic analysis of the individual interviews and the participatory analysis of the PAR groups were combined for the purpose of the thesis, revealing a number of benefits and challenges of volunteering and pointing to factors that support and hinder a positive volunteering experience. Three themes emerged namely: "Selfish Altruism: Journeys of Recovery Through Volunteering" describing the benefits of volunteering and how volunteering has contributed positively to recovery; “The Darker Side of Volunteering” describing the challenges of volunteering at both an individual and systems level including the wider political context and the impact of welfare reform on the volunteer experience; and finally, “Reflection and Action: Keeping Volunteering Voluntary” describing the challenges in agreeing the final participatory action in line with PAR. The final participatory action from the PAR project involved exploring the potential to affect change at policy level. Drawing on participant knowledge and experience and specific concerns about mandatory volunteering, the group produced a briefing paper in a joint submission with Volunteer Edinburgh to the Social Security Committee. This was a timely response to the Scottish Government’s call for consultation and evidence to inform newly devolved powers supporting the Social Security (Scotland) Bill. Following consultation and from the 1st April 2018, the Scottish Government through Fair Work Scotland removed the mandatory element of volunteering as a requirement for work preparation and the link to benefit sanctions. Thus, participants actively contributed evidence in line with their experience to support change at policy level to resolve the problem of mandatory volunteering for themselves, future volunteers with lived experience of mental illness, and the wider Scottish community. More significantly, when combining the participatory research findings with the findings from the individual interviews and revisiting the literature, five conditions emerged constituting an original theory for successful volunteering that are considered necessary to support recovery for people with lived experience of mental illness. These five conditions comprise of: readiness and support to volunteer; synergy between volunteer and experience to ensure volunteering is meaningful; flexibility to stay well; opportunity to meet needs for identity and connectedness; and opportunity for influence and activism. Arguably, this original theory makes a significant contribution to the literature on volunteering with lived experience of mental illness and is summarised below.

11.1. Contribution to theory, policy and practice

This project has generated a new understanding of the experience of volunteering for people with lived experience of mental illness in relation to their recovery arguably, filling a gap and extending the literature. Notably, it proposes an original theory of five conditions for successful volunteering that are deemed necessary to support recovery for people with lived experience of mental illness. Although developed within the context of volunteering and lived experience of mental illness, it is possible that findings from this project will have relevance and transferability more generally and may have national and international appeal. In making an original contribution to theory, policy and practice this project has:

1. Revealed the significant benefits of volunteering with lived experience of mental illness for participants in this study and has filled a gap in the literature by proposing a theory of five conditions of successful volunteering that are deemed necessary to support recovery.

Volunteering is recognised as having the potential to support positive mental health and wellbeing. However, whilst there is a range of research evidence on the health benefits of volunteering and the motivation to volunteer, there is less emphasis on the experience of volunteering itself. This study has addressed this gap to reveal a range of issues experienced by people volunteering in the course of recovering from mental illness. Whilst this study has highlighted a number of individual benefits of volunteering that are consistent with current literature, it also makes a significant contribution to existing research by proposing an innovative theory of five conditions for successful volunteering that are necessary in supporting recovery for people with lived experience of mental illness. The five conditions (see Figure 14 below) comprise of: readiness and support; synergy; flexibility to stay well; meeting needs for identity and connectedness; and opportunity for influence and activism.

Figure 14: Five conditions for successful volunteering.

Firstly, *readiness* on the part of the volunteer alongside the availability of *support* to volunteer is considered a necessary pre-condition to successful volunteering. Readiness can be described as a transition from having sufficient time to recover from the acute stages of mental illness to reaching a stage of internal recognition of wanting to do something to ameliorate the negative impact on mood and mental health of having nothing to do. Participants often referred to this as needing purpose, structure and a reason to get out of bed. This transition could also be prompted by recognition on the part of a supportive other that doing something at this time would be beneficial for the individual. Although volunteering can be something that people negotiate themselves, the value of having support to negotiate this transition can be invaluable particularly in the initial stages where it can be negotiated and discussed in a supportive environment from an attitude of understanding. Indeed, volunteering can accommodate a range of readiness abilities where flexibility and support are implicit in a careful matching process with graded exposure providing incremental opportunities regarding level of challenge through for example, hours volunteered, level of responsibility or degree of exposure to the general public.

Secondly, *synergy* or ease of fit between the volunteer and the volunteer experience is necessary to ensure that volunteering is meaningful. Meaningful volunteering depends on finding synergy between the values, passion, experience, abilities and aspirations of the individual which are deeply personal alongside the values and objectives of the organisation or charity, the type and scope of the volunteering role on offer and the level of support and training available. For example, many participants in this study chose to volunteer with organisations supporting people with lived experience of mental illness reflecting a synergy with their own illness experience alongside a desire to give something back often motivated by empathy, altruism and passion for social justice.

Thirdly, sufficient *flexibility* within the volunteering experience is necessary to enable participants to tailor their fluctuating mental health to their volunteering commitment and/or to curtail the volunteering experience if it is proving too stressful. Remaining mentally well was an on-going and underlying preoccupation for participants who in acknowledging their fluctuating mental health also recognised their fragility and vulnerability. Whilst participants agreed that volunteering had the potential to support them in staying mentally well, this required careful self-management and monitoring of their mental health and wellbeing alongside flexibility on the part of the volunteering engaging organisation to appreciate, accept and accommodate their fluctuating mental health needs. All participants valued the ability to have autonomy, choice and flexibility in their volunteering in order to make informed decisions and balance engaging in meaningful occupation with staying mentally well and out of hospital.

Fourthly, volunteering should offer the potential to meet needs for *identity and connectedness.* Participants recognised that their lived experience of mental illness had become a strong, positive part of their identity as an expert by experience which was invaluable in a volunteering capacity in sharing their knowledge, skills and experience. Indeed, participants recognised finding a new purpose by drawing on their lived experience to support others with lived experience of mental illness through volunteering that involved advocacy, advice, peer support and training. Participants were passionate about advocacy viewing volunteering akin to that of career or a calling that offered them status and job satisfaction, recognised their talents, supported their wellbeing and was preferable to paid work or other volunteering options. Crafting a volunteering identity was not only at an individual level but also collectively through affiliation with the ethos and values of a particular organisation, service or charity. Thus, participants experienced a sense of belonging to that organisation feeling connected to and accepted by a wider volunteering community with opportunities to develop new relationships. In addition, volunteering in offering a productive role external to the home environment strengthened participants' self-image providing a renewed sense of identity which appeared to be supported and valued by family members.

Finally, volunteering should offer the potential to support volunteers with lived experience of mental illness to realise personal power and autonomy through agency, free choice and control to act independently and/or collectively to become *influencers* and to make a difference through *activism*. This is specifically important in supporting the emancipatory potential of volunteering enabling people with lived experience by way of a collective identity to influence and improve organisations and the delivery of services to confront inequality, exploitation and injustice in the pursuit of social change. Further, this supports a multi-lens approach to volunteering locating it as a socio-political activity in the community thus challenging the more limited view of volunteering as a stepping-stone to paid employment.

2. Highlighted the significant challenges experienced by participants volunteering with lived experience of mental illness due to current neoliberal welfare reform policies and conditionality affecting out-of-work disabled people in the UK thus, making a compelling addition to literature highlighting the negative effects of government welfare policy on out-of-work disabled welfare recipients.

Volunteering also has a dark side. This project has highlighted how personal power, autonomy and choice are contrasted with the experience of interference and disempowerment through control exerted by government systems, through policies and legislation affecting people recovering from mental illness. More specifically, findings from this project have confirmed how policies supporting welfare conditionality, force vulnerable people to undertake mandatory volunteering or risk significant financial sanctions including loss of benefits. Participants reported being made to give up meaningful volunteering roles for ones deemed by workfare programmes to be more appropriate to gaining paid employment, despite no evidence to support this (Coote 2014; Keep Volunteering Voluntary, 2014; Moore 2014). Thus, volunteering no longer accords with the definition of being undertaken through free choice (Department of Health 2011) and has the potential to become unproductive, meaningless and health compromising. This theme of contradictions and Kafkaesque experiences is exemplified by language becoming ambiguous; volunteering becoming no longer voluntary; and volunteering and paid employment becoming conflated. Indeed, government intentions to reduce unemployment and welfare benefit payments for people with long-term health conditions are at odds with participant lived experience of mental illness where participants valued the benefits of volunteering in supporting recovery but recognised that paid work at this stage would exacerbate their mental illness and compromise their recovery journey. Finally, participants disclosed that the effects of current welfare systems and the reporting of these in the media further contributes to the polarisation and stigma of people with lived experience of mental illness as either benefit scroungers or violent, dangerous psychotic individuals. Social issues become individualised leaving no opportunity to consider the systemic causes of poverty or complexities surrounding the experience of mental illness (Patrick 2015; Gedalof 2018). Whist participants believed they were making a significant contribution to their community through volunteering, they continued to be labelled as out-of-work disabled benefit claimants and thus continued to be subjected to this stigma.

3. Demonstrated how PAR contributes to positive socio-political change with findings from this project providing evidence challenging mandatory volunteering as a workfare requirement in Scotland and promoting significant change by influencing Scottish Government policy development.

A key premise of a critical-emancipatory paradigm is to expose inequality, exploitation and injustice, to give voice to excluded and marginalised groups, to clarify oppression and precipitate social change (Henn et al. 2009, p.17). In this instance, PAR has brought to light contradiction and confusion for people who are volunteering with lived experience of mental illness as a result of a policy context with an agenda other than recovery. In enabling marginalised voices to be heard, PAR breaks down barriers for both listeners and speakers to promote collaborative action that is empowering and emancipatory (Maguire 2000). Whilst this thesis is an academic piece of work, PAR is not about creating academic knowledge but more about contributing to history and “transforming the work, lives and situations of people in the interest of rationality, sustainability and justice” (Kemmis and McTaggart 2014, p.211). Arguably, the action from this PAR project has done exactly that, by producing a timely briefing for the Scottish Government and responding to a call for evidence in supporting change at policy level and thus contributing to resolving the problem of mandatory volunteering for participants, future volunteers and the wider Scottish community.

4. Exposed how at a socio-political level, the hegemony of paid work in neoliberal times dominating UK government welfare reform constrains and limits an understanding of volunteering as one viewed solely through a vocational or work lens; and how at a practice level, this view of volunteering is mirrored in occupational therapy services with limited critique.

Findings from this study problematise the hegemony of paid work and highlight the need to challenge occupational therapy practice and taken for granted thinking that places volunteering as a second-best option for people recovering from mental illness in a hierarchy where paid work is the ultimate goal. This is perhaps unsurprising, given that the current UK context of welfare reform, austerity and neoliberalism is driven by a hegemony of paid work which is central to defining the dutiful citizen (Patrick 2017, p. 23); where everyone is viewed as capable of employment given the right support; and where paid work is viewed as unproblematic and endowed with transformative properties as the only way to beat poverty despite the reality that paid work is often poorly paid, precarious and potentially demeaning (Hamer et al. 2017; Patrick 2017, p.28; Bloodworth 2018; Gedalof 2018). However, despite the attraction of support into paid work for some disabled people, many participants in this study although volunteering, did not feel work-able; and many did not believe that paid work could offer them the same wellbeing effects as volunteering namely: flexibility, meaningfulness, choice, feeling accepted, valued and being able to make a difference. Arguably, participants volunteered because they understood the evidence that being unemployed has a negative impact on mental health, whilst also recognising that up to 30% of paid work increases the risk of mental illness and fails to lift people out of poverty (NHS Scotland 2016).

In contrast, occupational therapy literature suggests that the value of work is a given, with paid employment viewed as providing a sense of worth through the construction of a positive worker identity within a valued social context (Van Niekerk 2009; Hitch et al. 2013; Fegan and Cook 2014). Indeed, paid work is highly meaningful for many people recovering from mental illness in terms of self-perceived usefulness, social connectedness, income and structure (Marwaha and Johnson 2005; McKay 2010; Dominy and Hayward-Butcher 2012; Blank et al. 2015; Carmona et al. 2019). The dominance of vocational rehabilitation programmes supporting people living with mental illness to access meaningful paid employment is unsurprising given the UK government's drive to decrease the number of disabled people receiving out-of-work welfare benefits, including those recovering from mental illness (DWP 2008; 2016) However, whilst there is some recognition that paid work may hold ambivalence for people recovering from mental illness (Blank et al. 2015), this is rarely explored within occupational therapy literature. In this context, volunteering is viewed either as a pre-employment occupation for people with limited previous work experience or skills (Talbot et al. 2018); or a place where people get stuck as “career volunteers” signifying a lack of vocational progression due to fear of readiness or lack of sufficient vocational support (Fegan 2014, p. 162). Solely viewing volunteering as a steppingstone to paid employment, ignores its role in “connecting, belonging, and contributing to others” (Hammell 2014, p. 39) through for example, advocacy, peer support and activism. Further, it ignores the complexity of how discourses on occupation are shaped by socio-political and historical perspectives; it limits occupational possibilities by adopting a taken for granted approach to what constitutes meaningful occupation; and it challenges the perception of occupational therapists as instruments of occupational justice (Laliberte-Rudman 2010; Durocher 2017).

Indeed, participants in this study recognised a broader scope of volunteering beyond a means to paid work and were able to exercise personal choice to engage in philanthropy, governance, advocacy, campaigning and fulfilling personal passions and interests through volunteering whilst also recognising that this supported their mental wellbeing. Thus, volunteering was an active choice. Volunteering compared more favourably to their experience and perception of paid work, which for them was arguably less meaningful, offered less flexibility and although providing an income, offered fewer overall benefits to their wellbeing than that of volunteering. Indeed, participants in this study reflected a strong volunteering worldview and appeared to view it akin to that of a calling where they were heavily invested in the ethos and outcomes of the organisation that they volunteered with. Somewhat surprisingly, this wider scope of volunteering for adults under 65 years old is rarely addressed in the occupational therapy literature despite reflecting a number of values that occupational therapists hold dear in relation to meaningful occupation as a mechanism for wellbeing and the importance of personal choice, balance, agency and empowerment.

This research has identified a politically transformatory analysis of volunteering in line with Gorz’s (1985; 1989) consideration of the role of independent, autonomous work in emancipation from alienation, supporting Arendt’s (1958 in Dant 2003, p.43) criticism of labour as the necessary, ongoing, grind of everyday life that “must be accepted as part of the human condition” and specifically “alienated” labour, Marx’s view of loss of freedom and self-control in productivity through capitalism (Arendt 1958, in Dant 2003, p.44). Findings from this project therefore support the need for more critical exploration of occupational therapy vocational practice in adopting a paid work hegemony; and of the need to further explore volunteering opportunities for influence and activism. They provide a useful tool to challenge the accepted wisdom within occupational therapy of the hegemony of paid work and to begin to understand how dominant societal forces and power significantly influence the current day concerns and practices of occupational therapists and the value associated with volunteering (Stevenson and Cutcliffe 2006). This project calls for more exploration of the value of engaging in meaningful volunteering to support wellbeing, community capacity building and human flourishing as outlined in Gorz's (1985; 1989) theory and supported by strategies such as Universal Basic Income.

Pollard et al. (2008) remind us that occupation is political and call on us to challenge the perpetuation of occupational injustices that result from the divide between government and experience, to promote active citizenship and to ensure that occupational therapy remains relevant. As occupational therapists we need to pay attention to the political context of volunteering where it has been hijacked by governments who say that if you are able to volunteer then you are able to work. The findings from this study therefore call on occupational therapists to recognise a broader scope of volunteering beyond one viewed solely through a work lens and to engage with the complexity of occupation from a socio-political perspective to further explore the implications of neoliberalism, austerity and welfare reform on the occupations that people with lived experience of mental illness want to do to remain well and to contribute to their communities (Rudman and Aldrich 2016).

11.2. Recommendations

A number of recommendations are identified here based on participants' views, the research experience and perceptions of the practice context, which may be relevant to a range of audiences. These have implications for future practice and research.

Volunteering with lived experience of mental illness

1. This study has proposed an original theory of five conditions for successful volunteering for people with lived experience of mental illness. This could be helpful for volunteers and volunteer engaging organisations in recruiting and supporting people with lived experience of mental illness into volunteering.

Whether these conditions are sufficient to promote recovery could be tested with further research.

2. Additional research exploring the emancipatory potential of volunteering and opportunities for influence and activism is recommended to further challenge the view of volunteering as solely a stepping-stone to paid employment. Future research could also explore the value of engaging in meaningful volunteering to support wellbeing, community capacity building and human flourishing in line with Gorz's (1985; 1989) strategies and ideas in relation to occupation. It could also explore perceptions of people with lived experience of mental illness to the introduction of a citizen's income in line with Universal Basic Income.

3. Whilst the outcome from this project is favourable to volunteers in Scotland, volunteers in the rest of the UK continue to be subjected to oxymoronic mandatory volunteering and benefit sanctions. Findings from this project could usefully support policy change regarding work conditionality in England, Wales and Northern Ireland where volunteering continues to be mandatory through for example, awareness raising and lobbying of government.

4. Whilst it is known that volunteering contributes to Scotland's economic and social prosperity, more consideration could be given to measuring the contribution to society by people with lived experience of mental illness thus challenging the stigma of being out-of-work and volunteering. Indeed, the contribution of volunteering to the global economy, in building community capacity and social capital is under-recognised and requires further exploration. For example, at a local level, participants believed that volunteering kept them well and reduced the potential for re-admission to hospital. Furthermore, through their volunteering, participants believed that they were also potentially reducing admission for the wider community of people recovering from mental illness through the provision of voluntary services offering support and advocacy. These health and wellbeing benefits and potential savings to health service costs require further exploration.

5. The literature review exposed inconsistencies in definitions of volunteering and thus difficulties in capturing reliable and comparable data across the UK. Whilst it may not be possible to collect comparative data due to research methodologies reflecting different government surveys (Volunteer Scotland 2017), a key recommendation from this project, in line with Harper (2015), is that volunteering participation in its broadest sense should be recorded in Scotland to offer robust reporting and more realistically capture grassroots volunteering related to participation and community action.

Collaborative Working and PAR

6. This project supports more PAR and collaborative working with people with lived experience of mental illness and those involved in decision-making to expose inequality, exploitation and injustice affecting the lives of vulnerable people. Indeed, participants in this project remain committed to voicing their ideas and experiences within collaborative forums to clarify oppression and precipitate social change. For example, in exploring how there can be more flexibility and better understanding of living with mental illness more generally in government and wider society; and educating decision makers about the lived experience of mental illness and effects of social policy on mental illness, vulnerability and recovery.

7. Alongside any participatory research project, should be a commitment to building capacity in training participants in research methods.

Practice Contexts

8. Findings from this project support the need for more critical research exploring occupational therapy vocational practice to challenge the hegemony of paid work and to begin to understand how dominant societal forces and power significantly influence the current day concerns, practices, attitudes and values of occupational therapists in relation to volunteering for people recovering from mental illness. This would serve to challenge the perpetuation of occupational injustices that result from the divide between government legislation and experience, whilst ensuring that occupational therapy remains relevant.

9. Findings from this project call for occupational therapists to become significantly more critical and political in their practice. The findings support Rudman and Aldrich’s (2016) recommendations that occupational therapists must engage with the complexity of occupation from a socio-political perspective to further explore the implications of neoliberalism, austerity and welfare reform on the occupations that people with lived experience of mental illness want to do to remain well and to contribute to their communities.

10. Further research could explore the experience of mental health professionals who are working in neoliberal and borderline times. The study could explore participants’ reflections in relation to their work with vulnerable people at an individual, professional and systemic level. Topics could include issues of personal power, autonomy and choice as contrasted with experience of interference and disempowerment associated with conflict and control exerted by a range of systems.

Chapter Summary

In concluding the thesis, this chapter has summarised the research intention of this project, revisiting the key outcomes to highlight the contribution of this research to theory, policy and practice. Recommendations have been made supporting further exploration and change based on participants’ views, the research experience and perceptions of the practice context, that that have implications for future practice and research and may be relevant to a range of audiences.

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APPENDIX 1: Literature Review Search Strategy

The scope of the literature review encompassed research evidence from a range of disciplines including occupational therapy, sociology, psychology and politics; theoretical ideas; government documents, policy and legislation; book chapters; popular media reports; and opinion pieces, from a variety of sources not restricted to academia or emphasising positivist hierarchies of evidence. I was initially drawn to the integrative review originating from nursing (Whittemore and Knafl 2005) involving a broad review of evidence from a range of theoretical and empirical literature to define concepts and reach a fuller understanding. I liked this approach to identifying the problem and analysing the data using a constant comparison method and iterative process to identify “patterns, themes, variations and relationships” (Whittemore and Knafl 2005, p.550). However, Whittemore and Knafl’s (2005) strategies to enhance the rigour of integrative reviews and their intention to reduce bias appeared beyond the scope of this review and I was further guided by the simplicity of a narrative or traditional review concerned with providing background to the study, locating similar or related research, and giving consideration to how this literature informs the current study and how the current study fits into existing research in the field (Grant and Booth 2009). Therefore, a hybrid of these two approaches forms the style of this review.

The research process has spanned many years from conception to final write-up. An initial scoping review was conducted to investigate the need for the study and comprised a brief review for the probationary assessment. This was revisited and revised, evolving over time with additional topics emerging as the study progressed in a “cyclical, iterative and ongoing” process (Bloomberg and Volpe 2018, p. 144). A map was drawn up to consider the potential range of literature to be included and to ensure that the review remained appropriate, relevant and useful (see Figure 1 below):

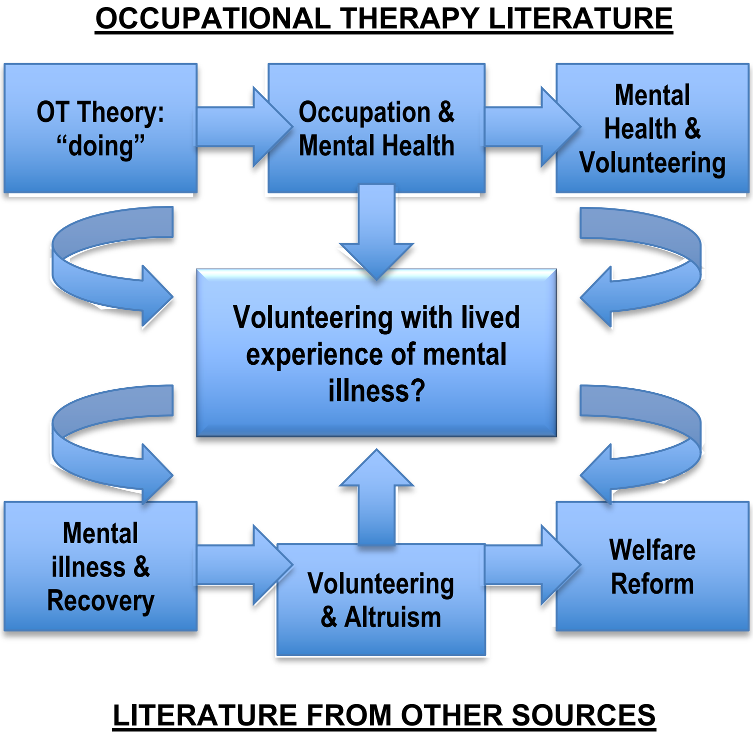


Figure 1: Mapping literature review themes.

In seeking literature I assumed a broad search strategy to identify relevant material using established databases (CINAHL (Cumulative Index for Nursing and Allied Health Literature), PsychINFO, Medline, The Cochrane Library, The Campbell Collaboration). The initial search used a combination of the following terms: “volunteer*” OR “volunt*” OR “altruism” OR “community engagement” OR “community participation” OR “civic engagement” OR “civic participation” OR “productive activity” OR “co-production” OR “meaningful occupation” OR “occupation” OR “social capital” OR “social inclusion” AND “mental illness” OR “mental health” OR “psychiatr*” OR “wellbeing” OR “health” OR “recovery” AND “occupational therapy” OR “occup*”.

Additional sources were both strategically and serendipitously acquired through manual searching of reference lists of primary articles, examination of social policy and legislation, consideration of underpinning theory and expert opinion through grey literature including non-research literature, book chapters, newspaper articles and social media and reflection on experience. Given that strict search criteria were not applied to all of the literature review themes, the search strategy would be difficult to replicate. No limits were put on search dates in order to capture seminal work. Literature was limited to English language with no discrimination on the basis of source or type of literature with all literature initially valued. The challenge in using the terms “volunteer” and “volunteering” became apparent as they appear to be used interchangeably with “participant” and “participating” in research studies. This generated a large number of results that required to be filtered. Literature focussing on volunteering for children and school leavers or evaluating volunteering in mental health settings, was excluded and regarded as out with the scope of this study. Whilst volunteering in retirement was recognised as a significant body of work, this was initially excluded with a view to revisiting this should older people choose to participate.

APPENDIX 2: Employment and Support Allowance (DWP 2017a)

Employment and Support Allowance:

ESA is an "income replacement" benefit for people who have a health condition or disability which limits their ability to work. As of May 2016, there were just under 2.4 million ESA claimants in Great Britain, including 429,000 in the Work-Related Activity Group. There are two forms of ESA:

- Contributory ESA, for those with a sufficient National Insurance contribution record; and
- Income-related ESA, which is means-tested.

Income-related ESA will eventually be replaced by Universal Credit; contributory ESA will remain as a separate benefit. The Government currently expects the introduction of Universal Credit to be fully complete by 2022.

A person must undergo a Work Capability Assessment to be eligible for ESA. There are three possible outcomes of a Work Capability Assessment:

1. The claimant is found “Fit for Work” and may instead apply for JSA or Universal Credit;
2. The claimant is placed in the “Work-Related Activity Group” (WRAG) and must undertake “work-related activity”;
3. The claimant is placed in the “Support group” and is not required to take part in any work-related activity.

Following the assessment, successful ESA claimants receive a standard rate plus an additional amount. The standard rate of ESA is currently £73.10 a week, plus either:

- £36.20 for claimants in the Support Group, or;
- £29.05 for claimants in the Work-Related Activity Group.

These additions are known as the Support Component and the Work-Related Activity Component, respectively.

In Summer Budget 2015, it was announced that the Work-Related Activity Component paid to those in the WRAG would be abolished for new claims from April 2017. The equivalent element in Universal Credit will also be abolished. This will involve a reduction of £29.05 a week (2017-18 rates) and aligns the rate of payment with those claiming Jobseeker’s Allowance (£73.10 a week). Existing claimants will not be affected, while there will be protections for those who may move into the WRAG or Universal Credit equivalent from the Support Group. The changes were introduced to “remove the financial incentives that could otherwise discourage claimants from taking steps back to work”. £640 million a year of savings were initially forecast by 2020-21; this was later revised to £450 million a year.

DWP (2017a) Commons Briefing Papers CBP-7649: Abolition of the ESA Work-related activity component. http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7649

APPENDIX 3: Preliminary Interview and Conversation Guide (Sept 2015)

Project title: An exploration of the ways in which voluntary work may impact on people's lives: Participatory Action Research with people with lived experience of mental illness.

- Thanks for coming. Offer coffee/ refreshment/ reimburse any travel expenses
- Check understanding of project, ability to make commitment to project and confirm consent by completing consent form. Specifically consent to initial interview being tape-recorded. Answer questions raised by participants/ provide reassurance on confidentiality.

This project gives you a chance to share your experiences of volunteering with others, to learn from others and to reflect on the contribution you have made to volunteering. I want to draw on your expert opinion. Your involvement is important and together there is an opportunity to influence change.

1. I am wondering how you feel/ what you think about taking part in this project?
2. What needs to happen for you to feel it was worth coming and taking part?
3. Is there anything that you would like to ask me about the project? (check for understanding and willingness to engage in PAR groups)
4. Is there anything I need to know about your health and wellbeing? (prompt for support systems, relapse signature, is there anyone I should contact in the event that you might become unwell in any way during the meetings – confirm emergency contact info?)

Gathering information on volunteering experience

1. Can you tell me about your experience of volunteering? (prompt for how long, how frequent, what kind, what got you started)
2. I am wondering how you feel / what you think about your volunteering? (prompt for positives and negatives, benefits, supports, challenges)
3. Can you say something about the difference you have made to others through volunteering? (prompt for reflection on contribution to others)
4. Is there anything you would like to change about your experience or wish it could be different in some way?
5. Is there anything else I should be asking? Do you think the sort of questions I am asking are the right kind of questions to help me understand your experience? (prompt for anything you want to elaborate on)

Thank people for coming and discuss next steps

APPENDIX 4: Participatory Action Research Group Topic Guide (June 2015)

Project: An exploration of the ways in which voluntary work may impact on people's lives: Participatory Action Research with people with lived experience of mental illness

1. **Introductions:**

Explain my role in this and what I can offer:

I've had contact for many years with mental health services and was involved 30 years ago in helping to set up volunteering for people with lived experience of mental illness. I am aware that there has never been any serious thought given to what makes volunteering work or not work. I wanted to set up a project that could draw on the experience of people who volunteer with the expectation that in sharing our experience there could be something of value that we could work on and create together.

I am independent from NHS /hospital and the volunteer centre.
I can capture what we discuss and give it back to you and see what you think and we can discuss it next time we meet.

2. **Reminder of aims and objectives of the project.**

Is everyone clear about why they want to be involved in the research project and what they want to get out of it?

3. **Working Agreement: discussion and agreement of ethical issues and guidelines for the group**

Using Durham University's Centre for Social Justice and Community Research (2012) community based participatory research: A guide to ethical principles and practice to guide discussion.

- Consider issues such as mutual respect, equality and inclusion, participation, active learning, making a difference, collective action, personal integrity and confidentiality.
- Consider how data is generated and stored.
- What kind of working framework is necessary? How should we record this and ensure everyone knows about it / adheres to it? How should we review/ revise it?
- Should include practical details of working relationships as well as an outline of how to ensure that people who provide research data are protected and credited.
- Working agreement might include: agreed ethical principles; protocol for communications; protocol for safety; protocol for handling difficulties and conflict; agreed aims and objectives of the research; methods to be used and how this reflects a commitment to participation; management of the

research and leadership of the project; any available funding; any training needs; practical details and responsibility; when and where meeting will be held; processes for reflection, evaluation and learning.

- Consider issues of informed consent; handling personal information; confidentiality; anonymity; ownership, and control and use of research data and findings.
- Participation is not automatic – what do we need to do to ensure that people in the group feel listened to and able to participate?
- What do we expect of each other? What do you expect from me?

4. **Possible areas for discussion:**

PAR is based on the idea that all people have valuable knowledge about their lives and experiences. What do you think about that? How can we best capture your voice and experience?

- How will you know it was worth coming today? What needs to happen?
- Discuss hopes and fears for the project and share common values and aspirations e.g. what brought you and what you want to get out of it. What are the commonalities and the differences? Is it going to be productive to work together?
- What do we need to know/ find out about each other? What sort of questions should we be asking ourselves? (?brainstorm for questions; when did you get involved in volunteering?; why?; what sort of possible benefits does volunteering bring you?; what are the challenges for you? etc.)
- How should we best capture the information we are sharing? (e.g. tape recordings, timeline, brainstorm. SWOB analysis etc.)
- From the information we have gathered, are there any similarities or differences or things that are missing? Can we group them into themes or categories? How would you rank them in order of importance?
- Might it be helpful to bring in other people and ask them questions? Would it be helpful to canvas wider opinion? Who might we ask? How might we do that?
- How frequently should we meet?

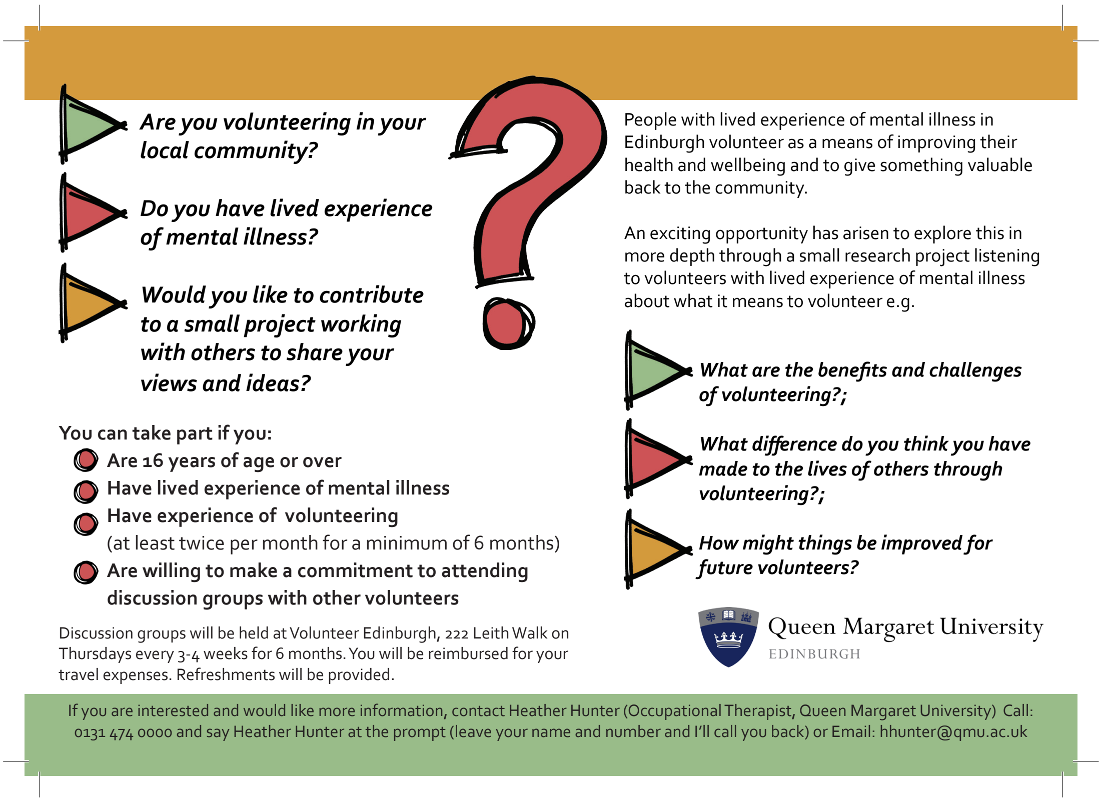
5. **Agree date, time and format of next meeting**

APPENDIX 5: Participant Inclusion and Exclusion Criteria

Inclusion Criteria:	**Exclusion Criteria:**	**Rationale:**
Lived or living experience of mental illness with a current or previous history of diagnosis of a mental disorder according to ICD 10 or DSM 5 classifications.	No current or previous history of mental illness or diagnosis of a mental disorder.	The project aims to engage people with lived experience of mental illness.
Independent of in-patient clinical services and/or currently receiving outpatient monitoring and review.	In-patient or recent in-patient admission less than 6 months ago. Currently subject to any compulsory detention measures under Mental Health Care and Treatment (Scotland) Act 2003.	To avoid placing undue pressure on people in an acute stage of illness or those requiring monitoring as part of compulsory measures who may be more vulnerable at this time and/ or may pose a significant risk to themselves or others.
Current experience of volunteering (at least twice per month) for a minimum of 6 months.	No experience of volunteering. Experience of volunteering less than twice per month and/ or less than 6mths in duration.	The project aims to engage people who have a regular commitment to volunteering in order to draw on that experience to discuss and reflect with others in a group setting.
New to volunteering or longer history of volunteering.	No volunteering role.	The project aims to engage people who are currently volunteering regardless of length of time. This is in recognition that all experiences are valued and that people new to volunteering may bring different and/or similar experiences to those who have been volunteering for some time.
Individuals of 16 year of age and upwards.	Individuals of less than 16 years.	Young people under 16 years will have developmental and educational considerations and may benefit from a project specifically for younger people.
Capacity to understand the research process. Curiosity, ability and willingness to engage in PAR groups and the research process.	Incapacity to understand the research process. Lack of curiosity, ability and/or willingness to engage in PAR groups and the research process.	Participation and action are key factors within the research design and the expectation is that people will be willing to share and reflect on their individual and collective experiences and be willing to work together to produce something of benefit for the group or wider community.

Table 1: Participant inclusion and exclusion criteria

APPENDIX 6: A5 Recruitment Flyer



- ***Are you volunteering in your local community?***
- ***Do you have lived experience of mental illness?***
- ***Would you like to contribute to a small project working with others to share your views and ideas?***

You can take part if you:

- Are 16 years of age or over
- Have lived experience of mental illness
- Have experience of volunteering
  (at least twice per month for a minimum of 6 months)
- Are willing to make a commitment to attending discussion groups with other volunteers

Discussion groups will be held at Volunteer Edinburgh, 222 Leith Walk on Thursdays every 3-4 weeks for 6 months. You will be reimbursed for your travel expenses. Refreshments will be provided.

People with lived experience of mental illness in Edinburgh volunteer as a means of improving their health and wellbeing and to give something valuable back to the community.

An exciting opportunity has arisen to explore this in more depth through a small research project listening to volunteers with lived experience of mental illness about what it means to volunteer e.g.

- ***What are the benefits and challenges of volunteering?;***
- ***What difference do you think you have made to the lives of others through volunteering?;***
- ***How might things be improved for future volunteers?***

Queen Margaret University
EDINBURGH

If you are interested and would like more information, contact Heather Hunter (Occupational Therapist, Queen Margaret University) Call: 0131 474 0000 and say Heather Hunter at the prompt (leave your name and number and I'll call you back) or Email: hhunter@qmu.ac.uk

APPENDIX 7: Project Information Sheet (September 2015)

Queen Margaret University
EDINBURGH

My name is Heather Hunter, and I am an occupational therapist and PhD student from the School of Health Sciences at Queen Margaret University, Edinburgh. My project is called: *An exploration of the ways in which voluntary work may impact on people's lives: Participatory Action Research with people with lived experience of mental illness*

What is this project about? The aim of the project is to hear from people who are volunteering in the community and who have lived experience of mental illness, what are the key issues that you experience through volunteering. For example, the positives and negatives of volunteering and/or the strengths and weakness of socio-political systems that support you to volunteer.

Why is this project important? I've worked for many years in mental health services and was involved 30 years ago in helping to set up volunteering for people with lived experience of mental illness. I am aware that there has never been any serious thought given to what makes volunteering work or not work. I wanted to set up a project that could draw on the expertise and voice of people who volunteer with the hope that in sharing our experience there could be something of value that we could work on and create together. Unlike many studies where you complete a questionnaire or answer some questions, this project uses a participatory action research (PAR) approach which is committed to actively including people whose voices are often ignored and working together as a small group to create change. The outcome of this project will be to produce something useful for you, future volunteers, and/ or the wider community. For example, we could produce a written guide or arts-based project (film, exhibition etc.) that would be useful for volunteer organisations/ future volunteers/ funders/ Scottish Government/ health and social care professionals/ community organisations/ friends, families and carers. The project could also be published or presented at a conference.

Who should participate? You can take part if:

1. You are 16 years or over, have lived experience of mental illness and are involved in some form of volunteering (at least twice per month for a minimum of 6 months). It doesn't matter whether you are fairly new to volunteering or have been doing it for some time.
2. You are interested in working with others in a small group and willing to share your experience and think creatively to create change.

If you can answer yes to all of the above, then this project is for you. No previous experience of this type of project work is necessary.

What will happen once I agree to take part? Once you agree, you will be asked to sign a consent form. You will then take part in a short initial interview with Heather before joining other participants in a series of discussion group meetings. The initial interview should take around 30 minutes.

Are there any risks in taking part? There are no specific risks associated with this project. However, some people find talking about their experience can trigger difficult memories and feelings; and some people dislike sharing their experience in a group. If you find that you are taking part at a difficult emotional time, it is important that you feel able to recognise this and can access support if this occurs. To capture our ideas, discussions will be audio taped. All identifying information (e.g. names, addresses, organisations) and personal information collected as part of the project (e.g. interview responses, tape recordings, artwork) will be anonymised and stored securely in a locked cabinet which will only be accessed by Heather Hunter. This means that it will not be possible for you to be identified in any reporting of the information gathered unless you choose differently. All recordings will be destroyed at the end of the project.

How often will the group meet? The discussion groups will take place every 3-4 weeks on Thursdays for about 6 months and will be held in "Volunteer Edinburgh", 222 Leith Walk. Each discussion group should last between 60-90 mins. Refreshments will be provided.

Can I change my mind about taking part? You are free to withdraw from the study at any stage and you do not have to give a reason.

Can I get help with travel expenses? Since your participation will involve travelling to Volunteer Edinburgh, 222 Leith Walk, you will be reimbursed for out-of-pocket expenses.

Can I talk to someone else about this project? If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Mary Weir. Her contact details are given below.

What happens now? If you have read and understood this information sheet and feel that any questions you had have been answered, and you would like to take part in this project, please have a look at and complete the consent form. If you have any further questions, please contact Heather.

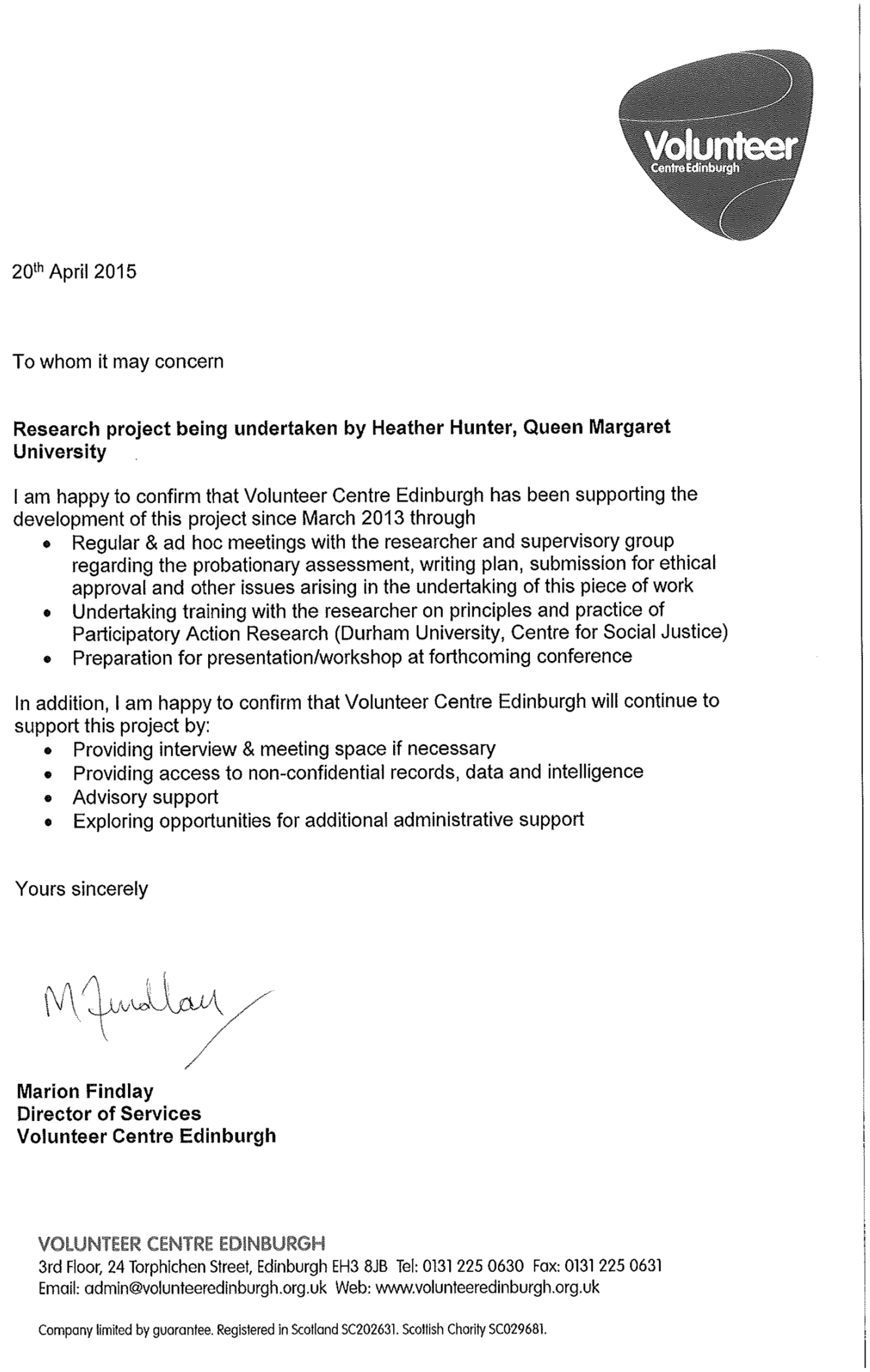
Contact details of the researcher:

Name: Heather Hunter
Address: Senior Lecturer in Occupational Therapy/ PhD Student,
Division of Occupational Therapy and Arts Therapies,
School of Health Sciences, Queen Margaret University
Queen Margaret University Drive, Musselburgh
East Lothian EH21 6UU
Email / Telephone: hhunter@qmu.ac.uk / **0131 474 0000** (and ask for Heather Hunter)

Contact details of the independent adviser:

Name: Mary Weir, Retired Chief Executive of Support in Mind Scotland
Email: maryweir75@yahoo.co.uk

APPENDIX 8: Volunteer Edinburgh Agreement Letter



Volunteer
Centre Edinburgh

20th April 2015

To whom it may concern

Research project being undertaken by Heather Hunter, Queen Margaret University

I am happy to confirm that Volunteer Centre Edinburgh has been supporting the development of this project since March 2013 through

- Regular & ad hoc meetings with the researcher and supervisory group regarding the probationary assessment, writing plan, submission for ethical approval and other issues arising in the undertaking of this piece of work
- Undertaking training with the researcher on principles and practice of Participatory Action Research (Durham University, Centre for Social Justice)
- Preparation for presentation/workshop at forthcoming conference

In addition, I am happy to confirm that Volunteer Centre Edinburgh will continue to support this project by:

- Providing interview & meeting space if necessary
- Providing access to non-confidential records, data and intelligence
- Advisory support
- Exploring opportunities for additional administrative support

Yours sincerely

M Findlay

Marion Findlay
Director of Services
Volunteer Centre Edinburgh

VOLUNTEER CENTRE EDINBURGH
3rd Floor, 24 Torphichen Street, Edinburgh EH3 8JB Tel: 0131 225 0630 Fax: 0131 225 0631
Email: admin@volunteeredinburgh.org.uk Web: www.volunteeredinburgh.org.uk

APPENDIX 9: Participant Consent Form

Queen Margaret University
EDINBURGH

Title of Project: An exploration of the ways in which voluntary work may impact on people’s lives: Participatory Action Research with people with lived experience of mental illness
Name of Researcher: Heather Hunter

Please initial each box that you are in agreement with.

1. I confirm that I have read the information sheet dated.......................for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I confirm that I am willing to be audio recorded during this study. ☐
4. I confirm that I am willing to be video recorded during this study. ☐
5. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Witness	Date	Signature

APPENDIX 10: Process for Obtaining Participant Informed Consent

1. Initial discussion between researcher and potential participant to identify interest through discussion about the research project.

2. Upon declaration of interest, a face-to-face conversation was arranged to discuss the aims and objectives and nature of the study and potential involvement. This included details of the purpose and use of the research data so that potential participants knew enough about the project to be able to decide whether to participate or not.

3. Information was repeated, explained and reinforced in order to ensure potential participants were in a position to give informed consent. Opportunities were provided for potential participants to ask questions and for the researcher to ask questions to check participants understood this initial discussion. In determining whether potential participants were able to provide informed consent the researcher ensured that participants were in a position to understand and retain the information provided and to weigh up the pros and cons of taking part in order to reach a balanced decision.

4. A permanent record of information about the research via the information sheet was given to potential participants, ensuring that this written format was appropriate in language and font size for each person.

5. A consent form was then provided to each potential participant and was discussed and explained in detail, answering any further questions arising, checking understanding and discussing all benefits and risks prior to signing. Once written agreement was received, participants were given a copy of their signed form for future reference.

6. Participants were made aware that the purpose and use of the research may change and develop over time, consent may need to be continually reviewed and renegotiated, particularly when plans for publication and dissemination were developed and where collective consent may be required.

APPENDIX 11: ECArTE Conference Submission, Krakow 2017

ECArTE 19th European Arts Therapies Conference, Krakow, Poland.

Negotiating Transitions in Borderline Times

Heather Hunter and Margaret Hills de Zárate, Division of Occupational and Arts Therapies, Queen Margaret University, Edinburgh

This masterclass was inspired by the facilitators' involvement in a Participatory Action Research project with a group of adults with lived experience of mental illness who engaged in unpaid voluntary work through personal choice as part of their journey of recovery. The themes emerging from this research highlight the continuities and discontinuities involved in transition. They draw attention to issues of personal power, autonomy, and choice as contrasted with experiences of interference and disempowerment associated with conflict and control exerted by a range of socio-political systems, policies and legislation affecting vulnerable groups.

Transition is the internal process that people must go through to adapt to external change, and the new situation it presents. Not surprising transition theory has changed emphasis with the passage of time. Adams, Hayes and Hopson (1976) refer to transition as a discontinuity in a person's life space whereas theories concerned with continuity emphasise making choices, while attempting to preserve and maintain existing internal and external structures, including personal and cultural traditions. This involves people in employing strategies informed by perceived past experiences of themselves and their social world (Atchley 1989) in a world where, as Nora (2002) argues, the most continuous or permanent feature is no longer continuity or permanence but change. This increasingly diverse and ever-changing socio-cultural landscape (Schlossberg et al. 2011) has highlighted the experience of loss of control and unpreparedness for a world that is at one level predictable and at another, unknown (Bussolari and Goodell 2009; Duchscher, 2009).

Participants in this experiential art-based workshop are invited to explore these themes as they impact upon their own lives and those of the people and populations with whom they work through their own art making. Participants will unpick the process and impact of transition. Implicit in this exploration is a reflection on the usefulness of factors influencing experiences of transition such as tradition, predictability and choice. It is hoped that this group will generate a discussion of ideas that will inform future research as to how art therapy might address these pertinent issues in contemporary practice in borderline times. The masterclass will be largely experiential session of one and half hours, followed by a short break and a 30-minute discussion session.

APPENDIX 12: Occupational Science Europe Conference Submission, Hildesheim 2017

Oral presentation abstract accepted for the Occupational Science Europe Conference, Hildesheim, Germany.

Is Volunteering Voluntary? Exploring the Dark Side of Volunteering.

Heather Hunter, Division of Occupational and Arts Therapies, Queen Margaret University, Edinburgh

In the current neo-liberal climate resulting in financial cutbacks within the public sector, governments are relying more on the voluntary sector for service delivery. Simultaneously, there is increasing requirement for young people and recent immigrants to demonstrate their suitability for employment through voluntary work experience, thus coining the term “coerced volunteerism” which is further illustrated in the growing trend for unpaid internships in the for-profit sector (Schugurensky 2013: 2).

In the UK, disabled claimants receiving welfare benefits are required by workfare programmes to undertake mandatory unpaid community work within charities or voluntary organisations in order to receive Job Seekers Allowance or they risk significant financial sanctions including loss of benefits. In carrying out this oxymoronic “mandatory volunteering” (Schugurensky 2013: 2), claimants are offered no choice in their volunteering placement and may be forced to give up a meaningful volunteering role for one deemed by the UK Government’s Help to Work programme as more appropriate to gaining employment, despite no evidence to support this (Keep Volunteering Voluntary 2014). This contradicts the definition of volunteering as an “...activity undertaken freely that involves spending time, unpaid, doing something that aims to benefit the environment or individual or groups” (Department of Health 2011:9-10).

Volunteering is recognised as playing an important role in supporting positive mental health and wellbeing (Tabassum, Mohan and Smith 2016). However, whilst there is a range of research evidence on the health benefits of volunteering and the motivation to volunteer (Schugurensky 2013), there is less emphasis on the experience of volunteering itself (Wilson 2012).

This paper will highlight the preliminary findings from a Participatory Action Research (PAR) project with a group of adults with lived experience of mental illness who are engaged in unpaid voluntary work in the community through personal choice as part of their journey of recovery. Drawing on the notion of occupational therapy as political (Pollard and Sakellariou, 2014) and occupation as many sided including that of a dark side (Twinley, 2013), this paper will explore the dark side of volunteering whilst considering the current socio-cultural and political context where engaging in voluntary work is experienced.

The themes emerging from this research highlight issues of personal power, autonomy and choice as contrasted with experiences of interference and disempowerment associated with conflict and control exerted by a range of systems, policies and legislation affecting vulnerable groups. This paper ultimately asks the question “Is volunteering voluntary?”

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APPENDIX 13: WFOT Congress Submission, Cape Town, South Africa 2018

Conference Theme: Connected in Diversity: Positioned for Impact

Oral Paper: **1211**

Is Volunteering Voluntary? Exploring the Dark Side of Volunteering

Heather Hunter, Margaret Hills de Zarate, Marion Findlay *Queen Margaret University, Edinburgh, UK*

Introduction: Volunteering is recognised as playing an important role in supporting positive mental health and wellbeing. Whilst there is a range of research evidence on the health benefits of volunteering and the motivation to volunteer, there is less emphasis on the experience of volunteering itself. Currently in the UK, disabled welfare claimants are required by workfare programmes to undertake mandatory unpaid community work or risk financial sanctions. Claimants may be forced to give up a meaningful volunteering role for one deemed more appropriate to gaining employment. This contradicts the notion of volunteering as an activity undertaken freely.

Objectives: Drawing on the notion of occupational therapy as political and occupation as many sided including that of a dark side (Twinley, 2013), this paper will explore the dark side of volunteering whilst considering the current socio-cultural and political context.

Method: This Participatory Action Research project involved a group of adults with lived experience of mental illness engaged in unpaid voluntary work in the community through personal choice as part of their journey of recovery.

Results: The preliminary themes emerging from this research highlight issues of personal power, autonomy and choice contrasted with experiences of disempowerment through control exerted by a range of systems and policies affecting vulnerable groups.

Conclusion: The research findings demonstrate inconsistencies and contradictions of engagement in voluntary work and this paper ultimately asks the question "Is volunteering voluntary?"

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APPENDIX 14: First Thoughts: Emerging themes from initial codes

Code:	**Emerging Themes:**
1. Positive aspects of volunteering	D. **Self-management and journeys of recovery**: gaining skills; training; building self up; employability and getting back to work; building relationships; having structure and purpose; reason to get out of bed; keeping flexibility in line with mental health and ability; keeping well and out of hospital; "selfish altruism" – do it for own benefit. E. **Lived experience, identity and belonging:** aligning with own values; expert by experience; volunteering as a career and a way of life. F. **Making a difference:** giving something back; feeling valued and empowered; community connectedness; stirring things up; challenging the system; influencing.
2. Negative aspects of volunteering	A. **The experience of the work itself:** culture of organisation and conditions-–not paid; not challenging enough/ too challenging and not enough support; not putting experience to best use; competitive and not enough places; relationships -tensions between paid staff and volunteers; difficult manager; pressure and target driven; no distinction between paid/ volunteering – application process/ interviewing/ waiting time; pressure same whether volunteering/ paid; not valued) B. **The impact on mental health:** personal and internal factors and resources. C. **The wider context and austerity:** funding cuts/ welfare reforms/ public perception of volunteering and stereotyping/ charities now commissioned vs truly representing the service user voice, business models, spouse to support)
3. Contextual aspects of volunteering	A. **Personal stories:** history; experience; values of social justice and inclusion; self-reflection +ve /-ve; mental health, illness and wellbeing; stigma; stories of determination and resilience; and support/ relationship with volunteering. B. **Reflections on volunteering context – time and place:** political situation- past and present; definitions of volunteering Vs "helping out"; Kafkaesque experiences of current context and contradictions; comparisons between volunteering and being paid in same job; are mental health organisations more understanding and supportive? C. **Use of language:** "we"= identity; ownership as a volunteer? D. **Assumptions about me as researcher.**

APPENDIX 15: Phase 4 rationale for refined themes

Revised Themes:	**Rationale:**
1. “Selfish Altruism”: journeys of recovery through volunteering. Including personals stories, experience, values and self-management	This theme combined 1A and 3A along with lived experience of mental illness, work and volunteering.
2. Volunteering as a career: influence, identity and belonging.	Combining 1B and 1C
3. The volunteering context: reflections on time, place and contradictions.	Combining 2C and 3B
4. Challenges and contradictions.	Combining 2A and 2B

APPENDIX 16: Briefing paper submitted to the Social Security Committee, Scotland

SOCIAL SECURITY COMMITTEE

SOCIAL SECURITY (SCOTLAND) BILL

SUBMISSION FROM VOLUNTEER EDINBURGH & QUEEN MARGARET UNIVERSITY

1. Introduction – benefits of volunteering

1.1. Volunteering is the giving of your own time and energy for the good of the community, society at large or an individual other than yourself, who isn't a member of your family. For individuals, it is widely recognised as a means to improve health & wellbeing e.g. by building confidence, resilience and self-esteem, developing physical stamina and combatting isolation by creating positive links with the wider community.

1.2. Volunteer Edinburgh is the local centre for volunteering in the city. It provides a range of services and support to members of the public who wish to volunteer, and to organisations who involve volunteers in their work. We receive referrals from a network of over 260 health & social care agencies in the city who identify volunteering as a recovery route for their clients/patients.

1.3. Queen Margaret University, Edinburgh has recently undertaken participatory action research with a group of adults with lived experience of mental illness who are engaged in unpaid voluntary work in the community through personal choice as part of their journey of recovery. Direct quotations from project participants are included in this submission (identifying details have been removed to preserve anonymity).

2. Inequalities in volunteering

2.1. 35% of adults in Edinburgh regularly volunteer; this compares well with the Scottish average of 27% (Scottish Household Survey 2015). However, while this picture of volunteering in Edinburgh is positive there continues to be a worrying socioeconomic divide to participation. Only 27% of adults volunteer from households with an income of up to £15,000, compared to 42% of those with a household income of over £30,000.

2.2. Volunteer Edinburgh works to reduce this inequality with specialist programmes for those who face barriers to volunteering. This includes people with long term and/or fluctuating health conditions. The majority of individuals who engage with Volunteer Edinburgh's health & wellbeing service are in receipt of social security benefits.

3. The right to volunteer

3.1. Volunteer Edinburgh & Queen Margaret University share the commitment to the principle of human rights proposed in this Bill. We support the human right of *participation* and urge Parliament to protect people's *freedom to choose* to volunteer.

3.2. QMU research highlighted a number of individual benefits of volunteering that are consistent with current literature. Specifically, participants valued choice and flexibility, in relation to volunteering and staying well.

> *"A key benefit* [of volunteering] *is that it allows you to develop as a person with your skills and assets and can contribute without putting yourself under pressure which might have a negative impact on your wellbeing."*

3.3. However, the prevalent theme which emerged from the research was a significant concern about the current welfare benefits system and how this is at odds with the recovery culture and thus undermining participants' health and wellbeing.

4. Experiences of the benefits system

4.1. Participants found the current welfare benefit system to be confusing and always changing, feeling at times misinformed and subjected to perpetual assessment and form filling that caused them stress. Participants commented on the arbitrary nature of how people are categorised and reported a lack of trust and cynicism with the current system. In addition, participants recognised that any form filling tended to focus on deficits rather than assets – this contrasted with their volunteering experiences which acknowledged and utilised their talents and assets. These experiences undermined people's experience of self-management, recovery and resilience.

> *"Part of the problem about volunteering now is that people are perpetually being assessed by the benefits system."*
>
> *"That process made me so ill and every time it came up for renewal I would get ill again. Having to fill in forms and gather all the evidence, and you have to focus on the negative."*
>
> *"So many people now even with quite serious health conditions, you know, medical conditions, have been* [categorised] *fit for work."*
>
> *"in terms of the assessments... people have to disclose some really difficult.* [information]. *A lot of questions that you're asked about especially about how you can cope with your personal care, daily living... One of the things is how a lot of people think on a day-to-day basis. You know, they struggle to cope but in order to be able to carry on; they just have to keep persuading themselves I can cope. I can cope. I can do this. But that's not the way to get the benefit though. On a day-to-day basis they survive by minimising their distress… Many*

> *people who had that personal pride element who said, "I can't cope very well but I find ways of overcoming it somehow" ... they didn't get it* [the welfare benefit]."
>
> "*The system forces you to exaggerate your condition in order to get what it is you need."*

5. Risks to individuals' volunteering & wellbeing

5.1. Volunteer Edinburgh is aware that many people who have much to gain by volunteering are dissuaded through fear of jeopardising their social security benefits i.e. by appearing "fit to work". We know of individuals whose ability to undertake a few hours of supported volunteering each week in no way reflects an ability to undertake employment in the open labour market. This is of particular relevance for people with fluctuating or hidden disabilities such as mental illness or chronic fatigue.

5.2. Participants in the research study commented that current systems are putting volunteering and the mental health and wellbeing of people at risk. Specifically, they reported that the welfare benefit system disregarded what volunteering they were currently doing and what benefitted their mental health and wellbeing. They viewed the DWP's railroad approach as intent on meeting targets to get people into work regardless of any detrimental effects on the person's mental health and wellbeing.

5.3. Current welfare benefit systems were reported to remove choice, purpose and meaning in volunteering; to prevent flexibility in the number of hours volunteered as a person's mental health allowed; and ultimately to disregard the fluctuating nature of mental health thus disempowering participants who have worked hard to build expertise in knowing what works to keep them well.

> *"People who are within* [the] *work related activity group... are required to take on various activities towards getting ready to work in the future. But quite often, you know they get allocated fairly arbitrarily to one of the work programme providers and they'll be required to do training and learning activities and maybe volunteering, which is maybe sort of allocated to them to do. So, somebody who may already be dealing with an organisation and be doing volunteering... They might be told "no you can't do that anymore - we're expecting you to go and work in this charity shop". So maybe somebody who has been trained as an advocate and been doing advocacy for a while and that was their passion, is now suddenly being told we want you to go and work in a charity shop as part of your training...It's this idea that if somebody you know gets a bit of experience in retail and whatever - they are more likely to get a job working in a shop or a supermarket… but it means that somebody who's, you know, trained up to do something that they're passionate about…are able to feel that they are contributing something useful, but also maybe gives them some self-*

> *esteem because they are using their knowledge and skills to help other people.. And then suddenly being told, you know, you just need to go and work in the shop and sort out old clothes in the back room, or something that they have no passion for."*
>
> *"...it also means that some people are worried about taking on voluntary work…because they worry about it being seen as an indication that they are fit for work and they will lose their allowance. You know, people are worrying about maybe doing studying or anything because they think "If I'm seen to be doing anything", you know whether it's going to college to learn some stuff or doing voluntary work one or two days a week, it's going to mean that people are going to think you know "I'll be assessed as being capable for work and lose that.." and I think that's really affecting people's ability to volunteer or their aspirations to volunteer because there are so many people with… long term mental health issues, who are at the moment just really, really worried about losing their benefits and being forced ..to find work because they..* [know] *that it is actually going to lead to a deterioration in their mental health because the pressure will be too much…it is really having a negative impact."*
>
> *"I think it is having a really negative impact on various aspects of volunteering...I think there is misinformation and people aren't clear and so maybe having clear guidelines about what people can do..."*

5.4. Participants reported anxiety that their own mental health would suffer when the pressure to find work becomes too much and this can ultimately lead to a crisis situation with loss of benefits and potential self-harm. Substantial gains from volunteering could be undermined by that anxiety. The participants stated that it was short-sighted of the government as there was a significant cost to servicing mental health crisis and managing deterioration in people's mental health.

> *"I went for a job interview and even though I wanted it, I was terrified of getting it…because for me I get very stressed, very preoccupied with it… and things become…bigger than they are…Someone in* [my] *situation can offer the community good voluntary work but stresses and becomes ill if they have to go into a paid environment."*
>
> *"I've just been invited to apply for a post and it was very flattering to be invited and you'll laugh because its seven hours a week for twelve weeks…and I realised I couldn't cope with that pressure."*
>
> *"At the Crisis Centre we've often had people who have ended up taking overdoses because they've lost their benefit."*
>
> *"It's so blind of the government, you know, its counterproductive. So, it's probably going to cost them more money to look after people who are in*

> *crisis and need to go into hospital or need a lot of care, than it is to, you know*."

6. Guidance on Volunteering & Welfare Benefits

6.1. Volunteer Edinburgh welcomes the joint guidance *Volunteering and DWP Welfare Benefits* (DWP & Voluntary Action Scotland) issued May 2017. The clear statements on claimants unable to work through illness/disability (p2) and freedom of choice to volunteer (p3) are particularly welcomed.

6.2. However, we are aware that knowledge on volunteering is variable among DWP staff and claimants can therefore receive inaccurate or contradictory guidance or instruction.

7. Further involvement

7.1. Volunteer Edinburgh and QMU's project research group support more collaborative working with those involved in decision-making about welfare reform and its impact on volunteering undertaken by people in receipt of benefits. We are keen to contribute ideas and share experiences within a collaborative forum to raise awareness of the issues faced and to contribute to effective and positive changes for the future.

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