# Towards Co-Production: An Exploration of the Impact of Technology on Future Citizenship Alongside People with Mental Health Challenges

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# Abstract

Phil Morgan

# Towards Co-Production: An Exploration of the Impact of Technology on Future Citizenship Alongside People with Mental Health Challenges

The central aim of this thesis is to explore how future developments in technology may impact on citizenship for people with mental health challenges. This study examines the following: The key factors that will shape future citizenship; the perceived challenges and opportunities for people with mental health challenges; and the key areas that may contribute to the development of future inclusive citizenship for people with mental health challenges. The purpose is to stimulate discussion and contribute new knowledge to the debate on citizenship in mental health.

Future Studies, co-production and community based participatory research methods were used within this study. This was underpinned by a critical realist philosophical position, which provided a framework to critique the use of co-production as a research method (Farr 2018). The research team included an academic researcher (the Doctoral student) and three peer researchers. Participants were from a peer-led mental health organisation (n=10) and a digital technology company (n=4).

There were two phases to the research: in the first phase participants from both organisations took part in semi-structured interviews and had the option to join a co-production workshop. The analysis of the interviews and workshops culminated in a film, co-created by the research team. The film, *Future Citizenship Broadcast*, is a news broadcast set in 2042. In the second phase, the impact of the film was discussed in a focus group with those from a peer-led organisation. All the data was subject to thematic co-analysis (Braun and Clarke 2006; Jennings et al. 2018).

Participants identified that the key factors affecting citizenship would be the impact of inequality and division, and the extent to which people had a voice and access to democracy. There were questions raised about the changing nature of what it is to be a human in an increasingly digital world.

In addition to the factors above, the citizenship of people with mental health challenges would be particularly impacted in response to whether technology increased connection or led to further fragmentation between people. Their citizenship may also be affected by the extent to which biomedical models of mental illness pervade or whether there is an increased focus on social models, which enable participation.

For there to be inclusive citizenship for people with mental health challenges, the rights and opportunities of all citizens need to be enhanced. This requires an increased understanding of intersectionality, lobbying governments and corporations for greater transparency, accountability and inclusion and a revision of mental health legislation. The research also raises questions around the role of mental health services in promoting citizenship and the complexities around how services can both support and suppress citizenship.

Participants identified that a key element of promoting inclusion is activism, the importance of people from seldom-heard groups having a voice, and being able to participate in co-production. The research highlights the importance of the role of peer-led mental health organisations in amplifying the voices of people with mental health challenges.

In addition, this thesis incorporates a reflective account and critical analysis of the use of co-production as a research method and how it contributes new knowledge to the use of co-production in the context of a PhD.

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# Chapter 1: Introduction

This thesis seeks to add a unique contribution to discussions on citizenship in mental health by focusing on the future impacts of technology. One of the coproduced outputs of this PhD, designed to promote discussion, is the film *Future Citizenship Forecast.* This film is a news broadcast looking at a forecast of the factors that will shape citizenship for people with mental health challenges in 2042. This fictional account of an imagined future is based on the findings from the research. Before reading any further, and to orientate yourself to the topic, I would like to invite you to watch the film.



In the paper *Future Studies, Mental Health and the Question of Citizenship* (Morgan et al. 2020) I made the case for the importance of exploring future citizenship for people with mental health challenges. The article has been synthesised into this introduction and background chapter 2. In this chapter I will also describe the research, the extent it has been co-produced, and describe how the thesis is structured.

# 1.1 Future Studies

Future Studies authors, such as Harari (2016), Potts (2018) and Chace (2018), state that there will be significant advances in technology which will influence what it means to be a citizen. They outline both utopian and dystopian forecasts. Dystopian futures are characterised by increased social control and inequality where the privileged elite have access to the benefits of a technologically driven society or even a society where Artificial Intelligence (AI) itself takes control of society and dictates to humans (e.g. Harari 2016). Utopian futures are described as heralding a new age of democracy, equality, and creativity due to technology (Bregman 2017); for example, AI will take on more work and people have more leisure time; there may be opportunities for a greater focus on happiness and wellbeing as a marker of national success rather than Gross Domestic Product (Harari 2016; Bregman 2017). Slade et al. (2017) have advocated this approach to promote the wellbeing and mental health of the whole population. These scenarios raise questions as to whether this will be a fairer future in which technology and society work to the benefit of all or whether marginalised groups, such as those with mental health challenges, will continue to be left behind. To address these questions, critical and participatory approaches to Future Studies are being used. In this sense Future Studies are not being utilised to predict the future but rather to offer the opportunity for marginalised groups, in this case people with mental health challenges, to explore, critique and challenge existing power dynamics and to promote alternatives for future societies (Inavatullah 2013). Critical perspectives in Future Studies are viewed as essential to bring about more equal futures as otherwise existing power relations are maintained (Bardzell 2018; Bergman et al. 2014).

Future Studies have had limited application within mental health and have primarily explored the future of psychiatry, largely from the perspective of psychiatrists (Bhugra et al. 2017; Giacco et al. 2017; Preibe et al. 2019). This is despite calls for leadership from those with lived experience (Russo and Beresford 2017). The discipline of Future Studies and its use within a mental health context will be explained in, the background, chapter 1. Future Studies has not been utilised in the field of citizenship for people with mental health challenges (Morgan et al. 2020) nor have the voices of those with lived experience been at the forefront of this discussion (Russo and Beresford 2017). Therefore, this study aims to amplify those voices and bring a unique perspective to both Future Studies within mental health and discussions around citizenship for people with mental health challenges.

#### **1.2** The Future, Technology and Mental Health

Technology is already shaping our behaviour and, whilst benefits such as greater connectivity and accessibility have been identified (Fry 2018), there are concerns about the harmful impacts on society, especially as it remains that the overarching goal of technology companies is to have greater insights into our lives to maximise their profits (Zuboff 2019). This is coupled with a lack of transparency regarding how our data is being used and commercialised (Zuboff 2019). In addition, it is being highlighted that current inequalities and bias are becoming "hard baked" into Artificial Intelligence (AI) and algorithms (Petersen et al. 2019; Mohamed et al. 2020), therefore increasing marginalisation. If AI and robotics lead to mass unemployment, how will citizens spend their time, find meaning and have access to social justice (Harari 2016; Susskind 2020)?

Currently, the development of this tech-led future society is driven by industry (Potts 2018), to the exclusion of other voices (Bergman et al. 2014). The technology industry's focus is to monetise the social value of people with higher levels of social connectivity and social capital, and these industries are less interested in marginalised populations (Skeggs and Yuill 2016). There is also evidence that social media companies are willing to put profits above the wellbeing of their clients e.g. concern that Meta suppresses research findings that highlight negative mental health impacts of Instagram (Przybylski et al. 2021). There is also evidence that people with mental health challenges are disadvantaged by some of the algorithms programmed into social media (Skeggs and Yuill 2016; McQuillan 2023). This raises the question of whose agendas are being served and how this will impact on citizenship? However, the issue is not just related to people's use of digital technology. People with mental health challenges are one of several groups who are more likely to be digitally excluded (do not have access to or are unable to access the internet). Therefore, they may not have the opportunity to engage in digital citizenship. This will potentially lead to further exclusion (Greer et al. 2019). These developments are raising new ethical questions about the current and future rights of citizens, in particular our rights regarding surveillance, privacy, data

and algorithmic programming (Harari, 2016; Luxton et al. 2016; Poulin et al. 2016).

Digital solutions are being increasingly adopted in healthcare, including within mental health, especially since the "forced digitisation" during the Covid-19 pandemic (Eiroa-Orosa, and Tormo-Clemente 2022 p9). This is largely through app development (Kuntsman et al. 2019), wearables (e.g. smart watches), smart technology, virtual reality (Birchley et al. 2017; Zanaboni et al. 2018), exploring preventative technologies to reduce suicide or relapse in psychotic disorders (Mok et al. 2016; Barros et al. 2019) and video conferencing (Eiroa-Orosa and Tormo-Clemente 2022). There is widescale uptake of apps, despite the absence of a strong evidence base on efficacy (Zanaboni et al. 2018; Kuntsman et al. 2019). People with mental health challenges are already interacting with non-mental health specific technology to monitor and support their own mental wellbeing; for example, people are using Alexa to discuss their emotional distress (Luxton et al. 2016; Poulin et al. 2016; Miner et al. 2017; Tal and Torous 2017). There are few critical perspectives on digital mental health, so digital health is usually framed as both inevitable and value neutral (Petersen et al. 2019). Where there are critical perspectives, concerns are focused on privacy and exploitation as the increased use of apps and wearables may reveal the most intimate areas of our lives to governments, corporations and criminals (Mittelstadt and Floridi 2016; Petersen et al. 2019). Technology can also be used to uphold people's rights; for example, Seni's Law requires the police to operate body-worn cameras in the UK when using restraint on people with mental health challenges. This is to make the police more accountable and has come from a campaign following the deaths of several black men, such as Seni Lewis, who have been killed during restraint by police whilst in psychiatric distress (Department of Health and Social Care [DHSC], 2021a). This highlights the importance of critically exploring what the likely current and, in the context of this study, future impacts are on citizenship for people with mental health challenges.

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This topic feels even more pertinent due to the Covid-19 Pandemic which, since March 2020 in UK, has impacted on all our lives and demonstrated the power of technology in supporting rapid societal change. Technology has changed how we work, socialise, and receive health and social care. This has impacted on people using mental health services (Eiroa-Orosa and Tormo-Clemente 2022). Within the UK and across the world our rights as citizens were at times fundamentally changed as the government put restrictions on our liberty as a public health measure through lockdowns. The pandemic has also highlighted the growing gulf in inequalities and how marginalised communities, such as people with mental health challenges, and/or those living in poverty, and/or are from minority ethnic communities, have been disproportionately negatively affected (Marmot et al 2020; Beresford et al. 2021). We are yet to see the long-term mental health impacts of the pandemic and the shift to increased online communication and what this means for citizenship. This highlights the importance of addressing not just current but also future citizenship.

#### 1.3 Citizenship and Mental Health

Citizenship is an important and contested concept within mental health (MacIntyre et al. 2021). It could be argued people with mental health challenges have a unique experience of citizenship, as their human rights are dependent on their health status, for example, when detained under the Mental Health Act<sup>1</sup> (Hamer and Finlayson 2015; Brannelly 2018a; Vervliet et al. 2019). The survivor movement has long fought for rights and equal citizenship, whether this has been campaigners such as Pat Deegan (1988) or Mary O'Hagan (2002) or national or grass roots survivor-led or peer-led organisations (such as National Survivor User Network (NSUN)). Despite this the pace of change has been slow. Neither the de-institutionalisation in the 1980s and 1990s, nor the Recovery movement have delivered the level of equality required (Rowe and

<sup>&</sup>lt;sup>1</sup> Please note, when the Mental Health Act is referred to without a date it relates generically to the mental health legislation within the UK, Europe, Australia, New Zealand, and United States. When referred to as the Mental Health Act 1983 it relates specifically to the mental health legislation in England and Wales.

Davidson 2016; Eiroa-Orosa and Rowe 2017). This lack of progress has resulted in social exclusions that perpetuate and sustain inequalities, leading to renewed calls to examine citizenship so that people with mental health challenges are able to access the same opportunities and enjoy the same rights as other citizens (Hamer 2012; Rowe 2015; Hamer and Finlayson 2015; Rowe and Davidson 2016; Slade et al. 2017; Harper et al. 2017; Hamer et al. 2018; MacIntyre et al. 2021). Morgan et al. (2020) therefore argue it is important not just to look at citizenship solely in the context of the present, but due to the impact of technology on the pace of change, it is also important to look at future citizenship.

Citizenship in mental health is being viewed as a lens through which to explore people's experiences of inclusion and exclusion, to promote social justice and enhance participation in society (Rowe and Davidson 2016; MacIntyre et al. 2021). It is also being promoted as an alternative approach to understanding people's experiences rather than those provided by illness-based models (MacIntyre et al. 2021). This increased focus on citizenship within the field of mental health is being proposed as a way of promoting the rights, participation, and inclusion of people with mental health challenges within and alongside wider society (Morgan et al. 2020; Davidson et al. 2021; MacIntyre et al. 2021). This citizenship approach has been driven by concerns within the survivor movement that promised changes to rights and inclusion from Personal Recovery have not come to fruition (Hamer 2012; Brannelly, 2018a); from the observations of clinicians working in mental health and homeless services that when people are housed and supported this does not lead to greater integration and participation in their local communities (Rowe and Pelletier 2012) and from the positive impact on people's experiences through the delivery of citizenshipfocused interventions (Clayton et al. 2013; Quinn et al. 2020; Reis et al. 2022). This positive impact has led to calls for citizenship-orientated mental health services (Rowe and Davidson 2016; Hamer et al. 2019) and citizenship public health policy (Rowe and Davidson 2016; MacIntyre et al. 2019). Most of these explorations have taken place in the English-speaking world (US, New Zealand,

and Scotland). This is the first study to specifically explore the lived experience of citizenship for people with mental health challenges within England.

Citizenship has primarily been seen as the relationship between the individual and the state and their participation with broader civic society (Ponce and Rowe 2018.) Alongside this there are different perspectives on citizenship, such as critical perspectives (Isin and Neilsen 2008), and feminist perspectives (Lister 2007) which seek to critique and address power imbalances. Alongside this, new practices of citizenship are emerging, including digital citizenship (regular users of the internet who engage in politics and social movements via information technology), consumer citizens (people who define their citizenship through their purchasing choices), global citizens (people who define their citizenship through a sense of shared humanity and roles and responsibilities that transcend the nation state) (Isin and Ruppert 2020).

However, within the mental health citizenship literature, other than in a paper I co-authored (Morgan et al. 2020), there has not been a discussion of the role of digital citizenship in mental health, and there has only been a limited a discussion based on the Covid-19 pandemic of the impact of technology on citizenship (Eiroa-Orosa and Tormo-Clemente 2022). This leaves the question of how current and future technological advances will impact on citizenship for people with mental health challenges largely unexplored. Therefore, this study has an important role in surfacing new and unique findings.

#### 1.4 Research Aim and Objectives

The overall aim of this PhD is:

To explore how future developments in technology will impact on citizenship for people with mental health challenges.

The research has been conducted using co-production and community based participatory research (CBPR) methods, with critical realism as the

philosophical basis (Sayer 2011). Critical realism has been utilised as a way of critiquing the co-productive process (Farr 2018).

This co-productive process has been supported by peer researchers and participants have been recruited from a peer-led mental health organisation and a digital technology company to examine the following objectives:

- What do participants think are the key factors that will shape citizenship in the future?
- What are the perceived challenges and opportunities for people with mental health challenges in relation to future citizenship?
- To examine the key areas for development to contribute to inclusive future opportunities for citizenship for people with mental health challenges.

As there are very few PhDs that have used co-production as a research approach throughout, this study will also have the following further research objective:

• To undertake a critical exploration of the use of co-production and participatory research methods within a PhD.

# 1.5 Positionality, Writing Conventions and Terminology

A key part of undertaking a critical exploration of the method is to be reflexive around my role and positionality within the research. Therefore, it is important to describe the writing conventions within this thesis. The thesis will be predominantly written in the third person, in line with academic writing conventions; however, there will be sections that are written in the first person, which enable the reader to understand the reflexive position of the author. The reason for writing in the first person is to generate a greater level of transparency of my role as a researcher. I am currently interim Head of Nursing, Therapies and Quality for Mental Health, Learning Disabilities, and Children, Young People and Families for Dorset HealthCare University NHS Foundation Trust (DHC). This PhD is funded by DHC. When I started this PhD, I was in the role of Lead for Recovery and Social Inclusion, within the same organisation. Whilst in this previous role I was becoming increasingly frustrated with the limitations of the Recovery Approach, which led me to explore citizenship as a concept that has the potential to deliver social justice. Throughout my career I have worked in partnership with people with lived experience to varying degrees, and over the past 10 years focused on co-production. I have found learning from and working alongside people with lived experience transformational. I was keen to bring this experience and my learning into this research.

To support the co-production of this research I recruited three peer researchers: George Reynolds, Bex Symons, and Ian Warrington. All three of them are experienced peer specialists who work for Dorset Mental Health Forum (DMHF). For clarity, I will refer to myself as the academic researcher and the peers as peer researchers. This refers to the intentionality of the roles, rather than a reflection of the academic skills of the peer research team and is in some ways an illustration of the tension of articulating complexities of co-production.

My position is discussed further in chapter 2, the Background, the role of peer researchers and the complexities of co-production are examined further in this chapter and subsequently in chapter 9, the Methodology, and chapter 12, the Reflections on co-production chapter.

The term 'people with mental health challenges' has been used throughout this thesis. The rationale for this is to acknowledge a shift away from a medicalised understanding, so the term mental illness has not been used. The word 'challenges' also suggests people's difficulties may be how they experience the world rather than solely their experience of their emotional distress. This is therefore in keeping with how citizenship is understood.

'Lived Experience' within this thesis has been used to refer predominantly to people's first hand experience of mental health challenges (occasionally it may refer to people's lived experience of other forms of marginalisation). Lived experience is described as personal knowledge that comes from direct experience that would not ordinarily be apparent if someone had not had those experiences (O'Leary and Tsui 2022).

The participants from the peer-led mental health organisation and the peer researchers are all people who self-define as having lived experience of mental health challenges. Self-definition is important as not all people who experience mental health problems or significant emotional distress will necessarily want a label (or be defined by a label) nor wish to access mental health services. Also, if people are being asked to prove their 'credentials' this then accentuates the imbalance of power as the academic researcher is not expected to reveal aspects of their medical history.

It Is important to note that, whilst there are positives to self-definition, this is also a limitation as it means there is a lack of transparency around the nature of people's experiences. However, there is an ethical tension here in asking people to share their personal experiences to establish their level of lived experience as participants or peer researchers as this may be viewed as tokenistic or be re-traumatising (Beresford 2019). For this reason and acknowledging the context of citizenship where people are encouraged to have roles and responsibilities, it has been important for people to self-select and self-define.

The other key terms, such as co-production, neoliberalism, Recovery and Future Studies are explained in chapter 2.

#### **1.6 Overview of Co-Production and Participatory Methods**

The National Institute for Health Research (NIHR) define co-production as follows:

"Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge." (Hickey et al. 2018 p. 4).

Due to the structure of a PhD it has not been possible to co-produce the study from the start; for example, the nature of it being an individual award and the requirement to have ethical approval to proceed. Therefore, within this PhD the development of research questions and aims, and initial study were led by the academic researcher. However, as the peer researchers came onboard the workshops became increasingly more co-designed and became more fully co-produced as the study developed. Although the research was increasingly co-produced, the literature review and thesis have been solely authored by the academic researcher. Therefore, it is important to be clear this research is not fully co-produced, but rather an increasingly co-produced approach was taken, hence the title, *towards co-production*. This takes a pragmatic approach to co-produce as far as possible (Farr et al. 2021). Please see Chapter 9, table 6 for which elements have been co-produced.

In order to analyse the power dynamics relating to co-production a three track approach has been used: firstly, being transparent about the involvement of myself, the peer researchers and participants at each stage (Hughes and Duffy 2018; Farr et al. 2021); secondly, the use of an Ethics of Care framework to support the reflexive process and the involvement of all (Brannely 2018b) and thirdly, adopting Farr's (2018) social realist framework to analyse the approach to co-production. This will be explored in chapter 9, with further reflections in chapter 12.

Participatory approaches are widely adopted in social research, often having a commitment to social justice through surfacing the inequalities experienced by marginalised groups, with the expectation of influencing change through political action (Brannelly 2018b). CBPR shares several features of co-production, such

as equitably involving community members, partners, organisations, and researchers in all aspects of the research process (Kindon et al. 2007). Coproduction takes a broader view of the wider meso and macro context within which the research takes place and can be applied as an approach to other research methods. CBPR focuses on the immediate relationships and power dynamics within the research project and is an approach that complements coproduction (King and Gillard 2019).

#### **1.7** Overview of the Structure of the Research

To effectively meet the research aims and objectives there are two phases to this research: the first is focused on knowledge generation and exchange, and the second on action. This mirrors the cycles of reflection, evaluation, and action within participatory research (Kindon et al. 2007). The first phase was a series of semi-structured interviews with participants from the digital technology company and peer-led mental health organisation. The themes from these interviews were discussed and developed through a co-production workshop. The outcome of the co-analysis of this first phase of research resulted in the *Future Citizenship Forecast* film. In the second phase of the research participants from the peer-led organisation watched the film and then participated in a focus group. In total there were fourteen participants, four different participants from the digital technology company and ten participants from the peer-led mental health organisation.



#### Figure 1: Diagram of the phases of research

The academic researcher led the interviews and co-production workshop. The peer researchers were involved in the analysis and planning the interview schedule and format of the co-production workshop. Their role and the level of co-production increased with the analysis of the data from phase one and led to the idea of creating a film. The second phase was then more fully co-produced. The levels of co-production, CBPR the research philosophy and research approach will be described further within chapter seven.

## **1.8 Overview of the Thesis**

By bringing together the voices of those with lived experience within a peer-led organisation and those working within the technology sector it is hoped that this research can stimulate a wider debate of what inclusive future citizenship could and should look like and what steps may be taken towards addressing some of the existing and potential future inequalities. This will contribute new knowledge to approaches to citizenship in mental health both through utilising Future Studies and digital citizenship. It is also the first study to discuss mental health citizenship within England. This thesis will contribute new knowledge by sharing the learning of using co-production as a research method within the context of a PhD.

The following section will take the reader through an overview of the chapters of this thesis:

**Chapter 2: Background** sets the scene by explaining my positionality as a researcher and provides further context and rationale for the study. It introduces the key concepts of Future Studies; Recovery; Neoliberalism; and Co-production.

Chapter 3: Future Citizenship for People with Mental Health Challenges:A Narrative Literature Review explains the methodology used for the literature review for this study. Due to the lack of literature in this specific area it has been

important to examine a broad range of literature. This chapter explains the approach taken.

**Chapter 4:** Future Studies and Mental Health undertakes an analysis of the Future Studies literature concerned with mental health. It identifies the key themes relating to future citizenship and mental health.

**Chapter 5:** Citizenship in Mental Health: Theory provides an in-depth narrative review of the mental health citizenship literature focusing on the theories of citizenship present in the literature.

**Chapter 6:** Mental Health Citizenship Research examines the key themes in the citizenship and mental health research.

**Chapter 7: Digital Citizenship.** As there is no specific mental health and digital citizenship literature, chapter 7 examines the digital citizenship literature, the theoretical positions and practical applications. It concludes by drawing out the key considerations for citizenship for people with mental health challenges.

Chapter 8: Future Citizenship for People with Mental Health Challenges: An Overview of the Literature Review concludes the literature review by drawing together all the literature and examining the key themes to consider for future citizenship for people with mental health challenges.

**Chapter 9: Methodology** describes the methods applied in this study. It includes a critical examination of co-production (Farr 2018) and CBPR as research methods. The philosophical position of Critical Realism is explained regarding its relevance to the study.

Chapter 10: 'Technology is redefining what it means to be human'-Findings Phase 1 presents the findings from phase 1, these findings were coanalysed with the peer researchers and co-created in the film *Future Citizenship Forecast.*  Chapter 11: 'Citizenship, it's about having a voice'- Findings Phase 2: shares the co-analysis of the data from the focus group.

Chapter 12: 'Lived experience is a unique source of knowledge about people in the world' - Reflections on Co-production as a Research Method is a reflection on the approach to co-production within this PhD, and discusses the research objective:

To undertake a critical exploration of the use of co-production and participatory research methods within a PhD.

The chapter concludes with recommendations to enhance the use of coproduction as a research method.

# Chapter 13: Discussion, Recommendations and Conclusion

This final chapter reviews the steps taken throughout this research. The discussion addresses the research aim and objectives relating to future citizenship. The chapter raises a series of implications for research, education, practice, and policy. These implications and discussions are drawn together into a conclusion.

# Chapter 2: Background

This chapter outlines how the topic for this PhD developed through a combination of my personal and professional interests. In this background chapter I will interweave personal reflections with the literature, starting with an introduction to Future Studies. This will then lead into an overview and critique of the Recovery Approach and how this relates to citizenship. This chapter will also introduce key concepts such as *neoliberalism* and *co-production*. All these concepts are fundamental in shaping discussions on citizenship for people with mental health challenges.

## 2.1 Personal Reflections

When I was growing up my brother Peter had very profound learning disabilities and this led me to recognise the unique contributions everyone has to society and the impact of discrimination on all aspects of life. I was struck by how we as a family had to fight for him even to receive life-saving healthcare. This experience has given me a strong drive for social justice and the importance of recognising everyone's talents, creating societies that value and support people with different experiences to access opportunities to participate and contribute. Whilst my brother experienced discrimination and I experienced what this is like at proximity, it was not my direct experience. It is important for me to recognise the limits of my experience and impact of my own privilege, of being a white, heterosexual, middle-class male. I see my role in this research as using this position to try to share power and amplify the voices of others; at the same time acknowledging the process of undertaking a PhD is one where I seek to gain personally and professionally and the need for me to ensure that I do not exploit my position of power. In doing this it is essential that I reflect on and critically assess my own role and position in the research by taking an anti-discriminatory stance utilising an Ethics of Care framework (Brannelly 2018b) (This will be explored further in chapter 9).

#### 2.2 **Professional Reflections**

Through my childhood experiences with my brother, I was drawn to working in health and social care, first as a support worker and then subsequently as an occupational therapist (OT). One of the settings I worked in was a forensic therapeutic community. This led to me understanding the value of democratic approaches to treatment, which I have tried to bring to this research and to my subsequent roles within mental health services.

It is important to note that whilst I am an OT by background, in this study I have not focused on OT citizenship literature nor recommendations specifically aimed at OTs. The reason for this is two-fold; firstly, the focus of this study (and my current role) is broader than one discipline and, secondly, to manage the volume of the literature and scope of the project within the limitations of the word count. The role of OT and potential integration with OT citizenship work will be addressed in the recommendations (chapter 13.7.3)

I commenced this PhD when I was in the role of Lead for Recovery and Social Inclusion. An integral part of this is being the co-lead of a partnership called the Dorset Wellbeing and Recovery Partnership with DMHF. DMHF are a local peer-led third sector organisation. The purpose of this partnership is to bring together lived experience expertise and professional expertise and to change the culture of mental health services in Dorset to be more focused on Personal Recovery.

As a partnership we have become increasingly interested in citizenship as a concept and how it may be beneficial in addressing social inequalities and making visible and challenging the power dynamics within mental health services. The impact of the Covid-19 pandemic brought an even sharper focus to issues of inequality and social justice. From my own perspective, whilst progress has been made in Dorset regarding the Recovery approach, for example: establishing peer workers, a recovery college, open access crisis

supports, and collaborative care planning; there are still fundamental and significant barriers for people with mental health challenges being able to live the life they wish to live.

#### 2.3 Reflections on Future Studies

I became interested in Future Studies when I saw Mark Stevenson (2017), author of *We Do Things Differently*, speaking at the Hay-On-Wye literary festival. He was talking about the importance of future thinking, the impact of technology and how we need a radical rethink of how we approach societal and global issues. This developed my interest in Future Studies and future thinking, which led to me reading various books on the future and the impact of technology (Harari 2016; Bregman 2017; Chace 2018; Fry 2018; Susskind 2020). Whilst none of these books were specific to mental health it highlighted both the importance of considering the future impacts of societal change on everyone's mental health and raised questions about the implications for people with mental health challenges.

This led to me reflecting on a presentation by Mary O'Hagan (2013), a service user activist from New Zealand (NZ), who I saw presenting the film 'The Care without Coercion Act' <u>https://youtu.be/Tle1trJhs2g</u> at the Refocus on Recovery Conference 2014. The film is set in 2042 and is about the repeal of the Mental Health Act and what has been put in its place. She imagined what happened in the years proceeding and how these changes were achieved. It encouraged me to think more ambitiously about social change and how what we see as progress now will be looked on in the future as potentially barbaric. As a tribute to Mary O'Hagan the film in this PhD has also been set in 2042.

One of my interests is that, if technologies were harnessed to promote inclusivity, they could provide some of this additional support. Many of these new technologies are already with us or are under development, but to what extent are they being shaped by those with lived experience of mental health challenges? These presentations led me to think about how this could apply to my work; what would/could the effects of technology be on citizenship for people with mental health challenges and to co-create a PhD that would try and explore the potential future impacts. As Future Studies have had limited application in mental health, it is first important to explore what Future Studies are.

## 2.4 What are Future Studies?

Future Studies is a discipline that includes elements of sociology, media, cultural studies, technology and business studies, and makes predictions on changes to society based on economics, climate, demographics, political theory, and developments in information technology (Potts 2018). Future Studies is predominantly used in business, policy making, and academic study. It can be used to reduce risk and avoid negative futures; however, increasingly it is being used to create desired futures through adopting critical sociological perspectives to promote opportunities to drive social change for marginalised groups (Bergman et al. 2014; Potts 2018). Critical perspectives seek to challenge the status quo by describing who has power, whose voices are privileged and whose are silenced (Inayatullah 2013).

There are debates within Future Studies about the extent it should be viewed as a science or social science. These are based on the extent Future Studies is or should be considered predictive, interpretive, critical, or participatory or a mixture of approaches (Inayatullah 2013). Lee (2012) argues that Future Studies should be considered a science as the future is knowable and predictable. He considers post-modern approaches that seek to look at multiple perspectives as being pessimistic and too concerned with uncertainty. However, this is not a widely held perspective. Potts (2018) states people are only able to see things from the perspective of their own time and therefore are not able to accurately predict the future: for example, failure to predict people having smart phones but assuming people would have jet packs. Inayatullah (2013) argues Future Studies is less focused on prediction and more committed to multiple interpretations of reality (including the unconscious, the mythological and the

spiritual); the use of imagination and creativity; and more participatory (including all stakeholders not just powerbrokers).

This study will focus on critical and participatory approaches to examine inclusive futures for people with mental health challenges. In this study the future is not considered to be knowable but rather an opportunity to look at differing perspectives. In this context, Future Studies is concerned with exploring at least one of what is possible, probable and/or preferable.

- The possible explores what possible futures could be within the bounds of plausibility. Fischer and Dannenberg (2021) argue that plausibility is not just about what happens but also how ideas and meaning are constructed and if meaning is not explored and deconstructed then basically the present is being reconstructed in the future.
- The probable examines the likelihood of what futures may look like and the extent they could happen.
- The preferable considers how preferable futures could be created and what would need to change (Amara 1991).

Odeleye (2015) state critical Future Studies can disrupt the status quo, explore complexity, and challenge power dynamics. Critical standpoints come from post-structuralism, and move beyond the interpretive, which seek to gain insight and uncover where power lies to actively disrupt and challenge existing power dynamics. Critical Future Studies asserts that the present is fragile, that it is merely the victory of one discourse over another (Inayatullah 2013). This study will focus more on the participatory and critical perspectives in Future Studies as the purpose of this study is to collaborate with people with mental health challenges by exploring desirable futures and stimulating debate regarding who holds power and whose voices are privileged; thus, moving away from academic expert analysis towards deep participation by all those directly involved. It will examine what the probable factors are, what preferable futures would look like and what steps would need to be taken to reach them.
Participants define the key concepts themselves e.g. the concept of citizenship, rather than drawing on a priori concepts. This seeks to open up the future to constructing alternative futures, which then become owned by those with a stake in these futures (Inayatullah 2013). For example, Bergman et al. (2014) propose that the purpose of utilising Future Studies with feminist methodologies is not to create a singular unified vision for feminist futures but rather to open new ways of thinking and innovative approaches. They suggest there are multiple ways of exploring feminist futures. These could be imagining what the future could look like; describing preferred scenarios; working as "alarm clocks" [sic] if the future is not wanted or as a way of showing things are on the right track. Gunnarsson-Östling et al. (2012) argue that participatory research methods are best suited to developing alternative feminist futures, as there is a commonality between Future Studies and participatory research methods.

It is important to note that, whilst feminism has only had limited involvement within the academic discipline of Future Studies (Bergman et al. 2014), future thinking has played a strong role in feminism in using creative methods to critique and challenging the status quo (eg the Cyborg Manifesto Haraway 1994). Equally, Afrofuturism reimagines the experience of people of colour, providing an opportunity for black communities and the African diaspora to engage in potential, real and imagined futures that can rupture the status quo, providing a link between the past, present and future (Womack 2013; Capers 2019). Morgan et al. (2020) discuss this further and draw attention to the importance of people with mental health challenges engaging in imagined futures, using creative methods, to challenge existing power strucutures. Within this study the use of creative expression has been important and led to the development of the film. Within mental health Future Studies has not played a major role in promoting equalities (Morgan et al. 2020). The Recovery Approach has been seen as one of the ways of tackling inequality and giving voice to people with lived experience of mental health challenges and it is to Recovery that the focus of this chapter now turns.

#### 2.5 Definitions of Personal Recovery

The Recovery Approach evolved in the United States (US) in the 80s and 90s, growing out of the service user/survivor movement. It aimed to create a paradigm shift in mental health, from a focus on illness and clinical recovery to one with a focus on the value of lived experience, peer support, self-management, and Personal Recovery. This meant a shift away from primarily focusing on clinical treatments and biomedical approaches to the importance of a person building a life worth living; a key component of this was the person having a sense of citizenship (Davidson et al. 2021). The seminal definition of Personal Recovery was given by Bill Anthony (1993):

"Recovery is described as a deeply personal unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness." (p15)

Based on this, Anthony (1993) put forward a new vision for mental health services that promoted a more person-focused approach by encouraging services to explore peer support and people building a life beyond illness. This led to Personal Recovery being widely promoted in mental health policy. After initially growing within affluent English-speaking countries, it has now spread across the globe (Slade et al. 2017).

Personal Recovery is distinct from Clinical Recovery, which is focused on symptoms and illness. Personal Recovery is a process of exploration and making the best of the challenges that one faces (Perkins and Repper 2015). Personal Recovery acknowledges that often people's struggle to recover is as much about their social reality in living with being labelled and being discriminated against as it is about their mental health condition (Slade et al. 2017). However, there are concerns this focus on social recovery has become lost (Rowe and Davidson 2016). A systematic review highlighted five key elements of Personal Recovery, known as CHIME, which are distinct from the traditional concerns of mental health services. These are: Connectedness, Hope, Identity, Meaning, and Empowerment (Leamy et al. 2011). Specific interventions such as employment support, housing support, peer support and recovery colleges have been developed to address the elements of CHIME and there is clear evidence that these approaches have benefits for people (Slade et al. 2014). It is worth noting the empirical evidence in approaches to supported employment and housing are that people having access to housing and participating in employment with support are far more effective than any approaches based on recover and participate (Davidson 2016.) However, there are also criticisms that these approaches are too focused on the needs of individuals who already have social and/or economic capital (Rose 2014) and that the focus of the Recovery movement has been taken away from its social and collective roots to one that is more individualised (Davidson et al. 2021).

In my role, as Lead for Recovery and Social Inclusion, I have seen benefits for some people from these approaches. It is important to note that the Recovery approach is not just an additional layer to service provision but also a paradigm shift in mental health, moving away from 'treat and recover' model to focus on people building their lives and accessing their full rights as citizens. Slade et al. (2014) describe this as the final frontier, where people with mental health challenges can access the full rights of citizenship without this being conditional on their recovery. This is the area where I feel the desired progress has not been made. Whilst some of the offer of services and attitudes have shifted, wider culture inside and outside mental health services has not. This has been accompanied by a worsening social situation for people with mental health challenges with cuts to benefits and housing provision as well as rationing mental health services themselves. This is where citizenship approaches may enhance people's experience, as there is a direct focus on a person and their social context and their human rights. Before exploring citizenship, it is first important to explore the implementation of the Recovery Approach and draw out any lessons for the approach to citizenship.

# 2.6 The Origins of Personal Recovery

The origins of Recovery are within the survivor movement, with service-user activists such as Pat Deegan promoting the value of lived experience and aligning the process of recovery from mental health challenges with the experience of people with disabilities. She describes Recovery as the process of people "*…recovering a new sense of self and of purpose within and beyond the limits of the disability*" (Deegan 1988, p.12). This focuses Recovery as an interaction between an individual and society and proponents of the Recovery approach draw upon the social model of disability and the importance of not just focusing on the individual but also adaption in society; for example, a job coach being as vital to someone with long standing mental health challenges as a wheelchair is for someone with a physical disability (Davidson 2016).

However, as Davidson et al. (2021) describe, Recovery has drifted from its social roots to an approach that focuses on the individual and does not take into consideration the social conditions of people with mental health challenges. This has led to claims that Recovery has been colonised by mental health services (Rose 2014; Recovery in The Bin 2016). Citizenship has the potential to reconnect the Recovery Approach to its social roots whilst integrating the individual's journey to self-actualisation (Davidson et al. 2021; Carr and Ponce 2022). Rowe and Davidson (2016) call for mental health services to focus on citizenship as the central component to transforming mental health care and reconnecting Recovery to its radical roots and to interface with antiracist, and other groups that support marginalised people's fight for socio-economic justice.

#### 2.7 The Risk vs Autonomy Criticism of the Recovery Approach

The Recovery Approach has not just been criticised by people who access services, but by clinicians too. Primary criticisms from clinicians have related to professionals who are wedded to a more biomedical, risk averse approach to mental health services, who argue that giving people more autonomy is risky and not safe practice (Slade et al. 2014; Hamer and Finlayson 2015.)

A key element of my day-to-day work in promoting Personal Recovery has been challenging these existing stigmatising views of people with mental health challenges. It could be argued that the link between risk, recovery and mental health is one of the key barriers for people with mental health challenges accessing full citizenship and is not applied to people with other disabilities (Davidson et al. 2021). It will be important to pay attention to this when looking at future citizenship for people with mental health challenges and ensuring that the dynamic between risk and rights is examined. In my own experience, the implementation of the paradigm shift relating to Recovery gets pulled out of shape as tensions between risk and autonomy surface and professional agendas dominate and dilute the core survivor-led values of Recovery. It will be important to consider the context in which citizenship interventions are implemented to avoid similar tensions playing out, where risk discourses dominate and undermine the intended social change. Davidson et al. (2023) identify the importance of organisational readiness and the significant systemic barriers when trying to implement a citizenship approach.

# 2.8 Critiques from the Survivor/Lived Experience Movement

The concept of Recovery has not been adopted unquestioningly by the survivor movement. Whilst being an early advocate for Recovery, Mary O'Hagan, a New Zealand Survivor/Activist, raised a few concerns. These include use of the word 'Recovery' itself and the confusion associated with the different meanings, but also the question of whether it was even desirable to recover: *"I don't see my madness as undesirable, so what is it I need to recover from?"* (O'Hagan, 2002, p. 16).

O'Hagan also highlighted concerns about the increasingly individualistic focus of the American approach to Recovery and the importance of needing to emphasise the social, political and economic aspects of Recovery. As it became more widely implemented, she saw this divergence appearing in the promotion of Recovery within mental health services. The individualised approach was emphasised, and acknowledgement of social impacts were minimised (O'Hagan, 2008). The reason for this drift from the roots of Recovery has been perceived to be because of professionals and policy makers removing those with lived experience from the decision-making processes (Rose, 2014). This raises the question of not just who owns and defines the concept of Recovery but also about citizenship and who can claim what it means to people with mental health challenges. This is why co-production with people with lived experience is integral to this study.

The implementation of the Recovery approach in the UK has been in the context of neoliberalism and austerity and this has seen a rationing of services and welfare. Alongside this, the responsibility for change has been placed on the individual rather than understood within a societal context. These concerns are captured by the critical theorist and activist collective *Recovery in The Bin* (RITB) (2016), who, whilst holding to some of the original tenets of survivor-led Recovery, view Recovery as being colonised and corrupted:

"We stand opposed to mental health services using 'recovery' ideology as a means of masking greater coercion. We believe that this rise is a symptom of neoliberalism and that a meaningful 'recovery' is impossible for many of us because of the intolerable social and economic conditions, such as poor housing, poverty, stigma, racism, sexism, unreasonable work expectations, and countless other barriers. The under-funding and under-resourcing of mental health services means that service users are under pressure to conform to a narrow idea of recovery." (RITB 2016)

Defenders of the Recovery approach acknowledge these criticisms but argue that the issue is not the concept itself but rather its application (Slade et al. 2014). However, there perhaps has not been the acknowledgement of the extent of the impact of neoliberalism and the importance of the political

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dimensions of Recovery. As citizenship is subject to the same neoliberal paradigm it will be important to explore neoliberalism in more detail below.

# 2.9 Neoliberalism

Probably the most significant paradigm that has shaped health and social care over the past 30 years has been neoliberalism and it is important that discussions relating both to Recovery and Citizenship are understood within this context (Quinn et al. 2020). Neoliberalism has been adopted with the most enthusiasm in the English-speaking countries, such as the UK and the US, to the extent it is often taken for granted and seen as 'common sense.' Whilst there is not a single definition of neoliberalism, its defining features are freemarkets, individualism, and decentralisation (Gabe et al. 2020). Cruikshank (1999) describes neoliberalism as alienating people that stand below the economic hierarchy and citizens are subject to systems of control that make them 'docile' as the technologies the state and industry use are focused on gaining voluntary compliance; for example, promoting discussions of the deserving and undeserving poor, increasing anxiety about immigration or the use of data that people give access to when signing up to social media platforms such as FaceBook or Instagram.

The impact on health and social care is that there is a particular focus on individuals being responsible for their own care and making 'choices' based on increased marketisation of health and social care (Gabe et al. 2020). Within mental health services this has meant a greater emphasis on difficulties being located within the individual from a biomedical perspective (Faulkner 2017) and then a need to take personal responsibility to resolve these difficulties (RITB 2016). This has occurred simultaneously with the minimisation of the impact of rationing of services and cuts to welfare provision which leads to a disorientating and harmful experience for people accessing mental health services (Torrents 2022). Lampropoulos and Apostolidis (2021), argue that even some involvement of people with lived experience is part of the neoliberal project to reduce spending on professionals and promote individualism.

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This focus on individualism is shaped by normative conceptions of agency and responsibility and making poor decisions being the fault of the person alone (Gabe et al. 2020). This normative individualism is based on economic productivity and how citizens contribute to the economy (Hamer et al. 2017). Those that do not meet the rules or norms of society, due to differences such as mental health challenges, ethnicity, political viewpoint etc, are seen as a risk and excluded from the dominant group (Isin and Neilsen 2008). Citizenship within mental health is being promoted as a way of challenging neoliberalism by creating new approaches to provide resistance and reconnect citizenship to service users and the radical roots of Recovery (Rowe and Davidson 2016; Quinn et al. 2020; Davidson et al. 2021; Ries et al. 2022). As the citizenship literature is explored it will be important to scrutinise the studies as to how they resist neoliberal thinking and are inclusive of the voice of those with lived experience.

# 2.10 Co-Production

One way of involving those with lived experience is using co-production. Coproduction is defined as:

"The relationship where professionals and citizens share power to design, plan, assess and deliver support together. It recognises that everyone has a vital contribution to make in order to improve quality of life for people and communities." (Slay and Stephens 2013, p3.)

At the heart of the work of the Dorset Wellbeing and Recovery Partnership is the collaboration between those with lived experience of mental health challenges and those, such as me, with learnt expertise, using the principles of co-production. Sharing power with people with lived experience is one of the ways we have tried to mitigate against the colonisation of the Recovery approach by mental health services. Within the Wellbeing and Recovery Partnership we attempt to co-produce everything: from the strategy to its implementation and operationalisation. It is this experience that I am looking to bring to this research. Co-production is incredibly challenging as there is a focus on sharing power, recognising everyone's contribution, and ensuring all people's voices are heard. If done poorly, it is possible to level similar criticisms of Recovery to co-production: that it is exploitative and tokenistic and seeks only to address the existing concerns of services and benefitting those with positions of privilege (Beresford et al. 2021). It will be essential as part of this study to pay attention not just to the outcome of the co-productive work but also the process and experience of all those involved. This is discussed specifically in chapter 12.

Co-production is also central in people being active citizens; in being able to share power and play an active role in the research process, rather than as passive subjects. I have learnt so much from working alongside people with lived experience of mental health challenges, much of which has changed my practice and contested some of the assumptions and approaches I was encouraged to adopt through my professional training. As co-production is a central facet of my day-to-day working, I also wanted to make it a key part of this research, both in terms of knowledge exchange, but also developing and delivering the research process. Co-production as a research method will be explored further in chapter 9. Before moving on to describe the methodology, it is important to examine the literature relating to Future Studies and mental health, citizenship and digital citizenship and citizenship in mental health.

# Chapter 3: Future Citizenship for People with Mental Health Challenges: A Narrative Literature Review

This chapter describes the methodology used for the literature review within this thesis. Using a systematic approach this chapter (and subsequent literature review chapters) seeks to review the research to understand the following question:

# What does the literature say about future citizenship for people with mental health challenges?

Despite citizenship in mental health being an emerging area of research, and future citizenship being an area of importance, there has been no research into potential impacts of future citizenship for people with mental health challenges; nor has there been an exploration of digital citizenship for people with mental health challenges (Morgan et al. 2020). Therefore, it will be important to critique the existing literature and how this relates to future citizenship for people with mental health challenges.

Five questions were developed to address the lack of literature on this specific topic. These questions enable a view to be taken on the different elements within this study e.g., digital citizenship, Future Studies and mental health, lived experience and theoretical perspectives on citizenship. They are as follows:

- What does mental health Future Studies literature tell us about future issues relating to citizenship for people with mental health challenges?
- What do the theoretical underpinnings of the approaches to citizenship and mental health tell us about how we can understand future citizenship for people with mental health challenges?

- What is the lived experience of citizenship for people with mental health challenges and what does this tell us about future considerations for citizenship research and practice?
- What does the current state of the application of citizenship approaches to practice and policy tell us about future considerations for citizenship for people with mental health challenges?
- How does exploring digital citizenship help us approach the impact of technology on future citizenship for people with mental health challenges?

The literature review is separated into six further chapters: Chapter 4, Future Studies and Mental Health; Chapter 5, Citizenship In Mental Health: Theory, Chapter 6, Mental Health Citizenship Research; Chapter 7, Digital Citizenship; And Chapter 8, Overview Of The Literature Review, Future Citizenship For People With Mental Health Challenges. This last chapter pulls together all the elements across this broad range of literature and draws out the key themes and questions.

# 3.1 Search Strategy

This literature search has been undertaken using a systematic approach through a scoping review based on the research questions outlined above. The search was conducted using an adapted framework proposed by the Joanna Briggs Institute (JBI). It was also informed by the approaches outlined by Levac and Denis (2019), who highlight how scoping reviews can be used to inform participatory research. A scoping literature review is an iterative process of summarising literature in the field to identify the breadth and key concepts of a given issue or issues (Tricco 2018). As opposed to a systematic review, the purpose of a scoping review is less focused on the quality of the studies but rather an analytic re-interpretation of the literature. A key element of this can be identifying gaps in the literature (Levac et al. 2010). A narrative approach was used to analytically synthesise the literature (Thomas and Harden 2008; Weed 2005). This will be explained further below. It is worth noting that, in line with Thomas and Harden (2008), the nature of the literature review meant that a simple search of electronic databases was not sufficient. There was additional hand searching of reference lists and reading and screening of abstracts and research papers. Studies were selected by relevance to the topic rather than to create a comprehensive review of the literature.

The literature search was carried out on 28/02/21. Prior to submitting the search was re-run 16/09/23. The search strategy included the three steps identified by the JBI (Peters et al. 2015).

- Limited search of Medline (including MEsH) and CINAHL (including CINAHL subject headings). This involved an iterative process of testing different searches and refining the search terms; then analysing the "Keywords" in the abstracts and titles of the papers retrieved.
- Using the refined search terms (see table 1), the following databases and search engines were searched: PsycINFO, SocIndex, SCOPUS, Web of Science, Google Scholar.
- The reference lists of identified studies were searched for additional research papers and articles.

# Table 1:Keywords and subject headings used in search:

Used for all search engines:

Citizenship or ((citizen or nation\* or country or community) N3 (feel\* or be\* or belong\* or involve\* or inclusion or empower\*))

CINAHL- addition subject heading search of (MH "citizenship") or (MH "civil rights+")

Medline – additional MESH search of (MH "civil rights") or (MH "patients rights")

AND

"mental health" or "mental\* ill\*" or "psychiatric disorder" or "mental disorder" or "psychiatric illness" or depression or schizopreni\* or "personality disorder\*" or bipolar or psychosis or psychotic

CINAHL – additional subject heading search of (MH "Mental Disorders+") OR (MH "mental health+")

Medline- Additional MESH search of "(MH "Mental Health"+) or (MH "Mental Health Recovery") or (MH "psychiatry"+)

AND/OR

Futures or Futurology or "Future StudiesFuture Studies" or Forecasting or Forecast or Futurism

N.B. Futures was not used when searching SOCindex or PsychINFO as it brought too many false positives.

The search was limited to papers published between 2010 - present and in English language

# 3.2 Study Selection Process

The JBI suggest using Population, Concept and Context as the frame to define which studies to include (Peters et al. 2015). In this study these are as follows:

- Population: Adults who experience mental health challenges
- Concept: Citizenship the experience of Citizenship
- Context: Future The likely impact of or suggested changes to create a different future.

As citizenship was the focus and, as described in the introduction, there are different notions of citizenship, including global citizenship (Isin and Nielsen 2008), worldwide studies that were published in English were included.

As the focus was on the Future and Future Studies the papers selected were those published after 2010, as it is likely those published before 2010 - if they were discussing the future at that time - would now be discussing the present. The only exception to this was those with Future Studies or Futurology in the title, as they may have had a longer timespan regarding the future. Because so few studies were future-focused those that just met the criteria for citizenship and mental health were included.

# 3.3 Inclusion/Exclusion Criteria

In addition to the inclusion/exclusion criteria outlined above, the following criteria were used to support the screening process:

Exclusions:

- Studies were excluded that used citizenship as a descriptive category, such as *Senior Citizens* or *American Citizens*, where the term could have been people.
- Studies that solely focused on the legal definition of Citizenship were also excluded.
- Studies where the mental health condition was secondary or tertiary to the focus of the article were excluded. For example, if the primary focus was on older people, prisoners or on people with intellectual or learning

disabilities. Those studies that focused specifically on the mental health of these groups were included.

- As the focus is on people experiencing functional mental health conditions papers focusing on those with organic mental health conditions such as dementia or Alzheimer's were excluded.
- As the focus of the study is adults with mental health challenges studies focusing on children were excluded.

# Inclusions:

- The use of Futures and Future Studies meant that multiple papers stated in their conclusion that "It is recommended future studies will..." Only those with a strong focus on mental health and citizenship were included where the inclusion of the term 'future studies' was incidental.
- Due to lack of Future Studies literature from lived experience perspectives, grey literature and multi-media elements (such as YouTube videos) that focused on Future Studies and lived experience of mental health challenges were included.

	Number of	Relevant
	articles	Papers
	returned	
CINAHL	523	35
Medline	1096	73
SOCindex	119	4
PsychINFO	1106	6
Total:	2844	118
Total once duplicates		
removed		97

# Table 2:Search results by database



# Figure 2: Identification and selection of studies

# 3.4 Narrative Review

The resulting papers were analysed using a narrative review. The literature has been thematically analysed using the approach described by Braun and Clarke (2006). This approach to thematic analysis is explained in detail in chapter 9, the methodology chapter. This literature review has involved a familiarisation with the data, an initial coding and identification of core themes. As the chapter has been drafted and redrafted this has led to a revision of and naming of the themes.

To avoid long descriptive passages on the various methodological approaches of the studies reviewed in chapter 6, the research papers have been presented in tabular form in appendix 1.

In a narrative literature review, themes can be descriptive or analytical; analytical meaning moving beyond solely what was described within the original paper (Thomas and Harden 2008). Within this review both approaches have been used: a descriptive approach to explore the theories behind citizenship in mental health and digital citizenship and an analytical approach when examining people's experience of citizenship, the application of citizenship interventions and future citizenship for people with mental health challenges. These discussions of theory and data have then been integrated into a discussion of the implications for future citizenship for people with mental health challenges and key considerations for this research. The key themes and subthemes (with corresponding chapter sections) for each overarching area are displayed in table 3 (the descriptive themes are in grey).

The literature review will first explore the literature focusing on Future Studies and mental health (chapter 4). There are no studies that specifically look at citizenship, so the literature is analysed with a focus on concerns relating to citizenship, such as: the role of mental health legislation and coercion; the role of digital health; the impact of social determinants of health. The social determinants of health are the economic and social factors that shape people's experience of health that are broader than the behaviours of the individual, but the results of inequity in society (Marmot and Allen 2014).

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Chapter	Key Themes	Sub-themes
Chapter 4: Future	4.3 Social Determinants of	
Studies Mental	Health	
Health Research	4.4 Digital Health	
	4.5 Human Rights and	
	Reducing Coercion	
Chapter 5: Mental	5.1 5 Rs of Citizenship	5.1.1 Citizenship and
Health Citizenship:		Social Class: T.H.
Theory		Marshall
		5.1.2 Aristotle,
		<i>Politics</i> , and
		Citizenship
		5.1.3 Citizenship and
		Intersectionality
		5.1.4
		Tocquevillian/Durkhei
		mian Approaches to
		Citizenship
		5.1.5 Critiques of
		Marshall
		5.1.6 Citizenship and
		Neoliberalism
		5.1.7 Collective
		Citizenship
	5.2 Critical Perspectives and	
	'Acts of Citizenship'	
Chapter 6: Mental	6.1 The Impact of Citizenship	
Health Citizenship:	Interventions within Mental	
Research	Health Services	

# Table 3:Themes within the literature

Chapter 7: Digital         7.5 Impact of the Digital         7.5 Impact of the Digital         7.5 Impact of the Digital           Citizenship         7.5 Impact of the Digital         7.4 'Critical' Digital		6.2 Defining Citizenship	6.2.1 Citizenship as
Image: Provide a state of the section of th			
6.2 Measuring Citizenship         6.3 Exclusion and Conditional Citizenship         6.4 Risk, Dangerousness, and the Mental Health Act         6.5 Experiences of Inclusion and Participatory Citizenship       6.5.1 Active         Participation and Reasonable Adjustments         6.5.2 Self-Advocacy and Having a Voice         6.5.3 Allyship and the Role of Mental Health Professionals         6.6 Barriers to implementing Citizenship Approaches within Mental Health Services       6.6.1 Do Mental Health Services Have a Future Role in Promoting Citizenship?         6.7 Community Action and Participation       7.1 Conceptualising Digital Citizenship?         Chapter 7: Digital Citizenship       7.1 Conceptualising Digital Citizenship         7.3 'Normative' Digital Citizenship         7.4 'Critical' Digital Citizenship         7.5 Impact of the Digital			
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Digital Citizenship       7.4 'Critical' Digital       Citizenship       7.5 Impact of the Digital	Citizenship	Citizenship	Digital Citizenship
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7.5 Impact of the Digital     Citizenship			Digital Citizenship
7.5 Impact of the Digital			7.4 'Critical' Digital
			Citizenship
Influence on Citizenship		7.5 Impact of the Digital	
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The literature review then turns to an examination of the concept of citizenship and a discussion of the theoretical underpinnings of the different approaches to citizenship within the mental health literature (chapter 5). Before analysing the research (or data-driven) literature in mental health citizenship there is an exploration of the digital citizenship literature (chapter 6). Whilst digital citizenship is not addressed in the mental health citizenship literature, except in the opinion piece by Morgan et al. (2020), digital health is seen as a key development in future mental health services (Bhungra et al. 2017; Giacco et al. 2017; Hariman et al. 2019; Priebe et al. 2019). Therefore, digital citizenship will need consideration for future citizenship for people with mental health challenges (chapter 7). The examination of future approaches to mental health, theoretical approaches to citizenship in mental health and digital citizenship provides context to explore existing mental health citizenship literature and enables an exploration of the current state of the application of citizenship approaches to practice and policy. This in turn allows an examination of the key considerations of future citizenship for people with mental health challenges (chapter 8).

# Chapter 4: Future Studies in Mental Health

What does Mental Health Future Studies literature tell us about future issues for citizenship for people with mental health challenges?

This section will describe and critique the use of Future Studies within mental health research literature. It will contextualise the use of Future Studies in this area, before outlining the main focus of Future Studies literature, which is global population health (Bhugra et al. 2017; Patel et al. 2018a; Patel et al. 2018b; Hariman et al. 2019; Lund 2019; Patel 2020) and scenario planning (Giacco et al. 2017; Priebe et al. 2019). Due to the dominance of the voice of psychiatrists and the relative lack of lived experience voices, O'Hagan's (2013) YouTube video has also been included.

The second part of this chapter draws out key themes in the Future Studies literature relating to citizenship for people with mental health challenges. These are the importance of an increased focus on: the social determinants of health; increasing digital healthcare; and human rights and reducing coercion. This section concludes with a summary of the key considerations in the Future Studies literature to take forward into the wider discussions relating to the literature and research findings.

# 4.1 The Use of Future Studies in Mental Health

Whilst there are numerous studies looking at future developments in mental health (a search of Medline and CINAHL returns 100,000 articles) the utilisation of the academic approaches of Future Studies have only had limited application within mental health (Vollmar et al. 2015). Connolly (2012), over ten years ago, argued that Future Studies is under-utilised in mental health research and that, even when there is a discussion on the future, the focus is on the immediate threats and consequences, not the medium to longer term future. From the literature search this study does not appear to have changed significantly within the mental health futures research. For example, Hariman et al. (2019), in

exploring the Future of Digital Psychiatry, do not use forecasting but rather look at the present to highlight current concerns and describe the pressing need to address them as future concerns.

Future approaches to mental health tend to be focused on global population health, largely exploring the next ten years. These have been produced through expert commissions, conference presentations, or opinion pieces. The focus of these articles are on the importance of the opportunities digital mental health care affords, the drive towards a more rights-based approach involving people with mental health challenges and the impact of climate change and income inequality and health care funding between high and medium to low income countries (Bhugra et al. 2017; Patel et al. 2018a; Patel et al. 2018b; Hariman et al. 2019; Lund 2019; Patel 2020). These papers tend to be based on the 'expert' opinions of psychiatrists and lack methodological clarity; they do not explain the philosophical position of authors. Therefore, the themes may have been dominated by professional concerns, which are not necessarily the same concerns as those who access mental health services (Faulkner 2017).

To add balance to the debate and give weight to lived experience voices alongside those of psychiatrists, the YouTube video created by service user activist Mary O'Hagan (2013) has been included. In this video she enacts an imagined radio interview set in 2042. Whilst this may not be traditionally considered research, there is an absence of the voice of people with lived experience within the research literature. The academic process of submitting journal articles can be a barrier to those with lived experience (Faulkner 2017). O'Hagan has been included as an important voice to have in this discussion, especially as when exploring citizenship, it is necessary to think about power dynamics and reflect on who decides what is research or not and whether those presenting lived experience perspectives should have to conform to the research orthodoxy to express their views (Morgan et al. 2020). Interestingly, the approach Mary O' Hagan uses has a lot in common with the Future Studies approach of back-casting (Davidson 2017) where people describe an ideal future and then work backward to how this would be achieved. O'Hagan uses

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the example of the current United Nations Convention of the Rights of People with Disabilities (UNCRPD 2006) as being an important vehicle to bring about this desirable future. Within the video there is negligible discussion on the use of technology and how this could impact on restrictive practices within mental health services, so this is an important area to address within this thesis. However, O'Hagan's video is a good example of how future thinking approaches and creativity through the medium of film can contribute to discussions on citizenship and human rights in both the present and the future.

Where formal research methods have been used, the Future Studies research literature within mental health has focused on scenario planning. The purpose of this has been to explore possible scenarios to stimulate discussion rather than creating desirable scenarios; this has been either on a global basis (Priebe et al. 2019) or solely focused on Western Europe (Giacco et al. 2017). Vollmar et al. (2015) state that as scenario planning is becoming more prominent in health research it is important to develop some key methodological criteria to evaluate them. They suggest using critical questions such as: is the purpose of the scenario planning clear? Who are the stakeholders? What approaches have been used? What is the outcome and impact? This approach has been used to evaluate scenario planning research and to inform the methodological approach for this PhD. Only Priebe et al. (2019) use a robust and clearly articulated method involving purposeful sampling from a range of disciplines, interviews, and workshops. Giacco et al. (2017) published their research as an opinion piece despite using scenario planning as a methodology. However, the approach they used is not explained with clarity.

Bergman et al. (2014) argue if researchers discussing the future do not explicitly share their philosophical perspective this maintains the political categories, choices and conflicts present in current power relations. This is particularly problematic within psychiatry where there are already entrenched power differentials, particularly as psychiatrists are responsible for depriving citizens of their liberty due to changes in their mental health status. Even when Bhugra et al. (2017) address issues relating to future thinking and restrictive practices via

service user researcher and co-author Professor Diana Rose, the focus is on how psychiatry adapts its leadership role to meet future challenges. In fact, Bhugra et al. (2017) state *"a revolution is on the way—and psychiatrists need to take hold of the flag and lead from the front." (p810).* There is no explanation of why it is psychiatrists above others who should take this lead, it is almost taken for granted; therefore, upholding and maintaining the existing power structures. This becomes even more questionable when the themes and recommendations are socially and politically focused on human rights and equality.

Giacco et al. (2017), who explore social perspectives within psychiatry, recognise that using social approaches creates a paradigm shift and that these different scenarios would require different forms of leadership from either people who access services or from social scientists. Despite acknowledging these power dynamics Giacco et al. (2017) drew criticism from Russo and Beresford (2017) for excluding the voices of those with lived experience and wider society within the article. They argue that psychiatry has shaped thinking on madness and society for the past 200 years and that exploring the future of psychiatry, albeit from a social perspective, without people with lived experience is a continuation of psychiatry setting the agenda. This strengthens the argument presented within this thesis of the importance of people with lived experience as well as the involvement of technology experts contributing to the discussion of future citizenship.

# 4.2 Key Themes Relating to Citizenship for People with Mental Health Challenges

Whilst citizenship is not explicitly discussed in any of this literature, there are three strong themes that emerge that will have implications for future citizenship. These are: the increased focus on the importance on the social determinants of health; the increased focus on digital health; and the importance of addressing coercive practices and human rights. Overarching all these themes is the importance of addressing the transcultural and multinational experiences of mental health to meet the needs of increasingly diverse populations due to large scale migration.

# 4.3 Social Determinants of Health

The relationship between poor mental health and undesirable social conditions, such as cuts to welfare, lack of quality housing and unstable employment were acknowledged. As was the importance of challenging stigma and discrimination in order to promote better mental health (Priebe et al. 2019; Bhungra et al. 2017, Giacco et al. 2017). Therefore it was envisaged psychiatry would play a role in modifying people's social context to support people with employment, education, and parenting (Giacco et al. 2017). Alongside this was an exploration of mental health services having a primary function to challenge poverty and social disadvantage which would support advocacy and political change for socially disadvantaged groups (Bhungra et al. 2017; Giacco et al. 2017). This was very much about professionals advocating for people, there were tentative suggestions towards activism but nothing unequivocal nor was there a focus on people advocating for themselves (this may be due to the missing voice of those with lived experience). Whilst making claims for the importance of challenging stigma and discrimination there was little acknowledgement in the literature of the role of psychiatry in maintaining discriminatory views of people with mental health challenges, despite psychiatry's role in implementing mental health legislation and a historic focus on the individual rather than society (Torrents, 2020).

# 4.4 Digital Health

Digital mental health care is seen as a core development in the future (Hariman et al. 2019; Priebe et al. 2019; Bhungra et al. 2017; Giacco et al. 2017). Hariman et al. (2019) highlight how current trends such as: teleconferencing; the impact of social media on users' mental health; the potential for social media as an engagement and monitoring tool for clinicians; the use of apps and wearables, and AI to support diagnosis, will continue to grow. They describe how predictive technology will play an increased role in monitoring suicidality and psychosis. The article raises current ethical questions regarding privacy, the role of algorithms and psychiatrists' accountability (Hariman et al. 2019). The article describes the present framed as the future and fails to address the perspectives of people who access services. In calling for future work it calls for mental health experts and technology companies to participate but not those with lived experience.

Priebe et al. (2019) see that there are opportunities for universal access to global mental health care through technology. In this scenario they still describe health professionals having a role locally but that this would diminish over time as AI and robots replace them. Giacco et al. (2017) also explored the opportunities to think about a predominantly *virtual mental health service*. These perspectives raise fundamental questions about who would be programming the AI and robots, and what perspectives they would be taking. Would they maintain existing discriminatory perspectives or provide opportunities for viewing mental health in a different way?

# 4.5 Human Rights and Reducing Coercion

An increased focus on human rights and reduction in coercive practices was also a key theme. Priebe et al. (2019) explored the idea of universal standards for mental health care, which would have a focus on human rights including reducing coercive practices. Bhugra et al. (2017) saw a need to balance further the rights of the individual with mental health law, especially since the UNCRPD (2006) states that compulsion based on mental disability is discriminatory. O'Hagan (2013), using backward chaining, sees the UNCRPD as the starting legal position for the imagined future of the Care without Coercion Act 2042, which would mandate advanced planning and advocacy for service users alongside more humane alternatives to hospital admission.

Bhugra et al. (2017) also argue that linking mental health, risk and dangerousness is a discriminatory discourse, and this discrimination is further

compounded for people of colour when looking at the impact of colonialism and the application of Eurocentric mental health laws and restrictive practices. Therefore, there are calls for greater cultural awareness and transcultural approaches and more effective communication skills for psychiatrists to meet changing demographic needs.

Giacco et al. (2019) touched on the dynamics of power within mental health care when exploring service user/survivor-led mental health services. These services would not include coercion. Services would be provided by personal health budgets and people would purchase clinicians' time and the support they need. Violence and threats of violence would be dealt with via the criminal justice system. The ethical considerations of this were not explored within the study. This approach was not dissimilar to that proposed by Mary O'Hagan (2013); she also proposed humane reform to the criminal justice system. This could mean a fundamental redesign and positioning of mental health services, especially when coupled with a focus on equality and challenging poverty and social exclusion.

# 4.6 Summary

There is consensus across future mental health literature about the importance of exploring the role of human rights and coercion. These two elements sit at the heart of what it means to be a citizen: What are our rights? What are our responsibilities? When should or can the state intervene and whose interests does that serve? This indicates that citizenship may well be a useful way to explore future dilemmas within mental health care and wider society.

An increased focus on the social determinants of mental health also brings into question how mental health is conceptualised. This is particularly important as it could be argued currently mental health is primarily a biomedical concept (Torrents 2022). If there is a future focus on social determinants and a move away from a biomedical understanding this leads to the question of what the role of psychiatry should be in the future. Whilst psychiatrists propose they 'lead

from the front', it does raise the question of whether their role should have such prominence in the future.

It is also clear from the literature that digital technologies and interventions will play an increased role, even to the extent where people may not even access their mental health care through humans but with AI. This too raises questions, not just about what it means to be a citizen, but what it means to be human and the role of human connection. Concerns regarding surveillance, privacy and AI are key to citizenship, regarding a person's relationship with the state and/or corporations. It will be important to understand digital citizenship within this context.

There is a clear gap in the future mental health literature of lived experience perspectives. In this study it will be important not just to involve people with lived experience in debates around future citizenship but also for people to drive upcoming discussions on citizenship. It could be argued that the needs of people with mental health challenges in the present are so acute that exploring the future is a privileged indulgence which will be of limited immediate benefit and that all research should focus on promoting citizenship in the here and now. In both feminist Future Studies and Afrofuturism, it is argued that when exploring the future, it is also possible to impact positively on the present (Capers 2019; Bardzell 2018). It is not proposed that Future Studies should be the only focus of citizenship research in mental health but that it may complement existing directions. It is important first to provide the context for why citizenship has risen in prominence within mental health research and the theoretical perspectives that underpin citizenship.

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# Chapter 5: Citizenship in Mental Health: Theory

This chapter addresses the following question within the literature review:

What do the theoretical underpinnings of the approaches to citizenship and mental health tell us about how we can understand future citizenship for people with mental health challenges?

Citizenship is being presented by a range of mental health researchers as an opportunity to address some of the social injustices experienced by people with mental health challenges. This is being done by focusing not just on the individual but their relationship with their communities and how communities need to adapt and develop to be more accommodating (Quinn et al. 2020; MacIntyre et al. 2021).

However, citizenship is a relatively new concept in mental health and whilst it has been promoted for several decades, its theory and its application in practice has been under-explored and is often poorly understood (MacInytre et al. 2019; Cogan et al. 2021; MacIntyre et al. 2021;). Eiroa-Orosa and Rowe (2017) emphasise that implementing citizenship approaches needs to take into consideration the social, cultural, and political context of a country in understanding the relationship between mental health, service delivery and citizenship. Therefore, within this literature review the cultural context of the research has been taken into consideration in its evaluation and applicability to a UK, and specifically an English, context.

This PhD is the first research study to focus on citizenship and mental health within England and the first overall to explore people's lived experience of digital citizenship within mental health. As well as examining the cultural context it is also important to understand the theoretical perspectives on citizenship, particularly as citizenship is a contested and complex concept in relation to people with mental health challenges and other marginalised groups (Morgan et al. 2020; MacIntyre et al. 2021).

# 5.1 The 5Rs of Citizenship

Most of the work on citizenship in mental health has been conducted by Rowe and collaborators using the 5Rs approach. Rowe and Pelletier (2012) developed their ideas around citizenship through their work and observations of the exclusion of people with mental health challenges and experience of homelessness in the United States. Rowe and Pelletier (2012) noticed that after their clients were housed, they did not then go on to connect to their communities as citizens and continued to be outside of society. Therefore, they identified a need to focus on citizenship specifically.

This approach is rooted in the work of T.H Marshall (1987), who promotes political, civil, and social rights and the Tocquevillian/Durkheimian approaches which explore how social norms are formed and how solidarity and social participation play a key role in citizenship (this will be explained in more detail later in this chapter). Atterbury and Rowe (2017) use Marshall as a way of exploring "normative citizenship" to critique and promote a more participatory form of citizenship that is inclusive of people with mental health challenges.

The 5Rs stand for:

- Rights
- Responsibilities
- Roles
- Resources
- Relationships

Despite the dominance of the 5Rs approach to citizenship there are other theoretical approaches identified, such as: 'acts of citizenship' by Isin, as utilised by Hamer et al. (2014; 2017; 2019); feminist approaches, such as Lister (2007), as utilised by Vervliet et al. (2019). These different approaches mean that there are different emphases on citizenship which need to be explored.

#### 5.1.1 Citizenship and Social Class: T.H. Marshall

In the UK and in the Western world in general, current understandings of citizenship have grown out of the work of T.H. Marshall and his seminal work from 1949, *Citizenship and Social Class* (Marshall 1987). This work underpinned the establishment of the welfare state and described the rights and obligations that the state has to citizens and citizens have to the state. Marshall describes how people have civic, political, and social rights:

*Civic rights* - right to assembly, freedom of speech *Political rights* - right to vote or stand for election *Social rights* - access to welfare, healthcare and education

These rights were balanced with obligations, which are: franchise, taxation and, at the time, conscription into the military (this practice stopped 50 years ago in the UK). The framework suggests that equality is promoted for all through this universal approach. However, it becomes exclusionary when that universal archetype is white male, able, and heterosexual, which is how Marshall (1987) conceived his approach to citizenship. For this reason, Marshall's definition of citizenship is seen as 'normative' and is used throughout the literature as a way of exploring whose voice is heard and whose is excluded (Atterbury and Rowe 2017). This exploration of the tensions of citizenship and tensions regarding who has power and status can be traced back to Aristotle.

#### 5.1.2 Aristotle, *Politics*, and Citizenship

Both Rowe and Pelletier (2012) and Hamer (2012) acknowledge how citizenship developed out of Aristotle's work, *Politics* in the 4<sup>th</sup> Century BC. Aristotle views citizenship as the relationship between an individual and the city state. He sees it as integral to human nature as people seek to co-operate and live together, and this coming together is based on service rather than kinship or race. Citizens can expect to flourish within the state and the state should be able to rely on citizens to follow their duties of citizenship. This is balanced by the concept of justice. However, as Aristotle describes, justice becomes distorted by the struggle for power, self-interest and the prioritisation of certain needs and rights. He describes this as *politics*, this being the uneasy relationship of men [sic] that by nature want to live together but struggle to do so (Aristotle 1995).

For Aristotle, citizenship was only available to men within the city state. This shifted over centuries, with the development of liberal thought, to men being able to self-actualise and assert their rights by participating in society (Aristotle 1995). As Western societies have developed, legal rights of citizenship have been passed to an increasing number of citizens. Examples within the UK are legislation such as: the Abolition of Slavery Act in 1838, the Representation of the People Act (Equal Franchise) 1928 giving voting rights to men and women over 21; the Sexual Offences Act 1967 which decriminalised homosexuality; the Representation of the People Act 2000 giving the right to vote to people detained under the Mental Health Act 1983 and the Equality Act 2010 which gives protection from and a right to challenge discrimination for people with protected characteristics such as mental health challenges. However, the legacy of prejudice, of structural racism, ableism homophobia, and sexism continue to exclude people's full engagement in society. Similar prejudices and exclusions are present for people with mental health challenges and when these intersect with gender, race, class and abilities, further exclusion can result (Atterbury and Rowe 2017).

#### 5.1.3 Citizenship and Intersectionality

Intersectionality refers to the interaction between different and multiple identities, such as race, gender, sexuality, ethnicity, class, ability and how they interplay with the dynamics of dominance and oppression (Fagrell Trygg et al. 2019). In this study, it has been important to explore intersectionality as a concept to critique citizenship research and inform the co-production of the research included in this thesis. This is because people do not experience their mental health challenges in isolation from their social and cultural context. Intersectionality is also important in relation to mental health as being a person of colour, non-heterosexual, living in urban environments, being of lower socioeconomic status means you are more likely to have poorer mental health and are more likely to experience trauma and violence than those who are white, heterosexual, and of a higher socio-economic status (Torrents 2022). A criticism of the Recovery approach has been that it does not pay enough attention to intersectionality and therefore benefits those with existing privilege (RITB, 2016). It is important to address intersectional citizenship directly. This is particularly important when citizenship is conceptualised as citizens as political actors (Isin and Neilson 2008) or is being understood in examining who has power and who is excluded (Atterbury and Rowe 2017).

Intersectionality has its roots in Black Feminism, when Crenshaw (1991) argued that the intersection of racism and sexism meant the experience of black women cannot be looked at independently of their race or gender nor can other aspects of a person's identity, such as mental health status, go unexamined. Understanding intersectionality is seen as a way of improving health outcomes for marginalised groups. This is because, in general, the distribution of health means that groups with more power and influence experience better health outcomes than disadvantaged groups (Fagrell Trygg et al. 2019). However, there are nuances and unexpected patterns that can arise between various social positions: for example, black men with a university education, and white men in blue collar jobs with a university education have a greater suicide risk than those with lower educational attainment (Seng et al. 2012). Therefore, it is important to pay attention to the layers of identity and oppression but also try to be aware of interactions between the layers. There are calls for systematic frameworks to explore intersectionality (Vu et al. 2019): in the absence of these frameworks, intersectionality will be used as an additional lens to critique the mental health citizenship literature.

# 5.1.4 Tocquevillian/Durkheimian Approaches to Citizenship

Rowe and colleagues, in developing their concept of citizenship, did not use Marshall's (1987) work alone. They also drew upon the work of 19<sup>th</sup> Century philosopher Emile Durkheim and political theorist Alexis de Torqueville. Durkheim is seen by many as one of the founders of sociology and De

Tocqueville studied the French and American revolutions and how new laws and morals are generated. With the 5Rs, Rowe integrated their approaches to civic participation and solidarity (Rowe and Pelletier 2012; Ponce and Rowe 2018).

Durkheim (2014) argues that citizenship is not just shaped through rights and responsibilities that are enacted through legal frameworks but through the ways in which social consciousness is constructed and behaviour normalised. He argues that morals, attitudes, and democratic structures are buried deep in the individual consciousness. This is expressed as national character and dictates habits and day to day roles. This creates a form of coercion through normalisation in egalitarian societies. It is important for these to be brought into consciousness so individuals are aware of social functioning and can enact change.

De Tocqueville (2002) believes, through studying the French and American revolutions, that there is a march to greater equality through irrepressible social movements. De Tocqueville highlights that democracy can also lead to what John Stuart Mill described as, the "tyranny of majority" and therefore needs to be mitigated by social movements that can represent the views of those that are marginalised: for example, people with mental health challenges can have their rights restricted and be subjected to coercive measures such as restraint and compulsory treatment for the 'benefit' of public protection.

Durkheim (2014), referencing the work of De Tocqueville, sees people as having a natural solidarity because people are required to collaborate in society, and this brings people together. He views disunity and excessive individualism as pathological and therefore some of the impacts of modern life require new social action to bring people together via civic participation through community groups and voluntary associations.

Rowe and Pelletier (2012) use this theoretical basis to provide a frame to expose and challenge the social conditions that create normative experiences of citizenship that can exclude those from marginalised groups through written or unwritten rules or expectations. They also draw upon Janoski (1998), who extends the Tocquevillian/Durkheimian model of solidarity and general exchange by introducing a fourth right to the *civic, social.* and *political* rights of Marshall (1987), which is a *participatory* right. This focuses on the right to participate for those who are marginalised from society and includes voicing dissent and political action, making the distinction between the legal notion of citizenship and those more participative components of being an 'active' citizen (Janoski 1998).

From these various philosophical positions, it is possible to see how Rowe developed the 5Rs, the rights and responsibilities coming directly from Marshall, with the *roles* element of social participation coming from Durkheim and De Tocqueville. Quinn et al. (2020) describe how the 5Rs hold the individualistic and collective nature of citizenship in a creative tension: creating the opportunity to challenge the highly individualised and neoliberal approaches to citizenship within mental health services and encourage the focus on empowerment of people with mental health challenges to develop their own projects and approach to citizenship to overcome marginalisation.

# 5.1.5 Critiques of Marshall

Rowe and colleagues also use Marshall's approach to citizenship as a way of examining who has power and whose voice is marginalised (Atterbury and Rowe 2017). Marshall's approach to citizenship was designed to support employed men when not in employment and excludes the perspectives of marginalised groups such as people with mental health challenges (Atterbury and Rowe 2017). It has also been criticised by feminists and post-colonialists for its gendered and ethnocentric stance (Lister 2007; Hamer et al. 2017). This balancing of rights and responsibilities through social norms also favours some groups over others and can sustain oppression (Atterbury and Rowe 2017; Vervliet et al. 2019). Both Hamer (2012) and Atterbury and Rowe (2017) document how people from marginalised groups, particularly those with mental health challenges, are disenfranchised from being full and participating citizens. Hamer (2012) in her thesis, in the absence of specific literature regarding

mental health and citizenship, reviews literature exploring the experience of citizenship of people from marginalised groups, whether that is through gender, sexuality, ethnicity or ability. She describes in detail the dynamics of how people are made to be second class or 'non-citizens' due to their mental health status.

Another limitation of Marshall's approach to citizenship is a lack of recognition that citizenship now extends beyond the boundaries of nation states due to globalisation, migration, and increased diversity within societies (Rowe and Pelletier 2012; Ruppert and Isin 2020). Whilst Rowe and Pelletier (2012) acknowledge this limitation, particularly regarding the legal position of undocumented migrants in the US, they do not offer a broader conceptualisation of citizenship as seen in the work of Isin and Neilsen (2008), which is explored further in this chapter.

#### 5.1.6 Citizenship and Neoliberalism

Marshall's approach to citizenship has also been criticised as outdated due to significant changes within the political landscape over the past 20 years. Some neoliberals have suggested the welfare state is no longer relevant as its funding has been diminished and there is a greater emphasis on individuals taking responsibility for their health. This reduction in the welfare state and push for individual responsibility also leads to greater alienation of those from marginalised groups. The impact of neoliberalism on citizenship is that there has been a shift away from social justice shaping citizenship to that of market forces and individualism shaping societal norms (Quinn et al. 2020). As a result, citizens are valued based on their ability to contribute economically (Atterbury and Rowe 2017). As people with serious mental health challenges are more likely to be unemployed, this exacerbates the exclusionary nature of citizenship for people with mental health challenges.

Cruickshank (1999) describes the new 'technologies of citizenship' [p2] within neoliberalism, which are used to secure compliance of the citizen body through directing people's will towards consumption, monetizing people's participation in society and directing their agency to be passive within this process, The targets
of resistance become harder to find and challenge: for example, as Ruppert and Isin (2020) identify, fewer people are voting. The reasons for this political inaction are not overtly visible, but governments within the UK and US are putting more constraints on democracy by adding restrictions on protest and introducing voter identification schemes (Krieger 2020; Mason et al. 2023). This is particularly important when exploring the role of digital citizenship and how technologies are used to engage and to distract.

As mental health citizenship literature is concerned with social justice and inclusion rather than valuing the neo-liberalisation of citizenship, there is a challenge to both the neoliberal understanding of citizenship and the individualistic conceptualisation of Marshall (1987). Rowe selected resources as one of the 5Rs because of the importance of social and economic capital in accessing the other aspects of citizenship. This considers the social, structural, and economic barriers to citizenship (MacIntyre et al. 2021). In the exploration of these barriers, it is crucial that attention is paid to neoliberalism, so that the application of citizenship does not follow the same individualised approach as happened with Recovery and undermines the claims for social justice. Quinn et al. (2020) describes the R for *resources* as the hinge influencing both an individual's ability to access their rights and responsibilities and the participatory elements of citizenship, their roles, and relationships. Rowe introduced relationships to demonstrate the importance of collective understandings of citizenship rather than solely as an individual's relationship with the state. Quinn et al. (2020) argue it is important to think beyond the individual and claim that political and collective approaches to citizenship can be forms of resistance to neoliberal dominance.

# 5.1.7 Collective Citizenship

Within the literature relating to the 5Rs, tensions are surfacing between the balance between individual and collective aspects of citizenship. Quinn et al. (2020) describe collective citizenship as being characterised by group membership and consensus-based decision-making, where the power sits

within the group itself and that group membership is predominately made up of those with lived experience and experience of marginalisation. Collective citizenship is more directly political in that it directly challenges the individualised and normative approaches to citizenship, encouraging mutual help and action for change (Quinn et al. 2020; Reis et al. 2022). As part of this collective citizenship, there are calls for co-production between mental health professionals and those with lived experience. There is also a call for peer-led and owned initiatives, including political and direct action (Quinn et al. 2020; Bromage et al. 2021)

Collective citizenship, in some ways, is less of a theoretical position and more of an intervention to support those rejected by neoliberalism to feel less despair and to experience less isolation. Mental health professionals are being encouraged to show solidarity and to fight for rights of people as citizens of their communities (Bromage et al. 2021). There are also requests for links with other marginalised groups for collective action to tackle causes and effects of marginalisation (Quinn et al. 2020; Bromage et al. 2021). Whilst Quinn et al. (2020) and Reis et al. (2022) acknowledge the need for professionals to share and cede power they do not explicitly explore the dynamics of power. There are clear questions around the role of mental health professionals and services in collective citizenship and the extent mental health services can help and hinder promoting citizenship approaches, which requires further exploration (Rowe and Davidson 2016). This is particularly pertinent when considering future citizenship with the potential for increased focus on poverty and inequality and service user-led services.

Quinn et al. (2020) claim the focus on collective citizenship, rather than that of the individual and their place in society, "does not denigrate" [p373] the value of the previous work of Rowe and colleagues. However, they do not unpack the tensions between the individual and collective experience, nor do they articulate the challenges of the two approaches co-existing. One of the fundamental difficulties with Rowe's 5 Rs is initially Rowe et al. (2012) did not explicitly try to conceptualise citizenship from a lived experience perspective but rather a

sociological or philosophical one. This is despite working with people with lived experience, and peer workers having a key role in the delivery and development of their citizenship interventions. The lived experience perspectives came later, as they recognised the gap between the conceptual and actual when putting citizenship interventions into practice (Rowe et al. 2012). Yet if there is to be a collective approach to citizenship, surely the voice of those with lived experience should shape it through defining what citizenship means: it could be argued that this is a political act in itself (Isin and Neilsen 2008). In some ways the collective approach to citizenship has more in common with critical perspectives on citizenship, and whilst Quinn et al. (2020) cite the work of Isin and Neilsen (2008), they do not align their position with their work.

### 5.2 Critical Perspectives and 'Acts of Citizenship'

Critical approaches argue that we understand the world through the concepts which we inherit, and through the dominant discourses which shape these concepts. For example, social norms shape what is considered mad, or the likelihood of someone receiving a particular diagnosis based on their gender or ethnicity. Critical citizenship sees citizens in their geographical and historic context also as dynamic, changing, and contested figures (Isin and Neilsen 2008). Therefore, citizenship is broader than the relationship between the individual and the state as it is multifaceted, with different forms of citizenship: such as, global citizenship, consumer citizenship, and digital citizenship (Isin and Nielsen 2008; Isin and Ruppert 2020). This dynamic perspective acknowledges the introduction of new rights, whether these are sexual, cultural, environmental, or legal: for example, traditional or expanded rights are now governed and established supranationally (e.g. The United Nations (UN) and European Union (EU)), as well as in devolved administrations (e.g. Scotland and Wales) and through the traditions of minority communities (e.g. Sharia Law) (Isin and Ruppert 2020).

Lister (2007) argues that it is important not just to have rights but also recognition, and that this is a form of cultural citizenship. People have the right

to be different and to fully participate, and the right for different forms of participation to become recognised and valued. She uses the example of unpaid domestic work being recognised as an important form of citizenship. This would not be recognised in either the conception of Marshal nor within a neoliberal perspective of citizenship. She uses feminist perspectives to bring to light the breadth of citizenship and the importance of participation and taking action.

Both Hamer (2012) and Brannelly (2018a) use the work of Isin and Neilsen's (2008) critical approach to shape their approach to citizenship. They do this by exploring the views of people with lived experience of mental health challenges, their perspectives on citizenship and how their actions and the actions of clinicians can promote inclusion (Hamer 2012) and set priorities for change (Brannelly 2018a). Vervliet et al. (2019), using photovoice, draw on Lister's critical feminist perspectives to explore the cultural experience of citizenship of those with mental health challenges.

Critical Citizenship explicitly explores power, influenced by the work of Foucault and Balibar. 'Acts of citizenship' describes how citizens are subject to power but also subjects of power and that this creates a contradiction in how citizens are both obedient and subservient but also disobedient and enact their own power (Isin and Ruppert 2020). These are *acts* that rupture and challenge social norms and can be enacted by individuals and communities. It is these acts in themselves that constitute citizenship and citizens come into being by performing politics (Isin and Neilsen, 2008).

The content of citizenship focuses on how citizens balance their responsibilities through social, cultural, symbolic, and economic practices in return for their status, which entitles them to their civic, political and social rights. Isin and Neilsen (2008) highlight that it is through the dominant discourses in these practices that people are included and excluded. However, they see this as a tension that can enable people to come into being as citizens as well as identifying who lacks status as a citizen. They identify three simultaneous

elements that bring citizenship into being, these are: legality, performativity, and imaginary. Legality is the right to claim rights and replicate the political, social and civil rights struggles; performative is taking actions towards these claims, which involve breaking and subverting conventions. To enact claims, there needs to be an imaginary citizenship which is a whole series of utterances of what citizenship claims to be, ought to be, has been and will be.

This positions citizenship as the 'acts' of striving for rights themselves rather than the end point of (self) acceptance as a citizen. These 'acts' can be collective or individual. Through focusing on the lived experience of citizenship for people with mental health challenges and that of people within mental health services, these 'acts' can enact change and claim and promote citizenship (Brannelly 2018a; Hamer 2012).

# 5.3 Summary of the Theoretical Perspectives

'Acts of citizenship' fits strongly with the design of this research as both participants and peer researchers, and myself as an academic researcher, are engaging in 'acts of citizenship' by attempting to challenge and rupture social norms throughout this study. Critical perspectives of citizenship give a broader view than that of the 5Rs which is primarily concerned with the person's role as a citizen within the nation state; whereas critical perspectives consider other forms of citizenship, such as digital citizenship, which is particularly important in this study given the future importance of technology in mental health (Hariman et al. 2019). Looking to the future and trying to explore what citizenship means engages in 'imaginary citizenship' and starts to describe what citizenship ought to be and can be (Isin and Ruppert 2020). There is an under-explored relationship within the literature between collective approaches to citizenship and critical perspectives, despite there being commonalities (Quinn et al. 2020).

The other key distinction between Rowe's research, and the approach of researchers such as Hamer (2012), Brannelly (2018a) and Vervliet et al. (2019) is their greater emphasis on the primacy of lived experience of citizenship of

those with mental health challenges, meaning people have a greater say in how citizenship is understood and developed in this context. Those who are perceived as vulnerable are often absent or excluded from the debate around citizenship (Vervliet et al. 2019). This may be due to the critical and feminist theoretical perspectives they take in seeking to amplify the voices of those who are marginalised, whilst seeking to promote those voices to surface and challenge power imbalances (Lister 2007; Isin and Nielsen 2008). This is not to say that Rowe does not value lived experience; his research involves peer workers throughout the development and delivery of interventions and research, although this is not clearly articulated within the published research papers. Rowe's location of citizenship in the 5R's emphasises his observations of people accessing services and his theoretical understanding of citizenship rather than an empirical understanding based on people's lived experience. This is important because citizenship is a political concept and having power and a voice when marginalised is fundamental in claiming rights and recognition as a citizen. It is key that this has attention paid to it, especially with the historic and current power imbalance within mental health services.

More recently this has been acknowledged in the work of Rowe and collaborators and there is an increased emphasis on participatory approaches in defining citizenship (MacIntyre et al. 2021) and implementing citizenship interventions (Quinn et al. 2020; Ries et al. 2022). It is to this research and the research into the lived experience of citizenship for people with mental health challenges we turn next.

# Chapter 6: Mental Health Citizenship Research

Having described the different theoretical perspectives of citizenship within the mental health literature and identified potential future issues for citizenship for people with mental health challenges, it is important to critically examine the research literature concerning how citizenship is understood and applied within mental health contexts. The methodologies of the individual research studies are available in appendix 1.

As a reminder, this section will explore the following questions:

- What does the current state of the application of citizenship approaches to practice and policy tell us about future considerations for citizenship for people with mental health challenges?
- What is the lived experience of citizenship for people with mental health challenges and what does this tell us about future considerations for citizenship research and practice?

There is a great deal of consensus within the literature on the exclusory experience of citizenship for people with mental health challenges and the negative impact that this causes in their lives. Over the past two years none of this is likely to have improved with inequalities growing through the Covid pandemic (Marmot et al. 2020; Eiroa-Orosa, and Tormo-Clemente 2022). Despite this there are several aspects people find helpful in promoting their sense of citizenship. Fundamental to people's sense of citizenship are having reciprocal relationships and a sense of belonging (Harper et al. 2017; MacIntyre et al. 2021; Reiss et al. 2022). It is also important that people have meaningful roles and occupations facilitated by practices of inclusion. Reasonable adjustments are key in enabling people to participate fully (Hamer and Findlay 2015; Hamer et al. 2019). What people value as citizens is also sometimes the day to day (Harper et al. 2017), small (Hamer et al. 2019) or banal (MacIntyre et al. 2021) aspects of citizenship. For communities to be accepting, there needs to be greater work promoting inclusion and challenging stigma (Harper et al. 2017; Clayton et al. 2020). There are further debates to be had on who is best placed to do this, whether this is people with mental health challenges themselves or whether this is a role for mental health services (Quinn et al. 2020) or both.

Mental health professionals and peer workers have a responsibility to work proactively to promote citizenship and potentially mental health services should work within a citizenship orientated model, with citizenship being the starting point of care not the end point (Davidson et al. 2021). This includes challenging and ending restrictive and coercive practices (Brannelly 2018a), which have been described as 'acts of citizenship' in themselves (Brannelly 2018a; Hamer et al. 2019). If mental health services are to have a role in promoting citizenship it is important that there is robust evidence in terms of interventions (Davidson et al. 2021). Therefore, the next section will explore the use of citizenship interventions specifically delivered within the context of mental health services, later in the chapter there are also interventions described but these are more community-based, rather than service-led, and co-produced (Quinn et al. 2020; Reiss et al. 2022).

## 6.1 The Impact of Citizenship Interventions within Mental Health Services

Following his work identifying the need for citizenship interventions, Rowe and colleagues undertook the Citizenship Project which was the first Randomised Control Trial (RCT) exploring the impact of a four-month citizenship intervention with a group of people who had serious mental illness and/or substance misuse difficulties and/or criminal justice involvement (Rowe et al. 2007; Rowe et al. 2009; Clayton et al. 2013). The citizenship intervention consisted of the following: individual peer mentoring, an eight-week citizenship class and an eight-week valued role component (participants undertaking projects that benefited the local community, e.g. teaching police cadets about working with people experiencing mental health challenges). This was based upon the 5Rs

of citizenship as defined by Rowe and Pelletier (2012); the other participants were offered treatment as usual.

Overall, both groups saw a reduction in participation in criminal activity. Participants in the experimental side had significant increased quality of life and reduction in substance use. The findings relating to reduced substance use and criminal activity are captured in separate papers (Rowe et al. 2007; Rowe et al. 2009). The results specifically looking at quality of life and citizenship outcomes more broadly are described in Clayton et al. (2013) and it is this later paper that this literature review will focus on. Interestingly, those on the citizenship intervention had higher rates of anxiety and depression. Clayton et al. (2013) hypothesised this may be due to greater exposure to social changes and engagement. This finding aligns with wider research. When we examine how people experience citizenship within the literature, people describe feeling apart (Hamer 2012) or experiencing micro-aggressions (Harper et al. 2017). People also describe the value of being with people in a similar position (Cogan et al. 2021). This links back to the importance of relationships as one of the five Rs and the importance of being part of a collective, but also how society can be experienced as a hostile place and that the changes required are not just for people with mental health challenges to develop citizenship skills but also for society and communities to become more accommodating.

It is worth noting that this is the only randomised control trial into a specific citizenship intervention. Whilst subsequent research has built on different elements of this work, such as developing a measure (Rowe et al. 2012), or exploring how mental health services can implement holistic citizenship approaches (Rowe and Davidson 2016), it is a notable gap. Further research into interventions has explored the more qualitative participatory approaches which, whilst they create a richness of data, are more challenging to implement within mental health services without the weight of RCTs to support them. This again highlights the balance of power within psychiatry and challenge of approaches that seek to disrupt the balance of power.

The other limitations identified by the authors suggest that it may not have been the citizenship intervention itself that made the difference but rather the extra input. It was also not possible to distinguish which of the three elements included in the trial made the difference to people. They identified the need for further research into the relationship between clinical and citizenship interventions and to continue to devise citizenship interventions (Clayton et al. 2013). The focus of a significant part of their future research has been on the collective participatory elements, such as the community-based work (Quinn et al. 2020; Reis et al. 2022), and the difference this makes to people's lives beyond mental health services.

Another limitation of how Rowe and colleagues had approached the citizenship RCT was that lived experience perspective of citizenship had not framed its theoretical development, so whilst peers were involved in designing and delivering the intervention, the conceptualisation of citizenship had been framed theoretically. This raises important questions about who defines citizenship and what successful citizenship entails and whether that sits with a normative view, or a more critical perspective linked to activism.

## 6.2 Defining Citizenship

Around the time Rowe and colleagues were recognising the need to include the lived experience perspectives of citizenship, Helen Hamer (2012) was the first to explore what citizenship meant to people with lived experience of mental health challenges. People with lived experience are not a homogenous group and therefore have different perspectives on citizenship and what it means. One of the differences of opinion is the extent people feel the necessity to comply with normative forms of citizenship and the extent to which it is possible to experience citizenship as individuals who can be excluded from citizenship. This reflects the theoretical debate between 'acts of citizenship' and the balancing of rights, responsibilities, and participation.

Lola (in Hamer et al. 2014. P205). described citizenship as "a collection of both written and unwritten rules...(and) protocols (that determine) the way we should... conduct and behave ourselves within a community." This links to the Durkheimian/Tocquevillian approach of Rowe which identifies there are rules and social mores. People describe, despite feeling different, trying to fit in or pass for normal in order not to experience discrimination or alienation. This will include lying or avoidance to appear to be a normal citizen (Hamer et al. 2014; Hamer and Finlayson 2015; Harper et al. 2017; Vervliet et al. 2019; Cogan et al. 2021). People describe this process as exhausting, as they battle to be included as a citizen, alongside managing their own emotional distress (Hamer et al. 2017). This theme of being forced to be normal comes up in Vervliet et al. (2019) in how this constrains people and how citizenship becomes a form of marginalisation and alienation. The less you can conform to the expectations of society the further you become from what is deemed to be a valued citizen. This theme of alienation is explored further in this chapter through the discussions of exclusion and conditional citizenship.

Maria challenges a normative or conditional idea of citizenship:

"Who gets to say what is normal? (I am an) expressive creative person who has spent my entire life not put in a box. Act normal for whom? Heaven help me from normal!" [Hamer et al. 2014. P205]

This poses the question: to what extent should we be trying to understand citizenship as something that people with mental health challenges should fit into and to what extent should we be seeking to change society or how citizenship is understood so it is more accommodating to diverse experiences? Communities are not always welcoming places to people with mental health challenges (Cogan et al. 2021; Harper et al. 2017) and are not necessarily safe environments (Clayton et al. 2020). This emphasises the value of this theme within the mental health Future Studies literature, highlighting the importance of social development and equality as a key concern. Participants in Hamer et al.'s (2014) study argue that citizenship should be about accepting people, their

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differences, and eccentricities and that an inclusive society values the diversity of its population.

Cogan et al. (2021), within their focus group discussions, found people with lived experience of mental health challenges who had experienced challenges being accepted in 'mainstream society'. They described their sense of difference creating a strong bond and a sense of citizenship amongst peer groups of people who had similar experiences. This created a different and valued form of inclusion, different from 'normal citizenship'. This again raises the question about citizenship and how there are potentially multiple forms of citizenship, and highlights to what extent citizenship is about where people feel that they fit and the extent this should/could be an overarching form of citizenship.

In MacIntyre et al.'s (2021) study, some people did not always view citizenship as making bold claims for rights but a wish for the ordinary. Participants referred to valuing the 'banal ordinariness' of the components of citizenship. They described citizenship as doing ordinary everyday things, although there were a minority who did not see these ordinary things as an aspect of citizenship at all, emphasising citizenship is a contested concept (MacIntyre et al. 2021).

It is important to highlight that in none of the studies did people discuss or describe digital citizenship as a concern or issue. This may have been to do with the framing of the question, a lack of access to technology - as participants may have been digitally excluded - or not a priority in people's lives in how they viewed citizenship.

# 6.2.1 Citizenship as Participation and Belonging

In parallel to the work of Hamer (2012), Rowe et al. (2012) identified that there was little empirical work exploring the concept of citizenship. Following the evaluation of their Citizenship intervention (Clayton et al. 2013) they identified a gap between theory and practice, between how citizenship is understood and how this is applied in the lives of the participants and those professionals and

staff who support them. They found discussions on citizenship were more focused on the legal definition of citizenship rather than the participatory understanding they had developed through the 5Rs. Rowe and colleagues then undertook CBPR in different contexts as a way of exploring citizenship. This was initially utilised to support the development of a citizenship measure. Rowe et al. (2012) identified seven clusters of the key components of participatory citizenship, which were:

- personal responsibilities
- government and infrastructure
- caring for self and others
- civil rights
- legal rights
- choices
- world stewardship

The focus of the discussion in this paper was very much about how this could be turned into a measure. It seems like a missed opportunity to reflect more on what citizenship means from a lived experience perspective and to revisit the 5Rs, especially as the concept mapping had seven items. For example, one area of interest is the theme of world stewardship, as this suggests the importance of being connected to something bigger than themselves and the world in general. This has implications for future citizenship as technology creates a supra-national opportunity and communities of interest can span international borders.

Whilst concept mapping is useful in developing categories of citizenship, it does not allow for in-depth exploration or description (MacIntyre et al. 2021). For example, whilst people were recruited from diverse backgrounds (in Rowe et al. 2012) it was not clear that there was an explicit focus on barriers to citizenship people experienced due to structural inequalities such as sexism, poverty, and racism, alongside their experience of mental health challenges. In fact, this is a limitation across the mental health citizenship literature in that there is little

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focus on intersectionality within the research, despite there being an acknowledgement and recommendations to work to promote citizenship in alignment with other disadvantaged groups and having a vision of mental health services that understands the barriers of racism, disability, and poverty (Rowe and Davidson 2016). However, at this juncture this does not appear to be a priority in understanding citizenship. A more critical perspective of citizenship, such as feminist perspectives (Lister 2007) or 'acts of citizenship' (Isin and Nielsen 2008) may have enabled a greater focus on this.

MacIntyre et al. (2021) sought to overcome some of the limitations of concept mapping by having additional focus groups to explore people's experience of citizenship in depth (Cogan et al. 2021). Macintyre et al. (2021) argue that they make an original contribution by clearly illustrating the practical application of citizenship whilst highlighting the interplay between relational and structural aspects of citizenship and acknowledging the barriers marginalised groups face in claiming citizenship rights. Alongside Eiroa-Orosa and Rowe (2017) they call for a top-down, bottom-up approach for policy makers to set goals to contribute to the social inclusion of those who have experience of major life disruptions. Lived experience and partnership working should be present in all elements of developing this approach across research, social policy, and its implementation (as was the case in their research). Thus, people with mental health challenges are participating as citizens in defining and changing citizenship through research. This seems fundamental in a truly citizenship informed approach.

Using the focus groups, and the richness of understanding this brings, Cogan et al. (2021) identified that a sense of belonging underpins all the elements of citizenship they identified. These elements are as follows:

- building relationships
- acceptance and autonomy
- access to services and support
- shared values and social roles
- civic rights and responsibilities

They view belonging as being inextricably linked to participation, as people are less likely to participate if they feel discriminated against or marginalised and then in turn are less likely to feel that they belong (Cogan et al. 2021). This is echoed by Harper et al. (2017) who argue that people's sense of belonging was driven by the desire to contribute something or give something back to others and this was important as part of feeling valued within their community. O'Connell et al. (2017) found that there was a strong relationship between the levels of satisfaction people had with their relationships and activities and their sense of citizenship. This highlights the importance of belonging and participation as core concepts in citizenship for people with mental health challenges. It also brings to the fore the importance of communities that are welcoming and support people's participation.

# 6.2.2 Measuring Citizenship

MacIntyre et al. (2021) acknowledge there are challenges in even trying to define citizenship, as by providing a definition it means that there will be people who are included or left out of that definition. For example, within their study having a shared language was seen as one of the items around civic responsibilities, but this potentially excludes migrants, refugees or asylum seekers being recognised as citizens in this context.

However, to evidence the impact of interventions, for people to be able to identify the areas of their life that may need additional support, it has been important to develop measures of citizenship. The focus of this PhD is not around developing measures, so there will not be an analysis of the measures here, but it is worth acknowledging some of the challenges of developing a measure to inform our later discussions when it comes to implementing changes to promote citizenship.

Two citizenship measures have been developed. The first is the Citizenship Measure, which was developed in the United States (O'Connell et al. 2017) and had a cultural adaptation for Norway (Nesse et al. 2022). This was based on the definitions of citizenship through the CBPR research undertaken by Rowe et al.

(2012). The second is the Strathcylde Citizenship Measure (Cogan et al. 2022), which was developed for the Scottish context and based on the concept mapping of Cogan et al. (2021) and MacIntyre et al. (2022) (which was also informed by the work of Rowe). Largely, the focus of this research has been establishing the psychometric validity of the measure in comparison to the existing measures of quality of life, wellbeing, and Recovery (Pelletier et al. 2015; O'Connell et al. 2017; Nesse et al. 2022). It has also been used to explore the relationship between wellbeing and citizenship in the general population (Georghiades & Eiroa-Orosa 2020).

One issue is the challenge of measuring citizenship when it is framed as the relationship between the state and the individual, as it raises the following questions: Is it desirable for people to trust the government if the government are not trustworthy? What if your experience of government institutions is a negative one due to racism? O'Connell et al (2017) also found that those who had been incarcerated had lower scores on trust of government and supportive infrastructure, therefore people who have accessed the criminal justice system are likely to be further excluded. The sampling within this study included a significant number of people from diverse ethnic backgrounds, so racism may also have played a significant role. Therefore, this again is a further consideration when looking at what and how citizenship is being measured and defined. Cogan et al. (2022) identify the importance of testing validity across a range of diverse populations.

Another key challenge is developing a measure that is focused on individual outcomes when there is an increasing focus on collective citizenship (Quinn et al. 2020) and utilising the social model of disability to support citizenship (Hamer et al. 2017). This raises the question: should there be measures of how inclusive communities are of people with mental health challenges? Interestingly, Wong et al. (2023) undertook a telephone survey in Hong Kong (n=1000) of people in the general population's attitudes to 'Recovering Citizenship' (Rowe and Davidson 2016). They used an adaption of Citizen Measure (O'Connell et al. 2017) to frame their questions. Their findings were

that generally the participants had a good knowledge of mental illness but that there was a need to improve people's understanding of Recovery and citizenship and humanistic approaches to people with mental health challenges. Fear was a barrier to accepting people with mental health challenges undertaking roles and responsibilities within the community. It would be useful to replicate this study in English speaking contexts to work alongside the development of individual measures to increase the understanding of the complexities of implementing citizenship approaches. Whilst the study of Wong et al. (2023) was undertaken amongst the Cantonese speaking population of Hong Kong, it could be surmised that there could be a similar cause in the experience of people with mental health challenges who are on the receiving end of people's lack of understanding, which is described in the next section.

## 6.3 Exclusion and Conditional Citizenship

One of the key discussions in the research was that some people's experience of citizenship was being excluded and some people described not being able to be a citizen at all (Hamer et al. 2014). Pelletier et al. (2017) found, as part of their *Projet Citoyen*, when trialling the citizenship measure with people with mental health challenges in Quebec that the lowest area of scoring was community participation and that their reasons for not engaging in their communities was due to their experience of stigma and discrimination. These exclusions are experienced across a range of domains: employment, housing, parenting, relationships, and health care. For example: not being asked to parties or being part of babysitting circles; having their children taken into care; not being offered work; or healthcare professionals' attitudes to physical health conditions (Hamer et al. 2014). This exclusion can start taking place from an early age, resulting in absent or delayed development of citizenship (Hamer and Finlayson, 2015; Vervliet et al. 2019):

"That's what the big problem is: some people get no opportunities in their developmental process because of stigma or bullying. That's terrible, but society pays no attention. It starts in school already: everything according to the standards and you have to be fast enough to follow. If you can't follow, you're out." (Man with mental health problems and a history of drug dependence, 34 years old) (Vervliet et al. 2019 p897).

Eiroa-Orosa, and Tormo-Clemente (2022), in their study analysing the impact of the Covid 19 pandemic on rights and citizenship for people with mental health challenges, state "*digital divide is wreaking havoc*" (p10) in further exacerbating some people's experience of citizenship. Particularly if they did not have access to technology or did not understand how to use it. This is an important finding for this study and will be interesting to explore whether the participants had a similar experience or pick up on similar concerns.

People describe not sharing their mental health status for fear of being judged or disadvantaged e.g., when applying for work (Hamer et al. 2014). This was even more keenly felt by those who had forensic histories (Cogan et al. 2021). This then creates a vicious circle where being socially excluded leads to isolation and this sense of ostracization leads to self-isolation. Associated with this are feelings of guilt, shame and being judged, which leads to further selfisolation and increases the feeling of being on the outside of society (Cogan et al. 2021; Eiroa-Orosa, and Tormo-Clemente 2022).

Even those who had been purposively sampled as successful in participating in their communities describe this internalised self-stigma; for example, feeling they are not qualified to vote or not knowing enough about who to vote for (Harper et al. 2017). People described feeling like second class citizens; once you have been labelled with mental health challenges people assume you have nothing to offer. Participants describe how this leads to self-stigma:

"The media are telling you that you can't because you have mental health (problems), you will actually soon identify with it because you are told, and you get it from the media, Government and the general public and probably health professionals who will say 'you can't do that'." Michael (Cogan et al. 2021, p361) Hamer et al. (2017) argue that those with mental health challenges have a unique experience in how they are treated due to their health status. People are not treated in society like others who have health conditions, as people's needs are not accommodated through reasonable adjustments (Hamer et al. 2017). When considering future citizenship, it will be important to consider the role of labelling and self-stigma as well as the external discrimination people experience across their lifespan. As well as the 'digital divide' and how this can drive exclusion, it will also be important to explore how technology may reinforce discriminatory views of people with mental health challenges or may be able to mediate against them.

# 6.4 Risk, Dangerousness, and the Mental Health Act

The relationship with exclusion and perceptions of dangerousness due to mental health status are inextricably linked. Once you are labelled with mental health challenges you are excluded, you are seen as different, dangerous, not effective and not to be trusted (Hamer 2012; Hamer et al. 2014; Hamer and Finlayson 2015; Hamer et al. 2017; Harper et al. 2017; Hamer et al. 2019; Vervliet et al. 2019; Cogan et al. 2021).

On a societal level the sense of dangerousness and difference are also reinforced by media portrayals of mental health challenges (Cogan et al. 2021) and by punitive mental health legislation (Eiroa-Orosa and Rowe 2017; Brannelly 2018a). People's experience of exclusion is compounded when they are detained under the Mental Health Act, removed from society and subject to coercive treatment (Hamer et al. 2014; Hamer and Finlayson 2015; Brannelly 2018a; Brekke et al. 2021). When clinicians put a biomedical lens on people's experience of citizenship, viewing a person's actions solely as symptoms of an illness, they then deny a person's agency or their experience of trauma. For example, when domestic violence is viewed not as a social and psychological trauma but through the symptoms of mental illness (Hamer et al. 2014). It is practices such as these that mean mental health services unwittingly reinforce stigma and discrimination (Hamer et al. 2014; Hamer and Finlayson 2015).

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Brekke et al. (2021), in their co-produced study examining the experience of people accessing the Flexible Assertive Community Treatment Team, found that whilst the team had a more informal approach which people valued, as the team were part of an authoritarian structure which could use coercive approaches, this put limits on people feeling they had a voice and choice.

Even when acting with the best intentions, services offering care view their clients as vulnerable and fail to identify their strengths and own resources (Vervliet et al. 2019). Furthermore, they deny people a role in their own decision-making, which further alienates people. As services become more paternalistic, people become more dependant and start to lose their own agency (Hamer and Finlayson 2015). Hamer and Finlayson (2015) describe how people once labelled then internalise this stigma and feel a sense of guilt and shame. Hamer et al. (2017), describe a vicious circle of people being regarded as a "dangerous other", which reduces their personal power, which perpetuates the symptoms of their mental health challenges leading to a 'collapse in their personal agency" [p3-4]

This means there are implications for citizenship not just in people's access to their communities but also how we understand and conceptualise people's mental health challenges and operationalise mental health services. If mental health services are to adopt a citizenship approach, as recommended by Davidson and Rowe (2016), it requires a realignment of the biomedical model within mental health services and a re-examination of mental health legislation to be more compatible with inclusive approaches to citizenship (Brannelly 2018a). This is one of the key themes for the future of psychiatry (Giacco et al. 2017; Priebe et al. 2019).

# 6.5 Experiences of Inclusion and Participatory Citizenship

The lived experience accounts identified from the literature do not solely focus on exclusion but also describe what society can be like and is like when people feel included as citizens. Hamer and Finlayson (2015) acknowledge that living in a country such as New Zealand already provides a degree of security and stability which affords a degree of citizenship. However, this is described as 'floor level' rights and that people with mental health challenges should have full access to the same rights as others. This sense of the corner stones of citizenship also comes through some of the concept mapping that has been undertaken and emphasises the importance of civic and legal rights and of access to support and services (Rowe et al. 2012; MacIntyre et al. 2021.) This cultural context is important when considering citizenship (Eiroa-Orosa and Rowe 2017): for example, countries such as Scotland (MacIntyre et al. 2021) and Norway (Nesse et al. 2022) are seen as places with a progressive approach to welfare and public health messages are likely to have public support, whereas in the United States there is a greater mix of public and private provision with public services having limited resources compared to the private and there is little public expectation or support for comprehensive welfare support. Politically, England is somewhere between the socially progressive attitudes in Norway and Scotland and the more individualistic one of the US.

## 6.5.1 Active Participation and Reasonable Adjustments

Hamer et al. (2017) identified that when people are engaged in meaningful activities this can lead to people feeling included and being "*part of something bigger than yourself*" [p82]: an example given was a knitting circle. When people are engaged in meaningful occupations, or employment, or volunteering this can be significant in feeling included and overcoming stigma. (Hamer et al. 2014; 2017).

Harper et al. (2017)'s study explored what contributed to those with severe mental illness who had successful community inclusion and participation. They concluded that it was useful to understand inclusion and participatory citizenship as a dynamic process working across macro, meso and micro levels. On a macro level, civic participation is described as being involved in activism or being aware of national and international events; at a meso level (immediate/neighbourhood), the importance of contact with neighbours and being seen as something other than someone with a mental health diagnosis, for example, the dog walker; and the micro level (intimate relationships) related to the importance of having close intimate family or friend relationships. This highlights the importance of these mutual and reciprocal relationships (Hamer et al. 2017; Brekke et al. 2021; Cogan et al. 2022).

MacIntyre et al. (2021) found some key distinctions between those with life disruptions and those without. Those with mental health challenges or life disruptions put a greater weight on the importance of relationship, wanting to repair and build relationships and having relationships with people who had similar experiences. It is important to note that across the studies these experiences of inclusion were not easily achievable for people. Many still had their primary relationships with people within mental health services; this maybe because people feel more accepted by peers (Cogan et al. 2021) or it may be due to experiencing micro-aggressions and/or feeling excluded from mainstream places (Harper et al. 2017; Brekke et al. 2021). In addition, people described difficulties with isolation and trusting others, due to previous experiences of abuse. Again, this was not straightforward as a number of these relationships were or had been strained due to substance use or the impact of mental health problems (Harper et al. 2017; Brekke et al. 2021). One participant in Hamer et al. (2014) describes having personal therapy to address childhood sexual abuse and how this helped with her sense of integration with herself and subsequently feeling integrated as a person was empowering as a citizen. This highlights the importance that mental health treatments and relational approaches can play in people's sense of citizenship. So rather than a citizenship approach abandoning traditional approaches to mental health treatment there needs to be a more fundamental shift in power from medical to social or trauma informed approaches.

It is also worth noting that the research in this area was largely focused on the experience of white people (Hamer et al. 2017; MacIntyre et al. 2021) and in the case of Harper et al. (2017), whilst the research was conducted in an ethnically diverse area, most participants were white and male (Harper et al. 2017). In Harper et al. (2017)'s study this may have been due to selection bias as

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participants were recommended as people who had made strides in being included in their communities. Alternatively, it could have been women and people of colour were not being included due to the impact of the intersection of gender and race leading to further exclusion and therefore a greater struggle to feel part of the community. This highlights the importance of understanding intersectionality as an approach to citizenship and not drawing broad conclusions from the limited sample size.

Nesse et al. (2021), when examining the value of the Citizenship Measure, specifically examined people's engagement in meaningful activities and found those who scored highly on 'caring for others' and 'community participation' correlated with positive Recovery and Quality of Life scores. Danielsen et al (2021), in their small-scale study of people with mental health challenges who had also experienced long-term institutionalisation, also illustrated this. They found that participating in an activity class had multiple knock-on impacts that increased people's sense of citizenship. This suggests that meaningful occupation and community participation plays a significant role in people's sense of citizenship.

Using an Occupational Science lens Hamer et al. (2017) applied an additional layer of analysis to their research and described the notion of *homo occupacio*, which is the persona of the citizen as a self-directed, self-initiated occupational human who takes possession of his or her world through a repertoire of occupations (occupations in this context mean activities) located within the rules and norms of society. However, those diagnosed with mental health challenges have this sense of self-determination undermined by the conditional nature of their citizenship (Hamer and Finlayson 2015). Having agency and defined roles can support engagement with relationships and wider participation as a citizen (Cogan et al. 2022).

Participants within Hamer et al. (2017) describe how when reasonable adjustments are made this can facilitate participation in employment. They also caution against the weight given to employment as a form of inclusion, due to the challenging and precarious nature of work within neoliberal societies. Hamer et al. (2017) join Beresford et al. (2010) in calling for an exploration of a social model of madness, which moves away from a biomedical individualist way of understanding mental health challenges to one that locates the importance of societal change in terms of attitudes and support. The consequences of this for future citizenship could be numerous, as technology could support the social model by offering innovative approaches to reasonable adjustments not just in employment but across education and leisure activities. It could also be used to develop sophisticated anti-stigma campaigns. Equally, technology could maintain existing power structures, further entrench the medical model, and increase the surveillance of people with mental health challenges and impact on people's human rights. Therefore, people with lived experience having a say or a voice needs to be a key part of citizenship.

#### 6.5.2 Self-Advocacy and Having a Voice

Personal agency is seen to be a key part of citizenship and part of that being able to disrupt existing norms through your own actions (Vervliet et al. 2019). Being open about your mental health challenges is seen as a practice of inclusion, which generates new opportunities (Hamer et al. 2014). Harper et al. (2017) recommend people accessing mental health services to be trained in advocacy skills, particularly skills outside of mental health so that people have a broader sense of agency. These forms of inclusion link back to this sense of belonging and being able to offer something back to society (MacIntyre et al. 2021). This discussion between affecting change and how we balance societal change and personal change, is addressed by Quinn et al. (2020), who share a case study of the FACE project, a user-led initiative for community development, which was initiated and supported by staff but was user-led. Through this study they wanted to understand the meaning and activities of collective citizenship. The core themes were mutual help, defining shared purpose, and collective action.

Quinn et al. (2020) argue that marginalised people must exercise their citizenship by acting collectively to address their marginalisation, negative

stereotyping, stigma, and discrimination and promoting the dignity and rights of people who have experienced marginalisation. The key learning from this paper is how professionals can support collective citizenship independently from services. It also calls for people with lived experience to take up the research challenge and development of this work. Reis et al. (2022) extend this discussion by describing a series of webinars entitled 'Citizenship, Social Justice and Collective Empowerment: living outside mental illness', how people with lived experience of mental health challenges have used the 5Rs citizenship framework to empower themselves to act collectively and develop their sense of citizenship. Reis et al. (2022) call for people with lived experience of mental health challenges of mental health challenges and participating in community connections to lead the teaching on this subject.

Whilst not discussed in relation to the findings in Quinn et al. (2020) or Reis et al. (2022), this community level approach has a lot in common with 'acts of citizenship', where individuals and communities enact their citizenship by creating ruptures to the norms. The FACE project itself could be seen as an 'act of citizenship' which could be a more empowering way of discussing citizenship with services users. As well as having a voice themselves people with mental health challenges also call for solidarity and support from mental health professionals in promoting their citizenship.

## 6.5.3 Allyship and the Role of Mental Health Professionals

Brannelly (2018a) and Hamer and Finlayson (2015) describe the importance of the allyship of mental health professionals in changing the culture of mental health services and this being important to people with lived experience, especially as mental health professionals are seen as those with power. However, allyship is a nuanced concept, and needs to be understood within the wider political context and the power dynamics in place. It is not enough to create space for people to have a voice, but rather being transparent about motivations and agendas and co-creating a shared commitment to change which seeks to structurally change these dynamics. If it does not do this, it can become another neoliberal 'technology' which colonises people's experience and locates problems and solutions within individuals (Russo et al. 2018). The extent to which a service upholds people's rights as citizens depends on the culture within the service or organisation. Brannelly (2018a) questions the lack of progress made in promoting people's rights and why people experience a lack of care within psychiatric services. There is a call within the research reviewed for the use of 'acts of citizenship' by mental health professionals to rupture and subvert practices to facilitate more inclusive citizenship-focused approaches (Hamer et al. 2017; Hamer et al. 2019).

Service users describe it as the small things that matter; when staff go above and beyond basic expectations it makes people feel human, like they matter; for example, getting a bus pass for someone. It can also be staff upholding people's rights which again can help people feel like citizens (Hamer et al. 2014; Hamer and Finlayson, 2015). This says something about the culture of mental health services in themselves that basic support to get a bus pass is seen as going above and beyond and may indicate the scale of the challenge within mental health services to implement citizenship-based approaches. Hamer et al. (2019) collaborated with Michael Rowe in the US and used the frame of 'acts of citizenship' to explore how mental health staff can facilitate citizenship. The findings mirror those in her previous articles (Hamer, 2012; Hamer et al. 2014) where she explored staff's views alongside those of people accessing the service. Their findings were that mental health professionals try to subvert the existing structures to promote citizenship, highlighting the importance of the idea of rupture of social norms as an 'act of citizenship'. These studies were undertaken with staff who had an interest in citizenship. At times they describe being criticised by colleagues for being too friendly or not having clear enough boundaries, and this has implications for staff attitudes to citizenship and their values linked to upholding people's rights. In Hamer et al. (2017) a clinician talked about social justice as a frame for his approach to offering support and discussing clients with colleagues. This is picked up by the authors who call for a rights-based approach to mental health that makes citizenship a priority; they suggest there is a need for a citizenship framework to

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support the engagement of all stakeholders, people who access services, their supporters, staff, and the wider community( Rowe and Davidson 2016; Carr and Ponce, 2022;). Eiroa-Orosa (2023) is developing a RCT of co-produced citizenship training for mental health professionals, with the aim of changing professional's attitudes, beliefs, and behaviours to be more Rights focused. Nesse et al. (2021) found when analysing the Citizenship Measure it co-related with Quality of Life and Recovery measures; they argue for mental health services a focus on citizenship should be the foundation, from which people can build their Recovery. This is important for the future development of mental health services as it encourages a shift away from the treat and recover model to supporting the conditions for recovery and fostering a sense of belonging, participation, and meaningful activity as a cornerstone to recovery. Nesse et al. (2021) identify that being valued as part of a community is key and that the reciprocity of being able to contribute is important in being a citizen, again a culture shift from the mental health patient being solely in receipt of services to being an active citizen. Whilst Nesse et al. (2021) focus on the importance of meaningful occupation, this study does not analyse the political dimensions of citizenship and impact of discrimination. Brekke et al. (2021) pick up on this and identify the importance of mental health services having a greater focus on tackling some of the structural inequalities and community access to support participation.

Carr and Ponce (2022) argue that mental health professionals should leverage their privileged position by integrating the concepts of recovery and citizenship so that this can create mental health services that promote social justice. They see this as a way of tackling the stigma and discrimination that people experience externally and within mental health services and of addressing inequalities such as people's physical health as people with mental health challenges are more likely to die earlier, less likely to be in employment and are more likely to be in poverty. They call on mental health leaders to promote those with lived experience to become leaders, have a role in education and promote social change. Davidson and Rowe (2016) view citizenship as the route to add social context to Recovery and connect it back to its radical survivor-lead roots.

# 6.6 Barriers to Implementing Citizenship Approaches within Mental Health Services

However, despite these calls for citizenship approaches to be embedded in mental health services, there are considerable challenges in implementing them (Ponce et al 2016; Clayton et al 2020; Flanagan et al. 2023). At an organisational level, Flanagan et al. (2023), in their attempt to implement a 'Recovering Citizenship' (Davidson and Rowe 2016) approach across a range of mental health and addiction services through the state of Connecticut found that training staff was not sufficient in implementing the desired change. Through the establishment of their learning collaborative, they identified that there were significant systemic barriers which required commitment from the highest levels leadership within the organisations, organisational readiness, and tools to provide structure and accountability in implementing organisational change. Interestingly, they viewed Recovery orientation as a foundation for organisational readiness.

From a workforce level when looking at staffs' interest in engaging in citizenship interventions or measures there were also problems. Although there was interest in using citizenship as a framework, there were concerns that in a high paced risk-focused that it was too time consuming (Clayton et al. 2020) or that they were unsure how to implement citizenship approaches in practice within the current context (Ponce et al 2016; Bellamy et al. 2017; Clayton et al. 2020). Staff felt that they had limited power to tackle some of the structural barriers that their clients faced, such as poverty, discrimination (specifically in relation to employment and housing), their clients' safety within the communities they are living in, and the relevance of citizenship for clients who were undocumented migrants (Clayton et al. 2020). This raises the question of wider social issues that citizenship touches upon; it cannot be seen in isolation from wider public policies, including access to housing and rights of asylum seekers. These are also concerns promoted in explorations of the future of psychiatry (Preibe et al. 2019; Giacco et al. 2017). These barriers to implementing citizenship

approaches raises the question of what extent is citizenship the core business of mental health services and to what extent is it a wider social policy issue.

# 6.6.1 Do Mental Health Services Have a Future Role in Promoting Citizenship?

Even if there is recognition that citizenship is the core business of mental health services this is problematic due to the role mental health services have in maintaining existing power structures and contributing to the mistreatment people continue to experience, especially as mental health professionals hold the power to detain people and deprive them of their liberty (Brekke et al. 2021). Without reform to the mental health legislation is this even compatible with a citizenship framework?

The implications for future citizenship will need to consider the power relations between mental health providers and people who access services and the role of mental health legislation and will require a radical rethink of what mental health services are and how they operate. Whilst the conflicted role of mental health services is acknowledged (Davidson and Rowe, 2016), and the need to radically redefine them has been identified (Carr and Ponce 2022), it is unlikely significant change will happen anytime soon. In the interim there is a call for action to implement a pragmatic approach which is for mental health services, in partnership with those with lived experience, and in alignment with other marginalised groups (such as anti-racist, and disability and LGBT+ organisations), to implement citizenship approaches (Davidson and Rowe, 2016; Brannelly 2018a; Carr and Ponce 2022). This is not to say that the importance of social policy and public health approaches to mental health are not recognised (Davidson and Rowe 2016). This work is being undertaken currently within Scotland through trying to define social policy based on citizenship to support people with mental health challenges (MacIntyre et al. 2019; 2021).

Nouf and Ineland (2023), identify the tensions within policy rhetoric, organisational and institutional practice, and people's lived experience within

mental health services within the Nordic countries. They argue despite progress, "out-dated mental patient ideologies remain" [p12]. Like the previous findings people's experience of active citizenship is significantly impacted by their relationships with and attitudes of the staff (Hamer et al. 2014; Hamer and Finlayson, 2015). Even when there is a sense of equality the existing hierarchies and policies act as blocks to co-working and sense of justice. They call for a commitment, enforced by policy, for organisations to implement empowerment and involvement programmes for people with lived experience to shape services and for this to be followed by a comprehensive training programme for staff working in services, focusing on staff understanding how to promote citizenship, justice, and rights.

As described earlier Eiroa-Rosa (2023) has established a research programme to develop and evaluate a co-produced training programme for staff working in mental health to promote citizenship and rights, the results of which will be eagerly anticipated. Training for professionals has been identified as a longstanding need (Hamer 2012). Using case studies, Carr and Ponce (2022) compared inpatient and community services and found that community services had greater knowledge of citizenship but lacked knowledge about mental health recovery and inpatient services had the opposite problem. They view the opportunity to share learning between the settings as a way of promoting a rights-based approach to mental health care. Soares et al. (2021), in their study of non-qualified paid caregivers in Brazil, highlight the importance of not just training professionals in citizenship but all agencies involved in supporting people with mental health challenges. They also highlight the importance of offering supervision.

Whilst training and supervision are clearly important it does not address the need for top-down approaches to drive changes which will be needed to be considered for the radical change required (Nouf and Ineland 2023). Cogan et al. (2022) call on leaders to use the 5Rs approach to citizenship to operate on micro, meso and macro-opportunities to generate novel approaches to innovate

and promote social justice. The macro-approaches also include consideration of wider societal change.

# 6.7 Community Action and Participation

The discussion between effecting change and how we balance societal change and personal change, is addressed by Quinn et al. (2020). They argue that marginalised people, including people with mental health problems, must exercise their citizenship by acting collectively to address their marginalisation and be supported to do so. Quinn et al. (2020) state that collective citizenship is not separate from individualised understandings of citizenship, complements 5Rs and is a development of the community participation work in the original RCT (Clayton et al. 2013). They argue community participation should be extended as part of the repertoire of interventions.

Reis et al. (2022) call for people with lived experience of mental health challenges participating in community connections to lead the teaching on this subject. They draw out the tension of 'recovering citizenship' and how this still focuses on the individual experience whereas collective citizenship embraces this tension, through focusing on social mobilization and political engagement in and outside mental health services. They describe the role of peer support, advocacy, art, and collective action (FACE Project) through various projects as being key in transforming people's experience of citizenship and stress the importance of solidarity with other marginalised groups. They give the example of Witness to Hunger, a poverty action group bringing mental health activists and other community activists together. There is an overtly political nature to this approach and assert that, by talking about mental health challenges and making mental health visible, this is a political act in itself, claiming public space and visibility. Reis et al. (2022) identify two key elements that they identify as being important to the success of participatory citizenship projects and these are:

• legally institutionalised rights to autonomy and dignity of persons.

- close relationships of love and friendship.
- networks of solidarity and shared values based on the worth of the contributions of the participants.

It is interesting how in mental health services this autonomy and dignity is often denied and when detained under the Mental Health Act those legal rights are taken away. For citizenship to gain prominence in the future there will need to be specific action regarding mental health legislation. In my experience close relationships, shared values and solidarity are also key factors in implementing co-productive approaches, raising the question of whether co-production is a citizenship intervention in itself. This theme will be picked up through the rest of this study. One clear gap within this literature is the lack of focus on technology and digital citizenship. It is to digital citizenship that we turn next.

# Chapter 7: Digital Citizenship

How does exploring digital citizenship help us approach the impact of technology on future citizenship for people with mental health challenges?

Like the concept of citizenship, digital citizenship is contested (Choi 2016; Isin and Ruppert, 2020). Interestingly, much of the discussion about digital citizenship has taken place separately from the social, political and economic struggles explored through the conceptualisation of citizenship in the non-digital world (Emejulu and McGregor 2019). Therefore, this section will critically analyse the literature exploring different conceptualisations of citizenship, considering the impact of digital citizenship in general and then specifically examine the impact of technology on future citizenship for people with mental health challenges.

# 7.1 Conceptualising Digital Citizenship

Choi (2016), Jørring et al. (2018), Chen et al. (2021) all undertook literature reviews exploring how digital citizenship had been conceptualised in different research arenas. There are multiple ways of conceptualising digital citizenship, due to differing perspectives. It is important not just to understand the impact of digital citizenship but also how it is being understood as a concept, as this will enable us to pose relevant questions about mental health and digital citizenship. It is also worth noting that discussions on mental health do not feature in these literature reviews (Choi, 2016, Jørring et al. 2018, Chen et al. 2021). Therefore, it will be important to understand the key themes within the digital citizenship literature and explore the potential implications for people with mental health challenges.

There are three different theoretical approaches to the definitions of digital citizenship (Chen et al. 2021; Jørring et al. 2018). These are: the 'conditional' approach of Mossberger et al. (2007); the 'normative' approach, which is based largely within Digital Citizenship education, on the work of Ribble (2015) and

Choi (2016), which describes the ideal way to behave online and can be used to discuss the moral and ethical dilemmas of engagement in a digital realm; and the 'critical' approach of Isin and Ruppert (2020):

# 7.2 'Conditional' Digital Citizenship

The concept of digital citizenship emerged in the mid-late 2000s (Mossberger et al. 2007). This primary definition was of someone who uses the internet effectively and regularly and can participate responsibly within the social norms of what are expected within the digital space. Mossberger et al. (2007) saw digital citizenship as an opportunity for greater democratic engagement by citizens who were able to access the internet. Through their work on digital citizenship, they were seeking to understand the 'digital divide', who is and who is not able to access the technology and the reasons why. Within this conceptualisation, digital inclusion is almost always unquestioningly promoted as a good thing (Isin and Ruppert 2020; Jæger 2021). Digital exclusion initially focused on access to equipment and then grew into exploring people's technical knowledge and their motivation to engage in technology. Mossberger's definition has a lot in common with Marshall's description of citizenship in that it is conditional. In return for participating within certain norms you are granted the 'benefits' of digital citizenship (Jaegar, 2021). The value of the conditional approach is that it can be useful to explore who has access to digital citizenship and the impact of social, economic, demographic and ethnic factors that can impact on digital participation (Jørring et al. 2018). This can be useful in understanding the access (or lack of) people with mental health challenges have to this form of digital citizenship.

### 7.3 'Normative' Digital Citizenship

The normative approach, as described by Jørring et al. (2018), grew out of the education field and is concerned with the norms of behaviour that are seen as appropriate and are aligned with responsible technology usage. Its focus is particularly on digital citizenship in relation to the education of young people

(Ribble 2015). Choi (2016) identified four key elements within the concept mapping that are seen as important in educating young people on digital citizenship, as young people experience mental health problems and also, as demonstrated further in the literature review, people with mental health challenges often feel the process of being left behind as citizens starting at an early age (Vervliet et al. 2019). Choi describes the following four concepts:

- Media and information literacy Digital access, psychological capability, technical skills
- Participation/Engagement Political, economic, cultural engagement, personalised participation
- **Critical resistance** Critique of existing power structures and political activism
- **Ethics** Digital responsibilities and rights, ethical use of technology, digital ethics

However, this analysis has been criticised for lacking academic rigour, due to the narrowness of the literature search (only focusing on education, not the wider social sciences), and the lack of critique of the analytic positions of those defining digital citizenship within the literature (Jørring et al. 2018).

Jørring et al. (2018) question the robustness of the four categories, claiming Choi does not engage in discussing the tension between them; for example, who defines what critical resistance is acceptable and how this relates to participation and engagement? Whilst not acknowledging the criticisms in Jørring et al.s' paper Choi and Cristol (2021) recognise the limitations of their 2016 review. Through the impact of the Covid-19 pandemic and Black Lives Matters movement in 2020, Choi and Cristol (2021) argue that these societal events have laid bare inequalities in society and therefore a radical critical approach is needed for digital citizenship. They examine the work of Emejulu and McGregor (2019) who call for an intersectional approach to digital citizenship, and argue that this should form a key part of educating young people in becoming digital citizens. Choi and Cristol (2021) acknowledge that whilst the 'normative approach' identifies the ethical and social inequalities within digital citizenship, it does not put them as central in understanding digital citizenship in the same way as a radical critical approach does. Chen et al. (2021) identify that critical approaches are particularly absent from digital citizenship education. This is potentially problematic for people with mental health challenges and other marginalised groups as it can reinforce social norms and exisiting power structures that act to exclude. Therefore being able to have discussions on digital citizenship and digital citizenship education in the context of mental health and people with mental health challenges is important.

## 7.4 'Critical' Digital Citizenship

The critical approach of Isin and Ruppert (2020) sees the limits of both the normative and conditional approaches to digital citizenship as being too focused on a singular narrow definition of digital citizenship and they do not take into consideration the complexities of citizenship that sit alongside and beyond the digital sphere.

Isin and Ruppert (2020) state that digital citizenship is dynamic and everchanging and that you cannot look at digital citizenship without examining it in the context of the multi-factorial impacts of transnational mobility and migration, the resurgence of nationalism, assertions of sovereignty, internationalisation of capital, decline of social state and the rise of neoliberalism.

Critical theorists do not assume that digital citizenship is a good thing, rather they critique it and examine it in context. This highlights the importance of a critical perspective on digital mental health. In future of psychiatry literature (Harman et al. 2019; Priebe et al. 2019) digital technology is considered as largely neutral rather than political. A key consideration in future citizenship for people with mental health challenges is a critical analysis of whose interest's digital health and wider technological developments are and will be serving: the people who are the end users, or governments or the corporations and their shareholders?
As described earlier in this chapter, Isin and Ruppert (2020) are interested in how individuals and groups of citizens rupture and change the status quo. They see digital citizenship as an extension of 'acts of citizenship' into cyberspace or the online sphere. These acts have legal, performative, and imaginary components, as with off-line citizenship. Digital citizenship should be seen as integrated with offline life and that cultural and social struggles online are no less real than those offline. In fact, as the internet allows digital life to flow over regulatory jurisdictions so do the claims of citizens traverse legal orders in the non-digital world; for example, Isin and Ruppert (2020) describe the role that whistle-blowers and hackers play in rupturing social norms where information is leaked that exposes the actions of those in power (e.g. Panama papers, Snowden). They view this as an 'act of citizenship', whereas hackers and whistle-blowers would be excluded from normative or conditional definitions of citizenship.

Traditional approaches to digital citizenship are often too narrowly focused on privacy and the relationship with the state rather than exploring citizens' own interactions and relationship with the internet (Isin and Ruppert 2020). Through 'acts of citizenship', citizens enact their rights by performing acts online or offline that create rupture and change rather than participate within a framework of rights given to them, thereby promoting the importance of digital activism (Chen et al. 2021). How citizens engage with cyberspace is informed by who shapes the internet.

Some of the key political questions of our age are: Who creates the content? Who legitimises different forms of knowledge? Who shapes the law and regulation? Who owns the growing volumes of data generated by saying and doing things on the Internet? Who has access to it? Who has the right to use it and who has the right to profit from it (Isin and Ruppert 2020)? These questions are all pertinent for people with mental health challenges, especially as the struggle for rights will be ongoing and the role of mental health activists will be important. Choi and Critol (2021) call for an emancipatory approach to digital citizenship education where it becomes an inclusive process through increasing awareness of diversity, exposing inequalities and promoting justice via inclusive digital practices. They call for educators to include the importance of intersectionality of race, gender, class and language. This author would add ability and mental health status to this intersectionality. Choi and Critol (2021) call for an approach where the individual develops a sense of belonging and identity struggles are to be negiotiated online though political participation or active personalised forms of politics. This has strong parallels to what Isin would call 'acts of citzenship' which create rupture and challenges the norms of citizenship.

Emejulu and McGregor (2019) argue that radical digital citizenship goes beyond what they describe as the 'fetishisation' of digital where it is seen as its own element separate to the material world, but like Isin and Ruppert (2020) see digital citizenship as inseparable from the non-digital world; within digital citizenship education there has been a failure to ask, 'Who has power?'. They call for radical approaches to make the invisible visible, including the racist, patriarchal, enslaving capitalist approaches to labour and mineral extraction that disproportionately affects the Global South. They argue for emancipatory social justice practices, using Black Lives Matter (BLM) as an example, promote digital networks as opportunities to expose power structures, resist and seek to create a common good. It is important that the intersectionality with mental health is included in this struggle for rights. It is now important to look at how digital technology is impacting on different spheres of life and on mental health.

## 7.5 The Impact of Digital Technology on Citizenship

To fully explore what future citizenship will consist of it is important to understand the impact of technology on what it means to be a citizen. Technology and the internet have disrupted the traditional relationship between the individual and the state and provided broader opportunities for political engagement. The boundaries of the internet mean that citizens can engage with people across the globe, sharing ideas and making new connections (Choi 2016; Jørring et al. 2018; Isin and Ruppert 2020; Chen et al. 2021; Jæger 2021). The #enoughisenough in response to high school shootings in the US (Jørring 2018) and Black Lives Matter movement internationally (Choi and Cristol 2021), illustrate how citizens can rapidly mobilise politically via social media and how this can transcend regional and national boundaries. This can also include recruitment of vulnerable members of society to extremist international groups such as Islamic State (Choi 2016).

The internet holds within it a paradox that it can be both used to manipulate societies and citizens to control them and at the same time can be a form of social participation that can critique traditional institutions (Choi et al. 2017). This depends on the level of openness and accessibility citizens will have in a given society. In Western democracies there are more opportunities to promote social change than in countries such as Russia and China. There the relationship between cyberspace and the state is stronger, as what can be accessed on the internet is restricted by the state (Isin and Ruppert, 2020). All of this changes what it means to be a citizen and has seen the development of the concept of digital citizenship.

As technology will play an increasingly significant role in the future it is important to explore the role of digital citizenship. Jaegar (2021) highlights public services are pushing people into accessing health and social care and support digitally whether they like it or not. This has been compounded through the covid pandemic where people have had to access their health and social care online (Marmot et al. 2020). If activism is key to driving social change, digital citizenship is integral to mobilise and share communications with a wider audience (Isin and Ruppert 2020; Jaegar 2021). Throughout the discussions within citizenship and mental health there is a focus on community, but this is solely understood as communities of geography. The internet allows for communities of interest that span the globe and in thinking about future citizenship this will also need to be a consideration. The other consideration as digital citizenship comes to prominence is that it may not just be the case of influencing governments, but it is corporations who are responsible for access to the internet and therefore activism and campaigning may need to be aimed at corporations as well as governments. In this study, it was important to involve a digital technology company to gain perspectives on the future impacts of technology on citizenship, in the context of mental health, as there is so little literature exploring this.

Within the literature relating to healthcare and digital citizenship, citizenship is never defined (Jæger 2021). The implications of this are significant considering people with mental health challenges and long-term health conditions are already excluded from participating as full citizens and, if this is not explored, can unwittingly lead to further exclusions within the agencies that are supposed to be providing support.

Jæger (2021) in her content analysis of the academic literature on digital citizenship argues that there has been significant impact on the relationship and interaction between the state and its citizens. Through her comprehensive review of the academic literature, she breaks these impacts down into four key areas. Table 4 considers the areas she identifies and then highlights the potential consequences for citizens with mental health challenges. It is important to recognise that these may not be the primary issues for people with mental health challenges as these have not been explored within mental health citizenship research.

Table 4:	Implications of digital developments (Jæger 2021)
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Key Impact Area of Digital	Implications for people with mental	
Technology:	health challenges:	
Digital Public Service: citizens are	As people with mental health	
being pushed towards being digital	challenges are less likely to be in	
citizens in the way they interact with	employment, they are more likely to	
services for example accessing social	have to access welfare payments and	
care, claiming benefits online. This	therefore forced into using the digital	
raises questions of whether people	space to access benefits and	
should have the right to have digital	therefore subject to the digital divide.	
access (and if so, who should provide	This may then become applicable to	
it?) and conversely whether people	other public services such as wider	
have the right not to engage online.	health and social care support.	
	However, people with mental health	
	challenges are more likely to	
	experience the 'digital divide' (Eiroa-	
	Orosa and Tormo-Clemente 2022)	
Digital Rights and Privacy: Citizens	With the associations with risk and	
are vulnerable to exploitation by	dangerousness for people with	
companies and governments and	mental health problems (Bhungra et	
cyber criminals in exploiting their data	al. 2017) the state, companies, or	
and it appears people seem to	criminals may look to undermine	
acknowledge this and see it as a risk	people's rights and privacy. People	
they are willing to take to participate	could be subject to additional	
on the internet.	surveillance.	
Training and Learning: Education is	Training that includes critical	
one of the areas that has undergone	perspectives that can promote the	
a significant digital transformation	rights of people with mental health	
and digital approaches to citizenship	challenges (and people from other	
are embedded in practice. However,	marginalised groups) could be more	
critical perspectives appear to be	beneficial than training focused on	
largely absent in this sphere of	normative approaches to digital	

development and therefore can	citizenship and reinforcing the status
reinforce existing inequality and	quo, thus entrenching disadvantage.
social injustice.	
Political Engagement: This area is	This is an important area for future
complex and the literature is	citizenship for people with mental
inconclusive as to whether the	health challenges as it will be a
internet increases political	potential key area where people will
engagement or not and if so in what	be seeking to promote messages of
ways.	understanding and inclusion or also
	to protest and take direct action.
It is not clear whether previously non-	
politically active citizens are being	There will be a need to explore the
involved in activism or whether it is	relationship between collective
primarily existing activists who are	citizenship (Quinn et al. 2020) and
being enabled with new technologies.	political engagement and how
	collective citizenship can work in
There are concerns that those who	online spaces rather than solely
are already disadvantaged are less	geographic ones.
likely to be able participate and this	
gap is widening. Alongside this there	
are concerns that the opportunities	
for greater deliberative democracy via	
the internet are being lost due to	
more polarised debates and echo	
chambers.	
Jæger also identifies political	
engagement online provides a more	
opportunities for citizens to mobilise	
and disseminate information but it	
also provides greater opportunities	
for State surveillance and oppression.	

# Chapter 8: An Overview of the Literature Review, Future Citizenship for People with Mental Health Challenges

From the experience of citizenship of people with mental health challenges it is clear people encounter negativity and exclusion. A number of these experiences overlap with the changes that have been identified in the mental health Future Studies literature, reducing the role of coercion and punitive mental health practices and legislation, and improving the social conditions that impacts people's experience. This highlights the importance of synthesising the different elements of the literature review to examine future citizenship. It is notable that, other than Morgan et al. (2020) digital citizenship is not discussed within the mental health citizenship literature. Eiroa-Orosa and Tormo-Clemente (2022) do explore the role of the Covid 19 pandemic and describe the impact of "forced digitalisation" and the "digital divide". However, they do not provide in-depth analysis on this topic but rather raise it as an area of concern. Digital citizenship maybe missing from the wider literature as people with mental health challenges are more likely to be digitally excluded or because participants in the various studies did not view it as important. However, in the digital citizenship literature there are clear impacts for people with mental health challenges regarding digital rights and privacy, training and learning and political engagement (Jæger 2021). Jaegar (2021) highlights that public services are pushing people into accessing health and social care and support digitally, whether they like it or not, this has been compounded through the Covid 19 pandemic (Marmot et al. 2020; Eiroa-Orosa and Tormo-Clemente 2022). Within mental health Future Studies literature with the emphasis on digital health (Giacco et al. 2017; Priebe et al. 2019; Hariman et al. 2019), this therefore is an important topic for further exploration.

The other consideration as digital citizenship comes to prominence is that it may not just be the case of influencing governments and social policy, but it is corporations who are responsible for access to the internet; therefore, activism and campaigning may need to be aimed at corporations as well as governments. This is why it is important to have a digital technology company participating in this study. However, these considerations may not be those of the participants in this study and it will be important to find out. As socio-cultural context is important (Eiroa-Orosa et al. 2017) and this is the first study to be undertaken in England, it will also be important to explore what citizenship in general means to the participants.

At the nub of the issue is: who defines citizenship and makes claims to knowledge and power; and what influence people have over what defines citizenship? Therefore, this work needs to be seen in its social context and any change needs to be bottom up and top down with those with lived experience playing a key role in any developments, in partnership with communities, services and government (Eiroa-Orosa and Rowe 2017; MacIntyre et al. 2021). There needs to be layers of work to support citizenship on micro, meso and macro levels (Carr and Ponce 2022). There will need to be those that support individuals' sense of themselves as citizens, including access to meaningful occupation (Hamer et al. 2014; Verviet et al. 2017; Nesse et al. 2021), and those that support people to self-advocate to develop skills as citizens and change their own communities (Clayton et al. 2013; Vervliet et al. 2019; Quinn et al. 2020). Mental health professionals and peer workers have a responsibility to work pro-actively to promote citizenship and, potentially, mental health services working within a citizenship orientated model with citizenship being the starting point of care not the end point (Davidson et al. 2021). This includes challenging and ending restrictive and coercive practices (Brannelly, 2018a). If citizenship is going to succeed in driving change where Recovery has stalled it will need to avoid the same pitfalls. It will need to directly engage politically with the neoliberalisation of healthcare, whether that is through 'acts of citizenship' (Isin and Neilsen, 2008) or 'collective citizenship' (Quinn et al. 2020). Both concepts appear to be interlinked but as the work around collective citizenship has grown out of the work of the 5Rs, there is a focus on exploring the interplay between individual and collective citizenship in that context (Reiss et al. 2022). This political engagement involves considering the very future of mental health services as they exist and whether they become fully peer-led,

have a role to challenge poverty and discrimination and raise the question of what role mental health professionals will have (Priebe et al. 2019).

The literature would suggest that if citizenship is going to be taken forward there needs to be a radical rethink of mental health services. If citizenship is to be prioritised this will require a different focus: on communities, social justice and empowerment, which will mean there is a shift in tasks that staff are asked to do. There will need to be a change within society and how society understands mental health challenges, alongside an understanding of intersectionality, and approaches to address poverty, housing, and employment as well as discrimination such as racism, sexism, homophobia, transphobia, and ableism. This is why social policy and political action must play a key role in any citizenship-based transformation. If activism is key to driving social change, digital citizenship is going to be integral (Isin and Ruppert 2020; Jaegar 2021). The other aspect to note is that throughout the citizenship and mental health discussion there is a focus on community, but this is solely understood as communities of geography. The internet allows for communities of interest that span the globe and in thinking about future citizenship, this will also need to be a consideration. It will be interesting to explore whether participants in this study highlight the same experiences and issues and to what extent their considerations are local or global.

Rowe and Davidson (2016) and Davidson et al. (2021) see citizenship as a key guiding concept within mental health care delivery. However, as seen from the perspectives of staff, this will be challenging within the existing demands and expectations on services and context within which they are delivered (Flanagan et al. 2023). Quinn et al. (2020)'s findings also raise the question as to what extent people should be empowered or empower themselves and the extent to which mental health services are placed to do this, especially as mental health services have been one of the barriers in enabling citizenship (Rowe and Davidson, 2016; Hamer et al. 2017; Brannelly 2018a; Brekke et al. 2021). Whilst Rowe and Davidson (2016) acknowledge this contradiction, they still assert that creating a rights-based citizen-focused approach to mental health

care can lead to culture change within mental health services and within communities.

Davidson et al. (2021) state that, pragmatically, mental health services need to do their best to reform in line with citizenship principles and therefore will need citizenship interventions. If mental health services are to have a role in promoting citizenship now and in the future, there needs to be robust evidence in terms of interventions. Whilst citizenship interventions have clear benefits (Clayton et al. 2013) they have not been replicated and there is a real need for further RCTs or at least other robust evidence to demonstrate their effectiveness. Citizenship interventions should address both community development, reasonable adjustments (in line with the social model of disability) and collective and individual responses to be congruent with the findings in the literature.

The 'acts of citizenship' approach would allow for that as there is a focus on acts that rupture and force change (Isin and Ruppert 2020). Within the citizenship literature there is an exploration of the immediate future seeking to influence the direction of social policy (MacIntyre et al. 2021) or the direction of the approach and theoretical underpinnings of services (Davidson et al. 2021; Flanagan et al. 2023) but not a longer-term view, as within Future Studies. Isin and Ruppert (2020) state claims for citizenship to be legal, performative and imaginary. This imaginary component will be key in exploring what future inclusive citizenship will look like for people with mental health challenges. These will need to be explored by people with lived experience as part of this study and examined through the findings of this PhD. Before turning to these findings, it is first important to outline the methodology and the co-produced element of the study.

# Chapter 9: Methodology

#### 9.1 Introduction:

The previous chapters have explained the key literature and underpinning concepts that support an understanding of how Future Studies and Citizenship apply to mental health. This chapter will restate the aims and objectives of the research, present the theoretical approach used and describe the application of the methodology in practice. There will also be a reflexive account of the process of co-production within this study. Whilst predominantly written in the third person, the reflective elements will be written in the first person. This integration of description, analysis and reflection is based on the approach of Parr (2015).

Co-production has been chosen as the overarching method and is being used alongside CBPR. The focus of co-production is sharing power with people with lived experience, and this disrupts the traditional approach to research. Coproduction is a relatively new and democratic approach where researchers, those with relevant technical and/or lived experience and/or participants engage in all stages of the design, delivery, and dissemination of research (Hickey et al. 2018; Trevellion et al. 2022). However, co-production is often poorly defined, and the meaningful sharing of power is undermined by existing structural inequalities or an unwillingness to share power (Farr et al. 2021). Co-production has been attempted, as far as possible, within the context of this PhD; however, as described in the introduction, not all elements of this study have been coproduced, hence the title is *Towards Co-production*.

Similarly, CBPR is an approach that equitably involves community members, partners, organisations, and researchers in all aspects of the research process (Kindon et al. 2007). The distinctions between co-production and CBPR will be discussed later in this chapter. Central to CBPR is facilitating empowerment within the community in relation to the research objectives (Baumann et al. 2020); in this case to support citizenship for people with mental health

challenges. Participatory approaches are widely adopted in social research, often having a commitment to social justice by surfacing the inequalities experienced by marginalised groups with the expectation of influencing change through political action (Brannelly 2018b). The key tenet of CBPR is that it is research 'with' rather than 'on' a community and that the community is supported to participate in all elements of the research process (Bergold and Thomas 2012; MacIntyre et al. 2019.) Participatory research facilitates knowledge exchange as part of social value (Edwards and Brannelly 2017). Due to its empowering approach CBPR has been used in existing mental health and citizenship research (Rowe et al. 2012; MacIntryre et al. 2019). Within CBPR the extent of engagement with participants and methods used may vary (Baumann et al. 2020). These principles of participation, democracy and sharing power chime strongly with the key tenets of citizenship for people with mental health challenges, whether this is from participating in research as an 'act of citizenship' (Hamer et al. 2019) or co-producing as part of participatory 'collective citizenship' (Quinn et al. 2020).

One key element of the co-productive approach of this study was the recruitment of peer researchers. MacIntyre et al. (2019) see the involvement of peer researchers as essential to CBPR, as people with lived experience are actively participating in and shaping the research process. Farr et al. (2021) argue paid lived experience researchers are a core component of co-produced research. Funding was secured to provide 180 hours of peer researcher time. Being able to work alongside people with lived experience in the development, delivery, and analysis of the research is fundamental when looking at citizenship and people defining what it means to them. It also strengthens the overall value of the research (Faulkner 2017). However, there is a tension in using a co-produced approach within a PhD, which is largely a solo endeavour, within a strict academic framework (Farr et al. 2021). Due to potential co-option and exploitation, it has been important to work sensitively with the peer researchers in the co-production of the research (Beresford 2019). Therefore, part of this study, is critically exploring the value and possibility of using co-production as a

research method in this context and how this can be achieved (Farr 2018). This is explored both within this chapter and chapter 12.

# 9.2 Research Aims and Objectives

The purpose of this research is to promote action-orientated discussions on creating inclusive future citizenship for people with mental health challenges by focusing on the impact of technology. The rationale for this has been explained in previous chapters. The overall research aim is:

To explore how future developments in technology will impact on citizenship for people with mental health challenges.

Exploring the future provides an opportunity to examine the possibilities and constraints for more inclusive citizenship for people with mental health challenges. It will be vital to work with people with lived experience of mental health challenges and people within the technology industry in generating this knowledge as neither of these groups have previously been brought together to explore the future in relation to mental health. As such, this is a unique and under-explored area and therefore seeks to stimulate discussions around future citizenship for people with mental health challenges and promote inclusivity. In addition, it is hoped that this research will provide new insights into the limitations and benefits of using co-production within a doctorate.

The research objectives for this study are:

- What do participants think are the key factors that will shape citizenship in the future?
- What are the perceived challenges and opportunities for people with mental health challenges in relation to future citizenship?
- To examine the key areas for development to contribute to inclusive future opportunities for citizenship for people with mental health challenges.

• To undertake a critical exploration of the use of co-production and participatory research methods within a PhD.

Inspired by the work undertaken in Feminist Future Studies (Bergman et al. 2014; Gunnarsson-Östling et al. 2012) the focus is not about defining a grand narrative of what inclusive futures for people with mental health challenges should be, but on promoting discussions that open up diverse and pluralistic (even contradictory) approaches to generate new ways of thinking and innovation. Within this PhD these feminist approaches are situated in the broader philosophical frame of critical realism, informed by the work of Parr (2015).

## 9.3 Critical Realism

The philosophical positioning of this research is Critical Realism; a postpositivist approach, concerned with understanding the world through the complex interaction of events, how we experience them, and the causal factors and mechanisms that shape them (Archer et al. 2013). This is important because Critical Realism provides a broader context than a positivist approach as it seeks to understand the complexity of different experiences and the power dynamics in play. It goes beyond the interpretivist approach of solely describing the power imbalance and seeks to bring about change (Parr 2015). Therefore, there is a focus on how to practically drive change, whilst acknowledging structural inequalities. The critical perspective maintains the purpose of research should be discovery and remediation of social problems. The research focus is on action and should address inequalities and bring problems to light, especially those affecting marginalised groups (Kincheloe and McLaren 2000).

Critical and participatory approaches work well together as they both aim to deconstruct power and privilege to develop an emancipatory praxis alongside marginalised communities, such as those with mental health challenges (Canosa et al. 2017). As Critical Realism seeks to bring about change, it lends a

useful frame for action research (Lather 2006). It works well with other qualitative methods such as focus groups, interviews, and workshops that allow for discussion and collaboration (Archer et al. 2016), especially when they are undertaken in ways that avoid discrimination (Mackenzie & Knipe 2006). Critical Realism then becomes both a way of articulating the mechanics of coproduction and a way to critique the process of co-production within this context (Farr 2018).

In exploring future citizenship, mental health and technology, this study explores how human action is socially produced through complex relations between individuals and groups. Bhaskar (1975) argues that reality is made up of the interactions between what is actual (these are events which may or not be experienced), the empirical (what is perceived or experienced by an individual or individuals) and the real (the context within which events are shaped or mechanics that generate events) (Archer et al. 2013; Parr 2015). This provides the opportunity to explore the threats and opportunities for citizenship. This includes questioning which "structures", such as social rules and norms, have causal powers, examining who holds power and where the opportunities lie to challenge power structures (Sayer 2000).

Archer et al. (2016) outline four key concepts as the foundations of critical realist research:

**Ontological Realism:** The ontology of critical realism concerns the existence of a *real* world, whether we have full knowledge of it or not. This means the world cannot be reduced to subjective experience. Equally, with the acknowledgement that reality is not necessarily knowable, the world cannot be reduced to a singular positivist explanation. Ontological realism is concerned not just with the physical world but also social forms and entities. In this study this relates to how citizenship is constructed, the scientific rules that inform the development of technology, and how we understand mental health.

Critical realists view reality as not just based on an observable objective world but also on our experiences. Ontological realism is therefore balanced with **Epistemological Relativism.** This describes how we each perceive the world in different ways which are culturally, socially, and historically constructed. In this research, this situates how we understand citizenship, mental health, and our relationship with technology through the experiences of the participants and within their wider socio-cultural context. It also acknowledges that all our accounts are fallible. This is important as it enables us to situate our understanding of co-production in its historical and political context, acknowledging how the voices of people who have been marginalised have been co-opted or ignored (Beresford 2019).

Judgemental rationalism is the process through which judgements are made between relativist and realist positions that generate a plausible account of what is being studied. This accepts that using the evidence and experiences available are better and worse interpretations of how the world is viewed. Aligned with this is the role of **Cautious Ethical Naturalism** which states that decisions about what is a better or worse interpretation are value laden and there is an understanding that there is a notion of what constitutes a "good life." For example, within this study the underlying assumption is that societies that are inclusive for people with mental health challenges are a good thing. However, cautious elements of ethical naturalism mean it is important to critique what "good" means and how it has been constructed (Sayer 2011).

This research has a fundamental social and political standpoint. This standpoint is that for people with mental health challenges, inclusive societies that value diversity are something to aspire to, and that citizenship is a concept that should be accessible to people with mental health challenges. As described in the literature review this does not mean accepting traditional definitions of citizenship. By focusing on 'acts of citizenship' (Isin and Neilsen 2008) which can disrupt the status quo or by seeking access to full participatory rights and responsibilities, this can change what citizenship means to people with mental health challenges (Rowe and Pelletier 2012). *Judgemental rationalism* is

important when talking about the future as judgements are required to discuss which versions of the future are possible or probable.

Rubin and Rubin (2011) describe the position of a researcher within the critical realist paradigm as a social activist seeking information to repair social inequities. In chapter 2 I explained my personal and professional commitment and drive for this work. Critical realists argue that the nature of reality has been interpreted in ways that preserve the structures of dominance, so the knowledge sought through the research explores the structures of dominance to work out ways of reducing them. Due to this explicit position, critical realism has been criticised for supporting explicit political agendas (Hammersley 2009). The counter argument to this is that all forms of inquiry have a political basis and that by having an agenda of reform, all participants' lives can be transformed for the better (Creswell 2003).

Despite a focus on social activism, Critical realism has been criticised as a method for engaging marginalised groups. This is due to the use of judgemental rationalism and ethical naturalism, and questions about what is 'better' or 'right', and if these sit with the researcher do they uphold existing power structures (Parr 2015)? Parr (2015), in her feminist research, sought to mitigate the limitations of critical realism through giving prominence to the voices of the women that she was researching, whilst acknowledging that there is need for interpretation. The researcher has a privileged position by having greater access to both theoretical and experiential information through their focus on the area of study. One of the reasons co-production was used in this study was to balance the analysis of the academic researcher, ensuring the voices of people with lived experience were heard and have agency within this study. The peer researchers had a key role, bringing their lived experience of mental health challenges, in both shaping this study and challenging preconceptions, whilst also acknowledging their own limitations from their own experience and position. In the interests of reflexivity, I have shared my personal background and reflections on the privilege of my position in chapter 2 to create transparency.

Co-production as a research method creates space for the interaction of technical expertise alongside lived experience expertise. As well as my own experience as a mental health professional, I bring technical academic knowledge based on the literature around citizenship, marginalisation, and intersectionality (as described in previous chapters). The co-productive process therefore supports an ethical approach to *judgemental rationality* and *cautious ethical naturalism,* for example, when addressing the future as to what is probable or possible. The relative value of these outcomes is being co-created with people with lived experience rather than being decided through academic knowledge.

Critical realism also provides a useful way of exploring the mechanisms of coproduction and exploring agency and power (Farr 2018). This approach is described in section 9.11. Due to the relative novelty, complexity, and challenge of using co-production as a research method within a PhD, this thesis has a chapter 12 dedicated to analysing and reflecting on the co-productive process.

# 9.4 Participatory Approaches and the Distinction Between CBPR and Co-Production

Increasing the use of participatory approaches within research is seen as one of the key methodological challenges of the 21<sup>st</sup> Century (Edward and Brannelly 2017); it is imperative to work with this challenge as a piece of future-focused research. Within Future Studies research there is a growing emphasis on participatory and critical approaches (Inayatullah 2013). The increased interest in participatory research approaches is thought to be due to changes in society and people's expectations of equal relationships and participation in decision-making. Participation also fits with the subject matter in relation to citizenship and in particular 'acts of citizenship' (Hamer 2019). As the aim of this research is to empower people to drive social action, these participatory and democratic research methods fit with both the outcomes and paradigm of the research.

Both co-production and CBPR are forms of participatory research (Edwards and Brannelly (2017) and whilst they are complementary approaches (King and Gillard 2019; Pettican et al 2023) it is important to highlight the distinctions between the two. It could be argued that there are two key distinctions. Firstly, co-production does not have a guiding structure, but rather it has guiding principles (Hickey et al. 2018), whereas CBPR is based around cycles of reflection, evaluation, and action which provide a structure to the research process (Kindon et al. 2007; Pettican et al. 2023). Co-production therefore changes the way the research is undertaken, potentially making it more accessible to people (Beresford et al. 2021). It is important to flexibly apply the structures of CBPR whilst using co-production as the overarching approach. Secondly, CBPR is primarily focused on a micro-level view of the relationships between participants and the researcher, whereas co-production sets this in a wider context, analysing the power dynamics and social context within which the co-production is taking place (King and Gillard 2019). Therefore, it is important to pay attention to all layers of relationships and power, especially as when people's lived experience is valued, it transforms the direction of the research by exploring and understanding what matters to people.

#### 9.5 Co-Production

Co-production in research is a contested concept, with discussions taking place about what constitutes 'true' co-production and the gap between theories of coproduction and actual practice (Lambert and Carr 2018). There is lack of consensus of what co-production is, the best approaches to take and how effective it is in achieving its aims (Oliver et al. 2019). Co-production is distinct from user-led research in that the focus is on sharing technical and experiential expertise and distinct from user involvement due to the sharing of power in decision making (Jennings et al. 2018). Co-production is also different from good public and patient engagement in that it harnesses the 'transformative' role of lived experience rather than solely the added value of lived experience as in 'patient and public involvement' (Williams et al. 2020). Co-production seeks to disrupt the normative methodological practice with the aim of ensuring relevant research impact, including value to the participants themselves (Lambert and Carr 2018).

Co-production does not have a 'road map' to follow, as the plan for the research itself is co-created, the focus therefore is on the process rather than being outcome driven. The approach evolves within certain agreed aims, objectives and constraints; in order to effectively share power, there is a need to tolerate uncertainty (Fletcher et al. 2020). The NIHR (Hickey et al. 2018) identified five principles to guide the process of co-production in research to address the gap between using an approach and a flexible method (see table 5).

## Table 5: NIHR principles of co-production

"Sharing Power: The research is jointly owned, and people work together to achieve a joint understanding in more equal relationships.

**Including all perspectives and skills:** making sure the research team includes those with necessary skills, knowledge, and experience. This recognises that people have multiple identities and can contribute from multiple positions.

**Respecting and valuing the knowledge of all** and giving equal weight to different forms of knowledge.

Reciprocity: everybody benefits from working together

**Building and maintaining relationships:** an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential."

Hickey et al. 2018

Despite these principles to shape co-production, there are questions about the extent that it is even possible to co-produce within existing structural and

institutional power structures (Farr et al. 2021). This is especially so for those with mental health challenges and/or people of colour as the approaches to coproduction still privilege knowledge founded in the enlightenment concepts of rationality and 'whiteness', and therefore co-production in health research has been argued as an anathema for people of colour and people with mental health challenges (Rose and Kalathil 2019). This highlights how important it is to take a critical perspective, examining how power manifests and is applied to the concept of co-production and its application (Farr 2018).

Beresford et al. (2021) argue that despite tokenistic practice and the prevailing structures of inequality and discrimination that inhibit participation in coproduction, this does not fundamentally undermine the possibility of change or possibility of effective co-production itself. They argue that the inequalities further entrenched through Covid-19 highlight the necessity for co-production, particularly from communities who are marginalised, where sharing power in coproduction can focus on addressing these inequalities and is better than not attempting to co-produce at all (Beresford et al. 2021.) Farr et al. (2021) contend *bringing co-production principles into the real research world is fraught with difficult and messy compromises* [p2]. Therefore, they advocate the importance of learning whilst doing whilst being sensitive and critical as a pragmatic approach to co-production. This, in addition to my experience of using co-production in my clinical role in practice, has informed the approach within this PhD.

The challenges of operating within institutional power structures are even more acute when attempting to use co-production as a research approach within a PhD. Research funders and ethics committees still value "scientific knowledge" over experiential knowledge and this can create barriers in involving people in all stages of the research process (Jennings et al. 2018); this can be particularly challenging for those lower in the academic hierarchy (Farr et al. 2021). For example, Hickey et al.'s (2018) definition of co-production in research is that it takes place from the beginning to the end of the project. However, without ethical approval or funding in place it is very difficult to have equal involvement and agreement to proceed from the university (Farr et al. 2021). This was the

case in this PhD; it was important to get the ethical permissions and funding in place to be able to start co-producing. Therefore, the original idea and initial research proposal was my own and not co-produced. However, the approach to co-production evolved over the life of the study and the research deviated from the original plans through the co-productive process; for example, during the research a film was co-created which was not part of the original plan.

In addition, the PhD is primarily a solo project, with the researcher having to evidence their own work and being the beneficiary in that they alone receive a doctorate. It is important in addressing the sole project versus co-produced research challenge to consider the research undertaken as being increasingly co-produced, whereas the thesis is the sole work of the researcher, informed by the experience of co-production. Therefore, the peer researchers will not be in receiving a PhD despite co-producing the research. These reflections led me to question whether it is possible or ethical to use co-production as a research method in this context or whether what is being applied is co-production.

As stated in the introduction, to pay attention to the power dynamics a three track approach has been used: firstly, a commitment to be transparent about the involvement and impact of the involvement of the peer researchers, participants and myself at each stage of the process (Hughes and Duffy 2018); secondly, the approach to the involvement of participants and peer researchers through an ethics of care framework (Brannely 2018b) to support the reflexive process; thirdly, adopting Farr's (2018) utilisation of Archer's (1995, 2003, 2007, 2013) social realist theory as a framework to analyse the approach to co-production (social realism is a form of critical realism which fits with the overarching philosophical approach to research). I will now turn to describe the Ethics of Care framework. I will then give an overview of the study design and application of co-production using Farr's (2018) social realist framework.

## 9.6 Ethics of Care

To provide a transparent approach to the involvement of peer researchers and participants, the principles of an ethics of care approach has been adopted as a reflexive tool to support inclusive practice. An Ethics of Care framework (Brannelly 2018b), draws from feminist and decolonising approaches, focusing on the surfacing of marginalisation, and addresses inequality across marginalised groups. It promotes a responsibility for the researcher to be vulnerable and be open to dissent to guide, change and analyse care and research practices. With a focus on intersectionality, it provides a framework for deliberating with care for solidarity with marginalised groups.

Research informed by an ethics of care values, enables, and prioritises the following:

- "• Longer-term responsive partnerships with communities.
- Participation of marginalised groups; researchers retain responsibility for enabling communities to voice dissatisfactions to inform directions for change.

• Participation from the multiple positions and identities which people inhabit in their lives. This is only possible by relational connection creating space for discussion and deliberation.

• Careful research practices that consider the experience of participation and takes the time to examine research practices with participants.

 Identification of the need for locally produced action to achieve change that is co-negotiated with participants."

(Brannelly 2018b p7)

These have clear overlaps with the principles of co-production but in addition provide another layer of reflection. I have attempted to apply these principles at all stages of the process. The ethical and dynamic issues relating to this will be discussed further in chapter 12, Reflections on Co-Production.

## 9.7 Study Design

Having discussed the philosophical and theoretical underpinning of the study it is important to give an overview of the study design and describe how the theoretical principles were applied in practice. There are two phases of this research, the first phase focuses on knowledge generation and exchange and the second on action (Kindon et al. 2007). The study design below describes what happened, the changes to the approach through co-productive process are discussed throughout the chapter.

**Phase 1:** The first phase involved interviewing people from a peer-led mental health organisation and those from a digital technology company and then bringing them together to exchange and co-create knowledge in a co-production workshop. The purpose of the interviews and workshop were to explore what people understood by citizenship, what they consider are the key factors shaping future citizenship and exploration of perceived challenges and opportunities. Data from this phase was co-analysed with peer researchers and a short film was co-created.



#### Figure 3: Stages of phase 1 data collection

**Phase 2:** Participants from the peer-led organisation and the digital technology company were invited to watch the film and participate in a focus group alongside the academic researcher and peer researchers to further explore the

topics discussed in phase 1. This included consideration of the key areas for development to promote inclusive futures for citizenship for people with mental health challenges.

Unfortunately, due to staffing issues the digital technology company withdrew from participating at this point. The implications of this are discussed in chapter 12.



Figure 4: Stages of phase 2 data collection

#### 9.8 The Application of Co-Production in this Study

I have learnt so much about the 'transformational' value of lived experience through working alongside people with lived experience in practice and I wanted to bring my experience and learning into the research arena. It was important to me and my positioning as a researcher that I use my privileged position to create opportunities to work with the peer researchers and participants as equal partners.

In this section, I describe the approach to co-production used within this study, and the values, challenges, and limitations of the approach. As described in the introduction, I approached co-production in a multi-layered way with both peer researchers and with participants, as well as peer researchers and participants together. I found exploring co-production in research different from my understanding from practice, and within research there is a broad range of activity that is considered co-production but often blurs lines between Public and Patient Engagement or involvement and actual co-production. In this study, the process has been informed by my experience of applying co-production in practice.

Within the Wellbeing and Recovery Partnership (as described in chapter 2) we use a set of principles to guide co-production which are practice-focused, as set out by Slay and Stephen (2013) on which Hickey et al.'s (2018) were based. They are:

- Being asset focused
- Building on existing capabilities
- Mutuality and Reciprocity
- Peer Support
- Blurring Boundaries
- Facilitating rather than delivering

We utilised these in our work and revisited them continually. Using these principles, the focus shifts from delivering co-production to creating spaces to co-produce by valuing people for their lived, learned, and life experiences. This also recognises the struggle and challenge of co-production as part of the process. This means continually negotiating and renegotiating the space to co-produce, including how disagreements are handled and how decisions are made. At each stage of the research these principles have been used alongside those of Hickey et al. (2019) and discussed with participants and peer researchers. From my perspective these have a slightly different focus; Hickey et al. (2019) highlight what needs to happen, whereas Slay and Stephen (2013) emphasise the 'how' as well as the 'what': for example, the importance of focusing on people's strengths and need to create spaces that facilitate discussion and the importance of peer support.

Alongside the use of the principles of co-production, another element from practice is to use the ladder of co-production, not as a stepped approach but as a descriptive tool to promote transparency.



http://creativecommons.org/licenses/by-nc-nd/3.0/

# Figure 5: Ladder of Co-Production (Slay and Stephens 2013)

It is worth noting that there is a move away from utilising the ladder of coproduction, towards a model that promotes a broad range of engagement and moves away from a sense of hierarchy, valuing all forms of involvement, as outlined by the figure below from NHSE (2022) statutory guidance for Working with People and Communities. There is also a critique that, by looking at hierarchies of involvement outside their political context, in particularly the politics of exclusion, they become meaningless or ways of maintaining the status quo (Beresford 2019).



#### Figure 6: Co-Production and participation venn diagram (NHSE 2022)

Despite this shift in focus to a less hierarchical approach to understanding coproduction I feel that it is useful to use the ladder to describe and analyse activity, ensuring at the heart of this is a critique of power and involvement. This is particularly important as it is not always possible to fully co-produce all activity, due to time or financial constraints or the parameters around the activity which cannot be changed: for example, people need time to recognise their assets and contributions, and may need to develop skills to effectively be able to co-produce (Farr et al. 2021). When the peer researchers initially came on board it meant they had to familiarise themselves with new skills, such as analysing data, and develop their understanding of the topic area. In addition, budget plays a role in the level of co-production, for example, how much time can be spent on analysis (Jennings et al. 2018). Compromises were made initially but additional funding enabled a more co-produced approach to data collection and analysis (as will be explained below).

Whilst the aspiration should be to fully co-produce, it is more important to describe where the activity sits on the ladder of co-production and to be transparent rather than involving people in a tokenistic way by pretending that something is co-production when it is not. Hughes and Duffy (2018) emphasise the importance of transparency when engaging in public involvement and participatory research and describing the level and impact of involvement.

Within this study the development of research questions and aims, and initial study design were at the Informing level led by the academic researcher (for the reasons explained in the co-production section in this chapter). However, as the peer researchers came onboard the workshops became increasingly more co-designed and became more fully co-produced as the study developed. Certain elements, such as the write up, remained in the informing stage as the peer researchers were not involved in this element of the PhD. This is where it was helpful to delineate between the thesis being the author's work and the research increasingly becoming co-produced.

This became particularly challenging when it came to the discussion chapter. Initially I had sat down to write the discussion independently (as a requirement of the thesis), but this felt in direct conflict to the approach we had taken to the analysis, and that it was important for the peer researchers to be able to share their perspectives on the findings. Therefore, we reviewed this process and agreed to do a round table discussion that would be transcribed and used verbatim. This has been included as appendix 16<sup>2</sup>. Whilst this is in the appendix it should be considered alongside the more traditional discussion chapter 13 which critically explores the literature, the round table discussion, and the findings together.

See table 6 below to showing the research steps and level of co-production on ladder of co-production. These stages will be described in the following section describing the research process.

## Table 6:Levels of co-production with this research

Research Activity	Level of	Led by:			
	Co-production				
Development of Research	Informing	Academic Researcher			
question, aims and					
outcomes					
Initial design of research	Informing	Academic Researcher			
study					
Literature Review	Informing	Academic Researcher			
Phase 1	Phase 1				
Design and preparation of	Consulting	Academic Researcher and			
research activities		Peer Researchers			
Interviews					
Design and preparation of	Co-design	Academic Researcher and			
research activities Co-		Peer Researchers			
production workshop					
Delivery of co-production	Consulting	Academic Researcher			
workshop					

<sup>&</sup>lt;sup>2</sup> The conventional labelling of this appendix has not been followed as the author believes it is important this appendix is the final section of the thesis, and it should be read as an adjunct to chapters 12 and 13.

Participation in co-	Co-production	Academic Researcher and				
production workshop		Participants (peer-led				
		organisation and digital				
		technology company)				
Development of process of	Engaging	Academic Researcher and				
co-analysis and initial		Peer Researchers				
analysis of data						
Co-analysis of data and	Co-production	Academic Researcher and				
decision to make and		Peer Researchers				
creation of the film						
Phase 2	Phase 2					
Design of phase 2	Co-production	Academic Researcher and				
		Peer Researchers				
Development and delivery						
of focus groups						
Participation in focus	Co-production	Academic Researcher,				
groups		Peer Researchers and				
		Participants (peer-led				
		organisation)				
Data analysis	Co-production	Academic Researcher				
		Peer Researchers				
Discussion round table	Co-production	Academic Researcher,				
(see appendix 16)		Peer researchers and				
		Supervisor				
Write Up (including	Informing	Academic Researcher				
Discussion chapter)						

#### 9.9 Peer Researchers

As described above peer researchers, bringing their lived experience perspective, are integral to co-produced research. The aim was to recruit 2-3 peer researchers; this would provide a range of perspectives and continuity if people needed to take time to manage their wellbeing or changed roles. Funding was provided by my employer, DHC, and the Peer Researchers were employed by DMHF.

The opportunity to become a peer researcher was offered to all peer workers (over 40 people) who work for DMHF as a development opportunity. They were invited to attend a workshop, facilitated by myself and one of my supervisors. The workshop explained the general processes of research, the specifics of this research, the peer researcher role and expectations, and there was an opportunity to ask questions. Within the workshop there was the opportunity to comment on the interview schedule for the semi-structured interviews and to generate learning for participating as a peer researcher. All participants were paid for their time via their existing roles.

Those who were interested in taking up the position of peer researcher were then asked to express an interest to the academic researcher. They would undertake this as an additional development opportunity and were paid for their time. The DMHF were keen to support as they saw this as an opportunity for both the individual staff and the organisation to develop skills in research. As well as being paid, the peer researchers were given the opportunity to co-author papers relating to the study.

Three peer researchers were recruited, each of them agreed to submit a thumbnail introducing themselves (please see below). We also discussed how they would like to be referred to. The peers suggested that we would use their full names and then initials. This was an interesting reflection as academic convention would have been to use surname only, the participants are referred to by their single pseudonyms, which are overall first names.

Bex Symons (BS):

I have worked in Healthcare for 7 ½ years, 5 ½ years as a Peer Specialist for Dorset Mental Health Forum. Most of my time is spent supporting our Perinatal teams (community and inpatient). I also work in Mental health rehabilitation (ward based).

I have no research experience prior to this project. I became involved to prove to myself that I can still achieve things and that stretching my comfort zone can be worth it. I've gained so much from my involvement and the topics that have come to light. I feel even more passionate about speaking my truth and empowering others to do the same. Plus, my acting debut!

George Reynolds (GR):

Peer Specialist working for the Dorset Mental Health Forum. Interested in utilising lived experience in mental health support and in research. Previous research experience.

Ian Warrington (IW):

I have worked for Dorset Mental Health Forum for over 5 ½ years, the majority of time spent working as a peer specialist utilising my lived experience & training in mental health on Acute psychiatric wards. I also work as a peer trainer within the Dorset Recovery Education Centre.

I was interested as the stated aims of the project were around mental health, technology & citizenship, all areas of life that affect me as an individual. Having had no previous experience in research this project gave me an opportunity to explore something that was totally new to me and stretch my own personal skills and attributes. The peer researchers were all were trained in research approaches by Dr T. Brannelly, who was a previous supervisor of this PhD. GR had previous research experience; it was therefore negotiated that he would take on a slightly different role to the other peer researchers. This was not planned but in line with co-production principles and was the opportunity to bring his skills and life experience to the project. All peer researchers contributed to the on-going design of the study, planning of the workshops and dissemination. GR focused on critiquing the methodological approach in particular the approach to coproduction, whereas BS and IW had a greater focus on the data analysis.

As part of the preparation process a reflexive approach was discussed and agreed with the peer researchers. We held regular meetings which discussed both the process of the research and the content of the theoretical and experiential elements of citizenship and mental health and what it meant to think about the future. This was modelled on learning from practice, from the citizenship research of MacIntyre et al. (2019) and based on the ethics of care approach (Brannelly 2018b).

The gender make-up of the research team including myself was 3:1 male: female. This was discussed within the team in terms of the role of feminist approaches within the research and negotiating spaces to challenge each other and to ensure that Bex's voice was heard.

The research team was also white. Therefore, it is important to acknowledge the lack of diversity of the research team and the impact that this will have had on the co-production of the process and analysis. Part of the purpose of using a critical realist standpoint is to highlight the mechanics of this co-productive process so that it can be critiqued. The study is not seeking to create a definitive sense of future citizenship but rather stimulate debate. However, it is important to note that representation is more complex than having involvement of people of colour, due to the conceptualisation of 'whiteness' and forms of privilege within both the mental health and academic sphere (King and Gilliard 2019). The lack of diversity within the research team is a limitation of this research.

It was not practical or financially viable for a study of this scale to involve the peer researchers at every stage. Therefore, the peer researchers were primarily involved in the following:

- co-creation of the data collection
- co-analysis of the data
- critique of co-production and methodology
- discussion round table
- dissemination

As the study evolved, the peer researchers took on a greater role in co-creating the direction of the study.

## 9.10 Participants

The participants in this study have been purposefully sampled utilising the academic researcher's professional networks. This is aligned to the approach of co-production and Ethics of Care which suggests building on existing networks to allow for greater trust and potential on-going participation beyond the research period (Edwards and Brannelly 2017).

The participants were recruited from:

 A mental health peer-led organisation: A peer-led organisation is one that is run and delivered by people with lived experience of mental health challenges. Peer-led organisations, despite having experienced significant funding challenges over the past ten years, offer a direct and effective way of ensuring the voices of people with mental health challenges are included (Beresford 2019).  digital technology company: The digital technology company recruited is one with a strong focus on inclusion and is involved in building future digital capacity in the Voluntary and Social Enterprise Sector.

Therefore, as part of the knowledge exchange both organisations have something to contribute and something to learn from each other. The peer-led organisation brings a focus on mental health and citizenship, the technology company a focus on digital approaches and inclusion. Within this there were also individuals who had knowledge broader than their organisational role, which was welcomed within the co-productive approach (for example, people working for the digital technology company may have had their own lived experience of mental health challenges or people within the peer-led organisation had advanced knowledge of technology). Through these two organisations coming together there is the potential to co-create knowledge within the research but also promote wider reflections within their areas of work (which brings social value). Due to the limited involvement of people with lived experience in the Future Mental Health literature (Beresford and Russo 2017), it was decided not to involve additional mental health professionals (other than myself) as it was important for the voices of people with lived experience to be at the forefront of this research as far as possible within the context of this PhD.

Rather than approaching people with mental health challenges or service users of mental health services directly a peer-led organisation was selected. They were selected for two reasons: firstly, as a peer-led organisation, it felt more ethical as an organisation is more likely to be able to take action regarding the issues raised whereas individuals may feel more powerless in thinking about how to address the future; secondly, was the question of support, in that a peerled organisation has existing structures to support all their staff.

The question of 'vulnerability' is interesting as by the nature of being a peer-led organisation staff will have experience of mental health challenges. If they were being approached as service-users, they may have been considered
'vulnerable' (from an academic institutional view) which surfaces additional questions in regard to support but also capacity to share power and work coproductively. However, as members of a peer-led organisation the participants were not considered vulnerable by the ethics committee. This is important as perceived or actual vulnerability (and how institutions respond) can be a barrier to work co-productively (Beresford et al. 2021).

In total there were fourteen participants, four different participants from the digital technology company and ten participants from the peer-led mental health organisation. The demographic make-up of the participants in shown in table 7. The participants where majority white British, middle aged and heterosexual, therefore not a particularly diverse sample. It is important that this is taken into consideration when analysing the implications of the findings. Participants were not asked if they identified as having mental health challenges, although this is implicit for those working within the peer-led organisation. It was interesting to note that the question about disability had the highest number people preferring not to say. This may relate to the extent people view having mental health challenges as a disability.

Table 7:1 Age		Table 7.2 Gender		Table	Table 7.3 Ethnicity	
Age	No of	Gender	No of	Ethn	icity	No of
	Participants		Participants			Participants
18-24	1	Female	5	Whit	e	10
25-39	2			Britis	sh	
40-55	6	Male	5	Blac	k	1
56-74	2			Britis	sh	
Prefer not to	3	Prefer not	4	Pref	er not	3
say		to say		to sa	ау	
Table 7.4 Sexuality		Table 7.5 Disability		Table	Table 7.6 Religion	
Sexuality No of		Disability	No of	Relig	nion	No of
Sexuality	Participants	Disability	Participants	Kené	JION	Participants
Heterosexual	8	Yes	1	Agno	octic	1
Gay/Lesbian	2	No	8	Athe		4
Bisexual	1	Prefer not	5		stian	1
	3		5			1
Prefer not to	3	to say		Mixe		•
say				Non	-	4
					er not	3
				to sa	ау	

# Table 7: Demographics of participants

Some participants, seven from the peer-led organisation and one from the digital technology company, took part in more than one form of data collection (see table 8 for more information). In addition, in line with coproduction principles (blurring the boundaries) the academic researcher and peer researchers participated in the focus group.

# Table 8: Participants and data collection points

	Data Collection	Number of Participants		Involvement of Research Team
	Point	Peer-led Org.	Digital Tech.	
Phase 1	Semi- Structured Interviews	7	4	Academic Researcher facilitated approach co-designed with Peer Researchers
	Co-Production Workshop	6	1	Academic Researcher facilitated approach co-designed with Peer Researchers
	Film Creation*			3 Peer Researchers and Academic Researcher
Phase 2	Focus Group	6	0	3 Peer Researchers and Academic Researcher – shared facilitation and participation
Total:		19 contacts (10 different people) 14 peopl contacts	5 contacts (4 different people e/ 24	3 Peer Researchers

\*film creation – data analysis rather than data collection point.

Due to pressures of work the digital technology company did not have many staff participating in the co-production workshop, with two people cancelling on the day. Whilst agreeing to participate in the second phase, the practicalities of staff being able to participate became impossible due to an internal restructure and therefore withdrew. It was collectively agreed to proceed solely with the peer-led organisation. This meant the action phase of the participatory research (Kindon et al. 2007) was focused on the peer-led organisation and research team. Consequently, the final focus was much more in-depth discussion on future citizenship through the experience of people with lived experience of mental health challenges rather than a wider discussion of the impact of technology.

The study originally aimed to have 30 participants which has been argued to be the optimum number for a PhD using qualitative interviews and for a study working with marginalised groups (Baker and Edwards 2012). There had been plans in the second phase of the research to work with a different additional set of participants: those who were working for a national mental health organisation (described as current leaders); and a group of digital natives (those born after 1981 who had grown up with the internet) who were either peer workers or student mental health practitioners (described as potential future leaders). The rationale for this was to try and extend the reach of the research and explore whether there was a generational difference towards the future of citizenship and technology. However, as data from the first phase was so rich and participants expressed how they valued the time to reflect on the issues, the collective decision was made to continue into the action phase with the original participating organisations. This decision was informed by discussions with the supervisory team and peer researchers and is an example of how the co-productive approach changed the direction of the research. Overall, this approach brought a greater level of coherence to the project. The generation of the film creates the opportunity to undertake post-doctoral research with the identified groups.

Due to the focus of the research on the peer-led organisation and digital technology company, a smaller number of participants were involved than initially anticipated (14 rather than 30). Critical Realist research does not seek to make generalisations but rather aims to be 'intensive' research which emphasises causal explanation in a specific context (Sayer 2000). Due to multiple data collection points and mixed approaches used, this generated rich data from the sample size (Baker and Edwards 2012). Working with a smaller number of participants was more manageable and maximised opportunities for in-depth discussions around co-production.

## 9.11 Using Realist Social Theory to Analyse Co-Production (Farr 2018)

Farr (2018) utilises critical realism to analyse co-production, which is the underpinning philosophical standpoint of this research. She draws on the work of Archer (1995), to describe and explore how people are conditioned by their structural and cultural contexts, but their actions are not determined. Therefore, people have the potential to make changes within themselves or others or institutions through social interactions (Archer 1995; Archer et al. 2013). These social interactions can then shift understanding and lead to change or they can maintain the dominant power structures. These concepts are much like 'acts of citizenship' that disrupt social norms and drive change (Isin and Turner 2008).

Farr (2018) proposes that the co-production process can be critiqued by analysing the extent that people with lived experience have power and can influence change. She proposes analysing four key elements which are:

- i. People (agents) involved.
- ii. Structures within which participation is set.
- iii. Quality of the social interactions.
- iv. How outcomes were achieved.

These elements and how they relate to this study will now be addressed in turn. The implications of each of these elements will be discussed in more depth in chapter 12, reflections on co-production.

# i. People (agents) involved

All the peer researchers have lived experience of mental health challenges, as do those from the peer-led mental health organisation. Some of the participants from the digital technology company also identified as having lived experience of mental health challenges. Whilst there was some diversity in terms of gender, sexuality and ethnicity, the participants were majority white and heterosexual (see table 7). The research team did include a range of educational backgrounds (see thumbnails and reflections on co-production chapter 12) and were predominately white and cis male. Therefore, some diverse perspectives are missing from the analysis, and it is important to acknowledge this. This also made it even more important to discuss feminist and critical methodologies as part of the approach and emphasises the value of having an Ethics of Care framework. There was a commitment to mutual recognition and respect throughout the phases of the research. At the heart of the study was a commitment to learn about the process of co-production and this was discussed with the participants and peer researchers.

The peer researchers were paid and had their own external supervision and so had a degree of independence and security to participate equally. However, the number of hours were limited, and this made it difficult for the peers to commit as much time to the study as I was able to, which created an imbalance. Whilst there may have been intentions to have non-hierarchical collaboration, the nature and structure of the PhD did not support this. This will be described further in the next section.

# ii. Structures within which participation is set

The peer researchers were employed by a DMHF rather than directly by the university. This had positives and negatives; the positives were the peer researchers had independence as part of an external organisation and could access expert support in relation to their experience of utilising their lived experience. The negatives were that they did not then have access to the organisational resources and understanding of the university. The university department was the Department of Social Sciences and Social Work which hosts the Centre for Seldom Heard Voices, which may have afforded more flexibility and support to a co-productive approach than another department.

As stated previously, the structure of a PhD does not lend itself to coproduction. In defining the context of co-production within a PhD, in discussion with my supervisors, it was agreed that the research was co-produced and the thesis was my endeavour. However, it includes the insights and support of the peers. The ethics of this will be discussed further in chapter 12.

## iii. Quality of social interaction

As far as possible there were attempts to negotiate as much of the process with the peer researchers as possible. However, my priorities as an academic researcher dominated, partially informed by the structure and ownership of the PhD, and the point when the co-production started to commence. Although there were three peer researchers, able to share their lived experience and expertise, the power inherent in my clinical and academic background also meant that this needed close attention. I completed a reflective diary in relation to co-production and sharing power. This included reflections on the construction of knowledge and gaps in representation. These were discussed and shared with the peer researchers.

## iv. Outcomes achieved and solutions proposed

It is difficult to know what the longer-term outcomes achieved will be. However, there is a commitment from my employer for me to undertake this study and I am in a senior role within the organisation with the opportunity to influence change. Feedback from the participants and peer researchers was that they valued being involved in the process (see chapters 11 and 12) and through the discussion round table the peer researchers had the opportunity to make their own recommendations and propose solutions in their own words (appendix 16). The rationale behind the discussion round table was to provide the peer researchers with the opportunity to provide their own solutions to the issues raised and to inform the discussion chapter from a lived experience perspective, alongside the academic literature.

It is hoped that through the presentation of the Findings chapters (10,11), through the discussions and the film, that it is evident that the voice of people with lived experience has played a key role and has shaped discussion of the challenges and opportunities that face citizens. There was clear co-analysis and co-production of the film and the second phase of collection and the data analysis, which is explained in detail later in this chapter. The intention is not for this research to create a fully representative perspective of future citizenship for all people with lived experience of mental health challenges but rather it is a good starting point to promote further discussion. It is also important to note that one of the solutions proposed is to be transparent about the approach to coproduction and to share this learning. There is also a commitment to co-deliver and co-produce the dissemination.

## 9.12 Ethical Considerations

The study obtained ethical approval from Bournemouth University Research Ethics Committee on 3/4/20. Due to Covid-19 an amendment was submitted so all data collection took place on-line via Zoom. This was granted 7/10/20. As the initial focus of the research had changed, a further amendment was submitted to continue to work with existing participants. This was granted 15/09/21 (see appendix 2)

One of the key ethical considerations was the approach to co-production itself. This was both in terms of avoiding exploitation of peer researchers and participants and in managing the integrity of the agreed research question and ethics. Having existing relationships with the participants and peer researchers enabled more open conversations about how the research was progressing and how it felt to be involved. Oliver et al. (2019) recommend weighing up the cost and benefits of co-production, to the research as a whole, to the participants and to the research team. They suggest continual reflection to address this, which has taken place within this study. To support the integrity of the study the peer researchers received training on co-production and any amendments were taken back to the ethics committee. As a research team we were aware of the possibility of people talking about the future and mental health being distressing. Support structures were put in place to signpost people to if they were distressed following the session. The researcher is an experienced mental health professional and peer-researchers are experienced peer workers so were comfortable to offer a level of support if required. The research team were all experienced group facilitators, so attention was paid to avoidance of overt disclosure, pressure by the researchers or other participants to contribute or share information. The researcher was able to seek support via the supervisory team and was able to access external emotional support. The co-researchers were able to seek support from the researcher and through their supervision via the DMHF. The co-productive process also allowed adaptations to be made if needed to support people's engagement and reduce people's potential distress. Working alongside the peer researchers enabled us to develop a sensitive approach to engaging people in the topic.

Participants were recruited internally within their organisations following a letter sent to each organisation's CEO, to avoid coercion and direct recruitment from the researcher (appendix 3). Issues of confidentiality and anonymity were managed by the organisations only being referred to by a descriptor, e.g. the peer-led organisation, rather than their real names and participants chose their own pseudonyms. This is distinct from the peer researchers who are using their real names.

Prior to taking part in each phase, participants were provided with an information sheet (appendices 4 & 6) and had opportunities to ask questions prior to the interview, co-production workshop or focus group. They were also asked to sign consent forms (appendices 5&7) and were made aware of their right to withdraw their data at the start of their involvement and at subsequent data collection points. Part of the consent process was agreeing to the ground rules of the focus group and the workshop which included keeping each other's information confidential.

	Peer-Led Organisation	Digital Media Company
Phase 1	<ul> <li>Aspienaut</li> <li>Auba</li> <li>Cash</li> <li>Colin</li> <li>Marmite</li> <li>Primate 10</li> <li>Rose</li> </ul>	<ul> <li>Bangsal</li> <li>Charli</li> <li>Charlotte</li> <li>Kat</li> </ul>
Phase 2	<ul> <li>Colin</li> <li>Janet</li> <li>Laurel</li> <li>Marmite</li> <li>Poppy</li> <li>Rose</li> </ul>	

# Table 9:Participant's pseudonyms

## 9.13 Data Collection

This section describes the data collection points within the study, how they evolved and the involvement of the peer researchers at each stage. There were three main data collection points within this study, two in Phase 1 (semi-structured interviews and a co-production workshop) and one in Phase 2 (a focus group).



# Figure 7: Phases of data collection

Originally the plan had been to conduct all the data face to face. However, due to the Covid-19 pandemic the data collection moved online using Zoom. All

interviews, workshop and focus group were digitally recorded and transcribed. This use of technology felt fitting given the topic and did not appear to provide a barrier to participant engagement, especially as most (if not all participants) were using video conferencing regularly for work. The digital transcripts were manually transcribed by the academic researcher.

## 9.13.1 Phase 1

### **Semi-Structured Interviews**

The primary rationale for interviews was that they were an effective way of preparing people for the co-production workshop. In my learning from practice, preparation for co-production has been central so people know what they bring to the process. Due to the complexity of the topic, the intention was that participants would have the chance to reflect on the topic. This would then generate content and discussion points to explore in the co-production workshop. It was also designed into the study to support those participants who were less confident in speaking up in a larger group. The academic researcher led on interviews and the interview schedule was consulted on as part of the peer researcher preparation workshop (see appendix 8 for interview schedule). The interview schedule included a question on intersectionality in line with the Ethics of Care approach (Brannelly 2018b). Each interview was approximately 1 hour. The data that came through this stage was so rich that it became a valuable data collection point, rather than primarily a preparatory step.

## **Co-Production Workshop**

The primary purpose of the co-production workshop was to facilitate knowledge exchange between the peer-led organisation, digital technology company and research team. The workshop structure and content were co-designed with the peer researchers. Knowledge exchanged focused on co-developing a shared understanding of citizenship and providing an overview of the likely developments in technology over the next 25 years. It also explored how these

may impact on citizenship, specifically for people with mental health challenges. This was primarily informed by the themes identified from the semi-structured interviews. It aimed to be a knowledge exchange where people shared their expertise from different perspectives. Within the workshop there were two additional objectives linked to the facilitation of the co-productive process:

- To explore people's experience of participating in the interview stage of the research
- To sense check the coding of the interviews

The workshop lasted 2 ½ hours with a 15-minute break. It started with a presentation summarising the main themes from the interviews (see appendix 9 for selection of slides from presentation). Participants (n=7) were given time in break out rooms for small group discussions to explore their ideas more freely and groups provided feedback. The transcript from the workshop was co-analysed with the peer researchers. This co-analysis was used as the basis to co-produce the film.

# 9.13.2 Phase 2

# **Focus Group**

The content of the Focus group was co-produced and co-facilitated with the peer researchers (n=3). The session ran for 2 hours with a brief 10-minute comfort break.

Prior to the Focus group, participants (n=6) were invited to watch the film. The participants were asked questions based on their reflections on the film (see appendix 10). These questions were designed to meet the research objectives in exploring the potential impact on and opportunities to shape future citizenship. They also had a focus on action that participants could take individually or collectively as part of the CBPR process. There were two questions on the experience of participating in the research and in particular a piece of co-produced research. The academic researcher and peer researchers

took turns at facilitating different questions. This provided the opportunity for the research team to be involved in the discussions as participants alongside their role as facilitators.

# 9.14 Data Analysis

This section outlines the theoretical approach using Braun and Clark's (2006) six stage reflexive thematic analysis. As the co-analysis is intrinsically linked to the co-production process, the chapter moves on to describing Jennings et al.'s (2018) approaches to data co-analysis and then describes the different ways this was applied to the various phases of the research and integrated with Braun and Clark's approach. These phases are outlined below:

# 9.14.1 Braun and Clarke (2006; 2019) Thematic Analysis

Data was analysed using Reflexive Thematic Analysis as described by Braun and Clarke (2006; 2019). This was selected as it is suited to democratic methods of research, such as co-production, and is one of the more accessible forms of analysis (Braun and Clarke, 2006; 2019.), which is important in this study as co-analysis of the data is a key element. Braun and Clarke renamed their Thematic Analysis (2019), Reflexive Thematic Analysis to highlight the subjective resource of the researcher(s).

Braun and Clarke (2006) propose a 6-stage approach to data analysis, not applied rigidly, but as a guide for people to develop their craft as analytic researchers (Braun and Clarke 2019). These steps are:

- 1. Familiarising oneself with the data
- 2. Generating initial codes
- 3. Searching for themes
- 4. Reviewing themes
- 5. Defining and naming themes
- 6. Writing the report

Thematic analysis relies on inductive (rather than theoretical) analysis, drawing the themes from the data not from a pre-existing framework. It also allows for an exploration of the latent (semantic) themes which provide an opportunity to explore the dynamics of power expressed within the data. This is particularly helpful with research topics that have had little or no previous research and are rich in data (Braun and Clarke, 2006). This is important within this study where the centrality of the voice of people with lived experience is key to the approach in the rebalancing of power (Parr 2015).

The emphasis on subjectivity, reflexivity and craft is one of the strengths of thematic analysis. However, it is also a point of critique. It can be vague and lack structure and rigour, and the researcher can put their own emphasis on what they see as being the key themes for their own ends or as a product of unconscious bias (Braun and Clarke 2019). The co-analysis of the data with the peer researchers is an important element, as people with lived experience bring a different perspective on what is important and can critique and challenge the academic researchers on their decision-making process (Faulkner 2017). This is not to say the peer researchers do not have their own bias and prejudices but by working collectively these can be explored. Examining the same data from different perspectives can provide novel sociocultural and political insights (Jennings et al. 2018).

Due to the cyclical approach of CBPR and the co-productive methodology the analysis was not followed through in a stepped way, but as a series of overlapping processes that were frequently revisited. This was particularly true for the first phase of the data analysis (see appendix 11). This is in keeping with Braun and Clark's (2019) approach where the analysis becomes a recursive process.

## 9.14.2 Approaches to Collaborative Data Analysis

Jennings et al. (2018) carried out a literature review of co-analysis which they describe as Collaborative Data Analysis (CDA). They identify successful CDA as being co-produced, with clear expectations which are manageable for all

parties, realistic within the time and resources and attention is paid to the group dynamics. Jennings et al. (2018) also identified four different types of approach, which they acknowledge can be constrained by practical factors:

a) Development and Application: where the whole process is coproduced. This is for studies that have significant funding and time to undertake the research (the gold standard).

**Application:** The academic researcher leads the analysis and then involves co-researchers in applying themes and codes.

**Development:** Co-researchers are involved in early stages of data analysis and inductively develop themes and codes based on a small number of transcripts. The academic researchers then apply these to the rest of the data. This analysis is then revisited with co-researchers.

**Consultation:** This is where academic researchers conduct the analysis and then present their work to the co-researchers for commentary and feedback.

Due to the development of the co-productive process across the study, the different stages of data collection had different levels of involvement due to time and finance; these were negotiated with the peer researchers. There are similarities to the ladder of co-production, in the interests of transparency these levels of involvement will be described at each stage.

## Table 10: Division of data analysis

	Academic Researcher	Peer Researchers
Interviews	Primary analysis	Sample transcripts and cross checking
Co-production Workshop	Shared analysis of workshop recording and transcript	

The initial steps taken to analyse the data were as follows:

## a) Interviews

Time restrictions and inexperience with research meant that the peer researchers only undertook sample transcripts of the interviews rather than full analysis. Peer researchers were given two sample transcripts each, more to cross-check rather than setting the coding framework. This was discussed and agreed with the peer researchers as the most pragmatic approach. The overall themes were then discussed as a group. The academic researcher did the bulk of the data analysis using NViVO (see appendix 12 for initial coding and frequency of sub-codes). The peer researchers identified two additional themes around the emotional content of the transcripts - *isolation* and *personal disclosure* - highlighting the added value of lived experience researchers in providing different perspectives. This led to some useful reflections on what it means to code separately and how we could work collectively on future analysis. With the academic researcher taking a lead, the content and format for the co-production workshop was planned alongside the peer researchers. It was agreed that the data from the interviews would be presented in the form of a PowerPoint at the Co-Production Workshop. Using the CDA approach, in this first phase the research team did a combination of *Development* and Consultation (Jennings et al. 2018). The themes from the interviews were sense checked with participants as part of the co-production workshop and the opportunity was provided for them to critique or revise.

## b) Co-production workshop

The analysis of the Co-production Workshop provided the opportunity to undertake a more co-produced analysis, closer to the gold-standard of Development and Application outlined in the CDA approach (Jennings et al. 2018). The academic researcher and peer researchers all had the complete transcripts. The co-produced plan was to familiarise ourselves with the data and undertake some initial coding. However, the shared analysis of the coproduction workshop was challenging as the peer researchers reported finding it difficult to 'get on top' of the data due to its sheer volume, the complexity of the topic, their inexperience in data analysis and uncertainty on how best to use the funded hours. Farr et al. (2021) suggest it is unrealistic to expect people to be able to immediately co-produce due to the technical knowledge or experience required in research analysis, and skills development is needed. Therefore, the approach to the data analysis evolved (see figure 8). It became important to be creative about presenting data to the peer researchers in a format that was accessible, so through discussion, this moved from using NVivo to mind maps (appendix 12), to creating a summary document (see appendix 13). This two-page summary became transformational in making the findings more accessible to the peer researchers.

'Reading Phil's two-page document has amped up my enthusiasm again. I feel I can connect with the topic and those related. For a period, I felt like I was swimming against the tide, in murky intellectual waters, with my poor brain desperately trying to join the dots.' Bex [email correspondence]

This meant the analysis was not a linear co-production process, but rather a coproductive one that evolved through the first phase. Therefore, there has not been a detailed description of the frequency of codes, as the process has been layered. Central to the reflexive thematic analysis, the subjective involvement of the academic researcher and peer researchers has been key to analysing the data (Braun and Clarke 2019). Frequency of codes was also not a priority in this initial phase as the focus was on the attempt to capture broad perspectives on how citizenship is formed and the drivers of and barriers to current and future citizenship. This was especially true of the moral and ethical themes, which were the questions arising from the co-production workshop. However, for transparency the initial Nvivo coding and mindmaps have been included in appendix 12.

Despite the aspiration for the level of co-analysis of the Co-production Workshop being high, whilst having elements of *Application and Development*, there were still strong elements of *Consultation* and *Application* needed to practically undertake the analysis. This was all discussed with the peer researchers as we adapted our approach.



## Figure 8: Evolution of the analysis in phase 1

The process of creating the summary was incredibly important in shaping how we thought about disseminating the findings of this first phase to make them accessible. The summary created a shared understanding and led to a turning point in the levels of co-production throughout the remaining study. These discussions produced conversations on what the data meant and how to represent it, resulting in the idea of the film. The film then became an additional layer of analysis.

#### c) The Film

The film emerged out of the co-productive process alongside theme development and consideration of how to represent themes in the next phase of the research. In the original plan there was an idea to create a report and presentation to share the initial findings, however in discussion with the peer researchers it became more central to the study and almost a stand-alone piece. The value of co-production and peer researchers came to the fore by disrupting the traditional research process. The peer researchers highlighted that to be able to explore complex issues effectively it was important to make something that was accessible to people.

The use of creative methods, such as film making or video work, within research can provide approaches that express rich social. cultural and contextual factors that can go beyond traditional research methods and highlight complexities and ambiguities (Baumann et al. 2020). Film making has 'transformative potential' within participatory research by giving voice to marginalised groups and flattening the power dynamic between researcher and participants (Kindon 2003 p143). This is particularly true when critical feminist perspectives are incorporated (Parr 2007). For example, involving participants who have lived experience of mental health problems in participatory filmmaking can counterbalance stereotypes about mental health endorsed by the mainstream media (Manni et al. 2019). Therefore, this fits well with the approach and philosophy of this study. However, despite this, filmmaking has had limited use as a methodology within participatory research in health (Baumann et al. 2020). In other studies, it has been used to disseminate

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research findings, for example, research into a project that supports social inclusion for people with mental health challenges (Parr 2007) moves beyond text-based explanations of research data to embodied creative expression (Baumann et al. 2020).

The use of film and creative educational approaches are also discussed within Future Studies, to support people to engage in future thinking. These are: future-focused discussions, scenario planning, future focused role play, backcasting (developing an imagined future and working backward on how this could be achieved or highlight warnings that things are off track) (Davidson 2017). Elements of these can be seen in the development of the film. Gunnarsson-Östling et al. (2012) used future-focused participatory methods to create feminist futures but found it was challenging for people to engage with talking about the future. They suggested using creative methods or approaches to engage people to be more future-focused.

Initially photovoice interviews (such as those used by Vervliet et al. 2019) had been considered. However, the peer researchers felt that the film would create better stimulus for creative thinking. The research team decided to make a film based on a future weather/news report, including having different characters who live in the future, enabling us to represent different perspectives. For example, the script writing included developing the two characters XA754 and Juniper as a way to represent different potential future perspectives whilst highlighting some of the tensions and power dynamics; thereby creating multiple narratives of future citizenship (Bergman et al. 2014). The Morgan Philips *Citizen Scientist* character was introduced to provide an explanation of different understandings of citizenship. This was an opportunity to bring in some of the perspectives in the literature, adding additional context to the discussion by bringing together lived experience and technical knowledge.

The process of co-creating the film and sharing ideas as a creative process alongside the research process also provided another layer of analysis of data generated from the first phase of research. This included the lived experience perspectives of the peer researchers and the clinical and academic knowledge of the academic researcher. The academic researcher and one of the peer researchers agreed to 'act' in the film.

The style of the film was inspired by a number of participants talking (in their interviews) about science fiction and its role in shaping future thinking, echoing some of the ideas in Afrofuturism and Feminist futures that use science-fiction to disrupt existing power structures (Haraway 1994; Capers 2019). This influenced the development of the imagery in the film. There was a deliberate use of humour in both the script and visual imagery to engage the viewer. References to current people and events in the past tense were used as a technique to emphasis that this was a future broadcast. A green screen was used to project the news room, future apartment and future tv studio. GiFs (all available on CreativeCommons) were selected to enhance the drama and create a visual picture of some of the technological advances. This added an emotional nuance to the presentation of the data through the language used in the script, the images used, the development of the characters and the 'quality' of the acting. Therefore, the embodied creative expression enabled us to convey the complexity of the topic whilst engaging the viewer emotionally in the subject.

In the interests of reflexivity, I do not have film making or acting experience, neither did the peer researchers. Once the film was scripted, we then engaged with DHC's Learning and Development team. They supported us to use their video suite and helped us realise some of the design elements and editing. Because the film had been scripted the editing was a mechanical rather than creative process. All decision-making was left with the academic researcher and peer researchers.

#### 9.14.3 Data Analysis: Focus Group

The co-creation of the film and the agreement for additional funding for peer time was a tipping point for the research team being able to effectively share power and co-produce. This meant that the final stage of data collection was in the CDA framework *Development and Application* (Jennings et al. 2018). This included revisiting the purpose of the focus group and our roles within it (and whether this was the best way to complete this research phase), which participants to include once the digital technology company withdrew and agreeing the approach for data analysis.

Braun and Clark's (2006;2019) reflexive thematic analysis was conducted in a step-by-step way rather than in the more reflexive approach used in the previous phase. This is because the focus was on a single data set, the transcript of the focus group. The academic researcher and two of the peer researchers then analysed the data. It was agreed each would individually conduct stages 1 (familiarising self with the data) and 2 (generating initial codes). We then met together to start searching for themes (stage 3) and share our ideas; from this activity an initial coding table was created including frequency of themes (see appendix 14). We took this initial analysis away individually and met again to review, define, and name the themes (4,5). Because this final phase was much more fully co-produced than the earlier phase in the Findings chapters this second phase will have a greater emphasis and in-depth analysis in this thesis. As the pandemic had receded by this time, following an initial meeting on Zoom, there was the opportunity to meet face-toface and map out and discuss the themes and sub-themes using post-it notes which enhanced the process of co-analysis (also shown in appendix 14).

#### 9.14.4 Data Analysis: Discussion

Due to the co-productive nature of this PhD, it did not feel like the correct thing for the academic researcher to solely write up the implications of the findings independently, Therefore, there are two elements to the discussion; a traditional discussion, chapter 13, and a round table discussion, included as appendix 16.

This second element to the discussion was influenced by a conversation with George, who expressed that as a peer researcher, he felt had not been given the opportunity to share his own perspectives on the topic, as his role had been facilitating the process for others. This conversation led to further discussions with the peer researchers and my supervisors in which we agreed to a joint discussion based on a transcript of a round table discussion. This discussion was partially inspired by the roundtable discussion on participatory citizenship (Reis et al. 2022). It was agreed this would be edited but not be themed and analysed. Jones and Fenge (2017) argue that sometimes people's words should stand on their own rather than be subject to an additional layer of analysis. This brings energy to the experience of the reader, moving them closer to the group experience itself without re-interpretation, which is particularly important for people from marginalised groups (Parr 2015). This felt much more aligned with a co-produced approach rather than solely having the discussion chapter within the traditional write-up of a PhD. However, in recognition of the thesis not being co-produced, this roundtable discussion has been included in the appendix 16. The effectiveness and implications of this, and refection on the whole co-productive process are discussed in chapter 12.

## 9.15 Conclusion

This chapter has discussed the research aims and objectives, the philosophical positioning of the research, the research methodology and approach to data collection and data analysis. This includes the process of participant recruitment and any ethical considerations within the study. This chapter also contained a description and critique of the co-productive process and the associated developments and changes to both the approach to data collection and data analysis. The findings of the study will be discussed in the following four chapters: chapter 10, the findings from the first phase of the research and the development of the film; chapter 11 the findings from the second phase of the research, chapter 12 reflections on the use and effectiveness of co-production within this PhD and chapter 13 overall discussion, conclusion, and recommendations.

# Chapter 10: 'Redefine what it means to be human' Findings Phase 1

"...Digital technology potentially allows people, disenfranchised people, mental health problems or otherwise, to have more power but I think it's a world we don't really know... sometimes I feel that we are being encouraged to enter this world and it feels like we are just a load of sheep about to run off the cliff" Quote from Marmite participant from the peer led organisation from phase 1.

# **10.1 Introduction:**

This initial phase of data collection sought to explore the key issues and potential developments for future citizenship for people with mental health challenges, to stimulate discussion and action towards more equal futures. Participants speculated whether technology could positively *"redefine what it means to be human"* (Aspienaut) or whether it would *"break down the fabric of society"* (Marmite). These weren't expressed as opposing views but rather as a spectrum of the potential impacts of technology.

This first phase focused on knowledge exchange between participants, the academic researcher and peer researchers. This was to co-create a shared understanding in response to the following research objectives:

- What do participants think are the key factors that will shape citizenship in the future?
- What are the perceived challenges and opportunities for people with mental health challenges in relation to future citizenship?

As well as addressing the above research objectives, there were also some initial discussions on what could be done to promote *inclusive future opportunities for citizenship for people with mental health challenges.* To address these objectives, it was important to find out how people understood citizenship and what this meant for people with mental health challenges. The quotes<sup>3</sup> presented in this chapter are a mix of those from interviews and those from the co-production workshop. Braun and Clarke's (2006; 2019) reflexive thematic analysis was used to co-analyse the data. The culmination of this data analysis was the co-development of the film *Future Citizen Forecast*, which should be considered the overarching report for this phase. Please see Introduction, chapter 1, for the link to the film. This chapter outlines the themes and contextual literature that informed the development of film.

Through Phase 1 there were five main themes:

- **Personal Experiences:** This was an overarching theme relating to how people connected with the topic and shared their lived experience.
- **Technological Change**: These outlined what people thought would be the likely drivers, developments and impacts of future technologies.
- **Defining Citizenship**: These were the thoughts participants had about citizenship, what it meant to them.
- **Barriers to Citizenship**: These were the difficulties people face in being able to participate as full citizens, in particular people with mental health challenges. This included a focus on the impact of technology on citizenship.
- **Moral and Ethical dilemmas:** These largely came from the discussions in the co-production workshop and examined the moral and ethical implications of these potential technological changes and their impact on future citizenship, in particular for people with mental health challenges.

Please see table below for overview of themes and sub-themes (see appendix 12 for further break down of initial coding, including frequency and appendix 15 for how the themes and sub-themes were applied to the making of the film)

<sup>&</sup>lt;sup>3</sup> Those quotes from participants from the Peer-Led organisation are referred to as (PL) and those from Digital Technology company as (DT).

Theme:	Sub Themes
10.2 Personal Experiences	This was an overarching theme with no sub-
	themes
10.3 Technological Change	10.3.1 Impact of Covid
	10.3.2 Backlash
	10.3.3 Future technological developments
	10.3.4 Drivers of technological change
10.4 Defining Citizenship	10.4.1 Citizenship as belonging
	10.4.2. Citizenship as activism
10.5 Barriers to Citizenship	10.5.1 Inequalities as barriers to citizenship
	10.5.1 mequalities as barriers to cluzenship
	10.5.2 Generation gap
	10.5.3 Mental health challenges as a barrier
	to citizenship
	Intersectionality
10.6 Moral and Ethical	10.6.1 Impact of technology on mental health
Dilemmas	10.6.2 Finding meaning, purpose and identity
	10.6.3 Voice and choice
	10.6.4 Risk and surveillance
	10.6.5 Power and activism

# Table 11: Phase 1 themes and sub-themes

# **10.2 Personal Experiences**

This was a theme highlighted by the peer researchers. They noticed how much people brought of themselves to the study, sharing their anxieties, concerns, and personal experiences of mental health challenges. Whilst the topic of future citizenship could be viewed in some ways as an abstract discussion it was meaningful for people, and they were incredibly reflective about their present experiences and what their future experiences may be like. It is worth noting, it was not just those from the peer-led organisation that reflected on their personal experiences of mental health challenges:

It can be difficult to be part of a community if you have mental health challenges, because from my own experience, sometimes you can isolate yourself quite a lot. Charlotte (DT)

I mean, from, from my point of view, paranoia has always been a part of engaging in society as well, that actually, some things feel fundamentally unsafe. Primate 10 (PL)

# 10.3 Technological Change

# 10.3.1 Impact of Covid-19 Pandemic

Participants reflected on the impact of the Covid-19 pandemic and how this saw an acceleration in the use of digital platforms to communicate and, because of this, it brought the research topic alive for people. It raised questions for them about the impact and dominance of technology. Participants described how technology currently impacts on every sphere of life:

I think if we'd have had this interview, maybe a year ago, the answers that I would have given you back then would probably differ from what they do now in certain respects. I think what the last 12 months has shown is how essential technology is to society. Bangsal (DT)

...especially this year you've kind of looked at the places where fundamentally providing services for people with mental health has become, kind of, there's one game in the in the park and it's digital technology. Primate 10 (PL)

The impact of Covid-19 resulted in issues such as such as digital poverty and people increasingly being encouraged to access public services via technology being brought to the fore (Jørring 2018; Jæger 2021; Eiroa-Orosa and Tormo Clemente 2022).

There was also a question of how much the impact of the pandemic would have on people's understanding of mental health, as more people were exposed to emotional stressor, whether that would lead to increased awareness:

[Due to covid] people understanding what mental health is, communities understanding what mental health is... it will be interesting moving forward... with what we've been through... we are potentially in a different place and that perception changing. Marmite (PL)

Eiroa-Orosa and Tormo Clementes' (2022) findings also raised this question. The increased awareness of mental health challenges potentially provides the opportunity to make the conversation about mental health and future citizenship a mainstream one.

Within the digital citizenship literature, there was an acknowledgement during Covid-19 that through the Black Lives Matter movement people had a different perspective on race and inequalities and some authors identified that there was a need for more critical and radical approaches to digital citizenship (Choi and Cristol 2021). This raised the question of whether there would be a similar movement in relation to mental health.

# 10.3.2 Backlash

Interestingly, several participants thought, post-Covid, there might be a backlash against technology:

I don't know if we're typical or not, but if we are then there might be a pinch point where people have just had enough. Kat (DT)

Interesting to see what sort of backlash there'll be because there's going to be a backlash. Colin (PL)

Despite this, all participants thought the use of technology would rapidly expand into all spheres of life.

# **10.3.3 Future Technological Developments**

Participants described these rapid technological developments as involving improved hardware and increased processing speeds, and the expansion of the use of virtual/augmented reality; automation and semi-automation; user interfaces (implants, wearables, voice recognition); big data; and social media. These would shape all parts of life: domestic; leisure; employment; education; transport; healthcare; communication; manufacture; military; politics; and increasing accessibility (supporting people with mental health challenges and/or disabilities.)

These reflect the areas outlined in future forecasting (Harari 2016, Fry 2018, Zuboff 2019) and the use of digital, AI and robotics in the future mental health literature (Giacco et al. 2017; Harriman et al. 2019; Priebe et al. 2019; Bhangra et al. 2019). It is worth noting there was not a strong emphasis from the participants on discussing the role of digital mental health treatments. This links with the critique of future social psychiatry by Russo and Beresford (2017) who argue the priorities of people with mental health challenges sit wider than the realms of psychiatry, emphasising the importance of people with lived experience shaping the focus of future citizenship.

People found it difficult to know whether developments will be beneficial or how easy it is to get reliable information. Whilst there was considerable concern expressed about the potential impacts of technology, positives were discussed:

It's really easy sometimes to kind of miss the huge kind of positive changes which technology has allowed us to connect to solve problems, which would have been unsolvable, but only a few years ago. Aspienaut (PL)

# 10.3.4 Drivers of Technological Change

Primarily people thought technological developments would be driven by profit and consumerism, but also how government and large companies maintain power and privilege:

I think it will be driven by consumers, consumer-driven but I also think that that will be easily manipulated by organisations. Rose (PL)

I think there's lots of people with power, who are very focused on what's going to benefit them and that that just happens. It's human nature and they're thinking, whoa. Well, let's enhance all this technology and we'll keep it all in here. Charli (DT)

The most valuable commodity in the world is that human being's attention and so I think that will continue to be the biggest driver and it will be that all the money is spent on trying to get you to stay on your device that little bit longer. Aspienaut (PL)

Critical approaches to digital citizenship highlight the motivations of corporations and the importance of not seeing digital technology as neutral by understanding the dynamics of power (Isin and Ruppert 2020). Zuboff (2019) tracks the development of surveillance capitalism, by focusing on how technology companies try to maintain the end users' connection to digital technology through wearables and internet enabled domestic products (such as freezers, doorbells) to exploit their data. The consumers become the product as their data and preferences are shared and sold. This becomes pertinent when looking at the moral questions relating to health and wellbeing and what is sold to people and in particular mental health risk and surveillance. It is also important when thinking about power and activism and how to lobby for change.

Some participants thought there were also social and moral drivers, especially in relation to healthcare and sustainability:

One thing that I anticipate is with the advent of smart watches, Fitbits and such constantly taking readings of people's bio-science, I think that may actually spill out into the medical field as well. So... I think that having longer term information at a GP's [General Practitioner's] hands or medic's hands is going to be able to give better diagnoses. Bangsal (DT)

There are potentially increased opportunities for political engagement via digital technology, which can create greater global mobilisation across shared concerns (Choi 2016; Isin and Ruppert 2020; Chen et al. 2021; Choi and Cristol 2021). However, research literature is inconclusive about whether the internet increases political engagement or whether existing activists now participate online whilst the disenfranchised are increasingly left behind (Jaegar 2021):

I think social responsibility because, you know, if you look at things like Black Lives Matter..., Greta Thunberg as a great example of it. The fact is, is that if there are enough people saying it then actually these things can happen. You know, and I think that the more and more people kind of understand that these things can occur. Primate 10 (PL)

Participants acknowledged that there were also hidden developments which were perhaps more nefarious forces on the dark web:

...in... reference to the dark web. You know there were, there would always be communities with kind of malicious intent or individuals with some sort of malicious intent and obviously that has just moved to the digital world, to an extent. I guess the challenge with that is that as individuals [with mental health challenges] we all have more vulnerability in a digital world. Aspienaut (PL)

Participants were in no doubt that technological changes would shape society and what it means to be a citizen. Critical digital citizenship highlights the complexities and power dynamics of interacting on the web and how this can lead to people being manipulated by governments, corporations, and criminals (Isin and Ruppert, 2020). The vulnerability that Aspienaut highlights is not considered in the future mental health literature and is therefore an important consideration in supporting digital literacy that is inclusive and addresses the needs of marginalised groups (Chen and Cristol 2021).

## **10.4 Defining of Citizenship**

Informed by the literature review, very broadly the definitions of citizenship can be separated into three types: those that are linked to the legal, political and national definitions of citizenship (the traditional understanding of citizenship linked to the definitions of Marshall,1987); those that focus on belonging, identity, linking to the 5Rs rooted in the DeTocquevillian and Durkheimian notions of civic participation and participatory citizenship (Rowe and Atterbury 2012; Ponce and Rowe 2018); and critical citizenship (Isin and Ruppert 2020). This latter category explores more pluralistic forms of citizenship such as global, consumer or digital citizenship, which reflect the impact of neoliberalism and how the internet has enabled connection across the world (Isin and Ruppert 2020). In considering future citizenship, this broader perspective is important as, to date, the mental health citizenship literature has primarily focused on an individual or group relationship with the state in a specific geographic location, rather than digital or global citizenship.

Largely, participants started with the politico-legal definitions before further reflection and broader considerations, which included: participatory citizenship, discussed as belonging; 'acts of citizenship', discussed as activism or having a 'common goal.' Participants described citizenship as being shaped by a combination of power relations, cultural norms, and individual differences.

## **10.4.1 Citizenship as Belonging**

People acknowledged the legal and political definition of citizenship but generally saw it as something broader, which has a focus on *belonging*. This can be to a geographical community or to having a shared interest or experience. It can relate to belonging to a social movement. For some it was about being part of the world (being a global citizen) and there was something significant about citizenship being connected to the whole and being connected to something bigger. These descriptions of citizenship are aligned with the wider literature on how people with mental health challenges understand citizenship and that broader sense of connection (Harper et al. 2017, MacIntyre et al. 2021; Reiss et al. 2022).

One participant saw this as a connection to *compassion* (Auba). This led others to talk about citizenship being self-defined or that there are multiple forms of citizenships linked to a sense of reciprocity. This sense of reciprocity is related to what and who you are able to engage with and contribute to:

I think for me it is about this identity thing about belonging to a tribe and sharing, sharing their beliefs and their values. Kat (DT)

Citizenship therefore works at a level which is actually I'm a citizen of this town. I'm a citizen of this county. I'm a citizen of this nation... and I'm a citizen of the world and therefore I think that citizenship is about how you go about kind of affecting that world, how you go about kind of making changes within that world or supporting groups to make changes within that world. Primate 10 (PL)

None of the participants saw digital citizenship as an entity, but rather the means to broader forms of citizenship through *connection*. This relates to the critical perspectives on digital citizenship, that the 'digital world' should be understood within the context of 'real life' rather than an entity in and of itself. (Isin and Ruppert 2020). Participants raised concerns about the risks of solely connecting online:

I think if people feel like they're not citizens or not part of their immediate community, the easiest place to go right now is to go online and find a community that you do sit in that you can take part in and then you get into this whole world of the echo chambers and you kind of almost lose and forget that... even if it's a positive thing that you're believing in you suddenly being that have such a strong belief that you can't listen to anybody else's point of view is still really dangerous. Charli (DT)

This picks up on the potential vulnerabilities of people with mental health challenges being exploited and radicalised online (Choi 2016). Therefore, it is important not to view all 'connection' or sense of 'belonging' as necessarily being healthy or leading to increased inclusion. This is where digital literacy and digital citizenship education can have value. However, it is important that in the interests of inclusion it is shaped by people with lived experience so that it more effectively meets their needs.

#### 10.4.2 Citizenship as 'Activism'

Those from the peer-led organisation linked this sense of citizenship and belonging to collective or social activism and in particular the importance of 'having a voice.'

For me it's about community, belonging, connectedness, rights, being able to participate, being able to have a voice and being part of a broader whole. Marmite (PL)

I think citizenship goes beyond that [Belonging]. It's almost like you're working towards a common good. Colin (PL)

This notion of having a voice came across strongly as a defining feature of citizenship for people in the peer-led organisation. This may be due to the activist element in these roles or due to experiencing citizenship from an 'outsider perspective' whilst having to fight to have your voice heard. This links to 'acts of citizenship' through speaking up and challenging existing power structures which are consequently disrupted (Isin and Turner, 2008). Whilst not expressed as having a voice, speaking up or directly participating in peer-led activities strongly relates to participatory citizenship (Quinn et al. 2020; Reiss et al. 2022). The consideration of how people shape and define citizenship from their own perspective is an important theme. This is the experience of those

within a peer-led organisation. However, many people with lived experience do not have access to peer-led organisations that can support them to access their sense of activism. It is also worth considering if people who join peer-led organisations may be more drawn to activism. In thinking about promoting future citizenship, it is important to create spaces for people to participate and define their own sense of citizenship and be supported to do so by others with lived experience, alongside broader allies.

## **10.5 Barriers to Citizenship**

## 10.5.1 Inequalities as a Barrier to Citizenship

Participants described that people can be excluded from citizenship through poverty, the pressures of day-to-day life, lack of opportunity, the impact of sociocultural expectations, oppression and having a lack of power. This brings a sense of people being left behind, a loss of identity, purpose and control, alongside material hardship. As life increasingly moves online, lack of access to, and understanding of, technology can exacerbate these inequalities, further impacting people's mental health:

And there's a lot of people that are being left behind, even in such a small country [England]...there's just a big shift to be made, to better everyone's experience and it will have an impact on people's mental health. Charli (DT)

The Covid-19 pandemic further highlighted these inequalities (Beresford et al. 2021), These exclusions have been discussed in relation to people's ability to participate in co-production but is equally applicable when thinking about citizenship (Beresford 2019). This is why it is fundamental that discussions on citizenship and promoting citizenship are situated within their political context and the importance of the struggle for equal social rights.

Aspienaut thought these divisions, especially the socio-economic ones, would lead to new expressions of emotional distress:

...there'll be a greater division. That will be seen around how people present with their own forms of societal pressure and distress, which will lead to different mental health issues and I think you'll see the separation of the affluent and the socially excluded and there will be really weird, really weird expressions of human distress that we might not even know. Aspienaut (PL)

Aspienaut emphasises the tension of how neoliberalism is shaping citizenship as people are encouraged to engage online and as consumers (Cruikshank 1999). The danger is that this leads to a reduction in social participation and greater exclusion, which further undermines people's mental health (Atterbury and Rowe, 2017, Quinn et al. 2020). Therefore, it is important not only to understand future citizenship but also how we understand current and future conceptualisations of mental health.

# 10.5.2 Generation Gap

There was a particular concern about the pressures on the mental health of young people, and of older people being left behind:

I don't think people are going to keep up and there's going to be a thing that you'll see, different age groups are going to be able to cope with it in different ways and at different speeds. Kat (DT)

Even middle-aged participants felt they were falling behind:

## *I am probably behind because I am not a kid* Cash (PL)

Therefore, there may need to be different approaches to different age groups in promoting inclusive citizenship.

## 10.5.3 Mental health Challenges as a Barrier to Citizenship

Mental health challenges were seen to be a barrier in two ways: firstly, when mental health is impacted it is difficult to engage more broadly in society: If you're struggling with something like depression, you might not have the drive to go and volunteer. So, you are then kind of missing out on, you know, your local community because you can't physically go and I feel like if you weren't suffering from mental health issues that wouldn't be a problem. Charlotte (DT)

Secondly, the stigma and discrimination people experience in relation to their mental health:

I think there's really quite a lot of stigma still around, although there's an awful lot of work going on to reduce that stigma. It is that sense of belonging, and then I stand out. Because people crave, they crave belonging somewhere. And if they choose to be unique, that's their choice. But if they don't choose to be unique, I think it can be very isolating and lonely, which is one of the fears, I think we all have about being lonely. Kat (DT)

Primate 10 describes how the impact of mental health problems (in particularly the impact of trauma) and stigma intertwine in creating a barrier to citizenship:

...the thing that has kind of created quite a lot of stuff is that people usually visit trauma upon other people. And you know what that does, that breaches trust and that means that that you aren't quite as happy with society as you might have been... means that trusting things like big tech companies, trusting things even like the government...I think it prevents them from really being able to engage because they just feel disempowered. Society has judged them you know that lots of people have judged them. And you know what I am tired of feeling judged, I really don't give a monkey's about the rest of you, so you know it makes active citizenship a little bit difficult, you kind of end up being almost a passive citizen, rather than anything else. Primate 10 (PL)

Primate10 highlights the importance of understanding the impact of trauma and how this can impact on building trusting relationships. This in turn impacts on the relationship element of citizenship or the trust in the government or state. This reflects the importance of negotiating relationships (MacIntyre et al. 2021)
and overcoming trauma (Hamer 2014) to be able to participate as a citizen. This emphasises the importance of considering trauma-informed approaches not just in mental health but also more broadly in society.

Aspienaut raised how stigma is built into how we conceptualise mental health through the framing within the biomedical paradigm:

It's so hard to achieve [mental wellbeing] within the systems that we've created where we funnel people through an education system to fill economic societal needs. That detaches from our ability to connect towards the meaningful and important and that feeds the other system. But there's a lot of people who... are living lives of quiet desperation. And that's perfectly normal now you know, and I think that's the other mental health issue...There's an over medicalization of one part and an under recognition in another and then one feeds into the other. This kind of pinch point where one transitions from normal human experience into a pathology medicalized economic model. Aspienaut (PL)

This echoes the calls for a greater focus on the social determinants of health and social support in the Mental Health Future Studies literature (Bhungra et al. 2017; Giacco et al. 2017; Priebe et al. 2019), and those who call for a move away from individualistic to more collective ways of understanding mental health challenges (Torrents 2022). Hamer described how the biomedical approach collapses people's sense of agency (Hamer and Finlayson 2015). The concern is that in future, with an increasingly technocratic society, this will be exacerbated if these are not reconceptualised and shaped by those with lived experience. Auba (PL) calls for empowerment of people with mental health challenges:

I think in mental health that has to be empowered... not de-powered, which a lot of times happened in mental health. Lots of people are, even myself to a point, are de-skilled, de-franchised out.

Those from the peer-led organisation felt that people with mental health challenges experienced additional barriers to accessing citizenship that were

distinct from those from other marginalised groups, specifically related to the Mental Health Act 1983. This was similarly identified in Hamer et al. (2017):

There is that layer of the Mental Health Act you cannot get away from, there is that coercion and control, that a piece of legislation that has the power to do that makes the concept of citizenship and need for citizenship and having a voice even more important...if you have a piece of legislation that can take your liberty away just because you are ill, you've done nothing wrong, it's another layer. Marmite (PL)

Other additional barriers were depicted as due to a culture of low expectations, perceived lack of capacity regarding decision making, perceived concern about risk and having a "lack of a voice", particularly for those who have more moderate to severe mental health challenges:

How people are treated because they have a particular medical diagnosis or they have a particular experience or I think that it's very much filtered...we're not going to talk to you about this over here because we don't actually necessarily want to understand your perception, because it may be different or it may be unreliable, potentially... it's that stigma. So, I think there is a real issue. Rose (PL)

You have certain labels and you'll be medicalised and treated in certain ways... and I think the saddest thing is when you meet people who have bought into it and feel they don't deserve any better or they should be thankful that they've got a bed and a consultant continues to give them the same medication and they shouldn't have aspirations or dreams and their medication helps them to stay like that to a degree as well. I mean, it's a fucking tragedy isn't it. Aspienaut (PL)

Therefore, part of the struggle in promoting inclusive citizenship is challenging the biomedical dominance in how mental health challenges are conceptualised and treated.

#### 10.5.4 Intersectionality

Participants discussed the relationship between stigma and mental health activist groups and other groups who are marginalised. Some people felt the rights movement for people with mental health challenges is less prominent than the LGBTQ+ movement and Black Lives Matters activism:

You know there's definitely still a shame attached to mental health. You know, let it go through the maybe the lesbian, gay and transgender LGBT plus movement. 30 years ago, 40, let's go back to the Stonewall days there was almost a sense of shame around being gay and that Stonewall movement made a massive difference. Colin (PL)

Whilst, not naming it as intersectionality, Auba (PL) calls for the importance of combining the struggles of oppressed groups and how this is central to everyone's mental health:

When I heard about Black Lives Matter and LGBT and stuff like that, the statement I'd like to make around that is that any group of people, wherever they are from, the human psyche, whenever they are repressed or oppressed will compromise everyone's mental health. That how I see it.

Charli from the digital technology company felt that exclusion and barriers were common to all excluded groups:

I think they apply across a lot of groups in different ways, and I feel like if anyone who feels not able to be their whole selves within their communities will be affected in that way. It's not necessarily specific to mental health. Charli (DT)

Cash (PL) links the polarisation in society from deep-rooted inequalities:

Increasing polarisation of views and that leads to more marginalisation...

I think there's the reality that the system we currently live in comes from a long history of deep-rooted... marginalisation... there's a historical thing around actually the society we've built, you can trace that back to slavery and discrimination against all sort of groups.

Carr and Ponce (2022) call for a network of marginalised groups to support inclusive citizenship for all. These discussions highlight the importance of considering intersectionality, as having mental health challenges does not mean you are not subject to other forms of discrimination such as racism or homophobia. There needs to be a focus on collective struggles but also the subtleties of differing needs. For example, black men are currently subject to the most restrictive practices within the mental health system and gender diverse people have particularly poor experiences of mental health services (Torrents 2022).

### **10.6 Moral and Ethical Dilemmas**

### 10.6.1 Impact of Technology on Mental Health

...it's important for people to think about the degree to which their mental health influences what they use technology for or the degree to which their mental health is impacted by the use of technology...So that kind of two-way travel between those two states that people need to best understand what their relationship is in both those directions so that they can have some control over how they use technology, either to reinforce or to, you know, to be influenced. Aspienaut (PL)

Questions were raised about how technology will (and does) impact on mental health and reflection on how technology may shape experiences of mental health challenges. This builds on the discussions outlined in the previous section about definitions and challenges as to how mental health is understood (and the role technology plays): Yeah, so I think people are becoming more and more disconnected from any sense of being able to ground themselves in the world....and their validation is external, as is the locus of control and they'll lose more of the controls. Technology creates greater opportunities for them to draw their attention, out of the reality into this, into this self-perception. And that will exacerbate conditions like attention deficit disorder which again will be medicated hugely. You'll create these pressures and expectations and inability to switch off that will exacerbate things like bullying and will exacerbate things like a perfectionistic kind of personality traits which will lead to things like eating disorders and dysmorphias and yeah and those kind of associated conditions... Aspienaut (PL)

Marmite (PL) described how different scenarios may be enacted in how technology will change mental health services:

One scenario might be that it would enable services as we know them...to get even more prescriptive and medicalised around how they respond to people and the technology could make it easier for them to do more things that are unhelpful for people. Or you could argue the other way, the technology could enable a breadth of perspective, voice and breadth of experience that could challenge.

The impact of technology includes: the potential impact of echo-chambers; narrowing of world views; the draw on our attention; the addictive nature of the internet; and the impact of bad actors (dark web, trolls). People from the peerled organisation highlighted their vulnerabilities and vulnerabilities of others to negative impacts:

I know if I am struggling, particularly in a certain area... I'll look for things that validate my perspective or that helped me to feel a sense of belonging or a sense of purpose or whatever it is. And actually, I would say at those times, I would be more vulnerable. Rose (PL) Algorithms, especially on social media or any website nowadays, are trained to feed you things that they think you'd be interested in regardless of morality, regardless of anything else. So if you're in a bad mind, a negative mindset...then [it] feeds you that for the next two weeks because it thinks that's what you want to see and by being fed the information regularly, you probably are going to be affected in the long term. Charli (DT)

There were also discussions within the co-production workshop about the impact of fear and people's lack of engagement with technology and how this can lead to further fragmentation in society.

### 10.6.2 Finding Meaning, Purpose and Identity

As well as questions about how technology impacts on mental health, a broader discussion occurred thinking about how we find meaning, purpose, and identity in a changed world (particularly one with less work):

Do we just automate it for the sake of efficiency, or do we make sure that we've still got a population of people that can have jobs and feel like they, you know, have a role in society and to make money and all that sort of stuff? I think that will play a big part in where it goes next. Charli (DT)

You're losing your identity, it's your purpose and all of that...and the fact that you can't actually access normal daily things, like getting a plumber. Everything is a login, you forget your login so then you're locked out of something like banking, just all those little things that you used to be able to do and be in control of you've now lost that control. And so, I worry about those people and how that affects their wellness. Kat (DT)

Hamer et al. (2017) talk about the importance of 'Homo Occupacio' and how participation in occupations enable people to act as citizens. Consideration needs to be given to occupational identity within a digital world and how we find meaning and identity in an increasingly technological world. As an occupational therapist myself it is an important area of consideration for our profession,

working alongside people with lived experience to shape and understand these opportunities.

This is particularly important for people with mental health challenges, (Hamer et al. 2014; Pelletier et al. 2017; Vervliet et al. 2019), and this is echoed by Rose, who suggests that people with mental health challenges are often already excluded from many opportunities that shape their own identity:

...particularly those people who experienced serious mental illness are given access to those opportunities that we talked about, whether that's education, finance, or knowledge so that I think there is a power imbalance, where there is still kind of narrow you can participate within the constraints of what we described is suitable for you. Rose (PL)

Technology was thought to provide opportunities to promote a greater sense of shared humanity, compassion, and acceptance around mental health:

There's just a big shift to be made, to better everyone's experience, and it will have an impact on people's mental health because they feel like they're taking part. It will have a better impact on people's understanding and empathy for each other. And I would imagine that it would probably also have an impact on politics in our country as well. Charli (DT)

Technology has got a huge, huge opportunity, you know, just 30, 40 years ago, people didn't leave their communities...whereas through digital engagement, you have the real opportunity...You could be in a digital classroom alongside people from different cultures, different backgrounds, you know, there's loads and loads of opportunity to learn from one another. I think there's an opportunity to become much more global in our outlook and engage much more. Rose (PL)

However, concerns were expressed about the impacts on people's lives as the lines between human and AI become increasingly blurred:

Are we going to find ourselves in a place where people don't necessarily know if they're interacting with a real person or a computer? Where we're now approaching that point where it's going to become increasingly difficult to tell the difference between the two. So, I think there's going to be lots of moral questions, ethical questions that get asked over the next 10 years of how far should the reach of technology go? Bangsal (DT)

There was also much concern about the lack of human-to-human connection, people losing their skills, being able to relate to each other, and the importance of the *"5 Senses"* (Marmite). The future mental health literature raises the possibility of AI mental health professionals (Giacco et al. 2017) but does not address the ethical issues from a lived experience perspective that were highlighted by the participants in this study.

#### 10.6.3 Voice and Choice

One of the key elements in promoting positive outcomes is ensuring people have a voice and the opportunities for technology to support this. This was especially important for those who worked for the peer-led organisation. The need identified was to ensure people with mental health challenges (and other marginalised groups) have a **voice** and, alongside this, have **choices**:

When you don't have voice and when you don't have power, but you seek out like-minded people and you start to realise that perhaps the way things are isn't the way that it should be, then you know you can assert your right to citizenship, your rights to have some kind of influence. Rose (PL)

It's the rights-based stuff and having a voice – what technology does is gives the opportunity to bring more voices and perspectives into the mix in a way that broadens it out and brings that groundswell, the movement, it's a social movement... digital can be a real game changer around moving power. Marmite (pL) Where they put forth the idea that the AIs could probably get to the point where they might be able to detect whether somebody is actually going into a crisis from a mental health point of view... I guess it's the choice as to whether you let it in or not. That's always been my thing...choice. Primate 10 (PL)

This relates to both mental health treatment and engaging as a citizen. It includes increased equality of opportunity and the material conditions to support people and without this there is a concern that people will be left behind. In the co-production workshop, the issue of not having access to technologies in the future was raised in terms of restricting access to certain elements of society:

The biggest challenge, I think, is literacy. So, and I don't mean in the traditional sense. I mean, in the actual concept of what citizenship means I think being able to access, you know, for lots of people and the relationship between, for example, poverty deprivation and mental health issues, the exposure to the opportunities of citizenship are so minimal that it wouldn't even be a consideration that they would have any influence, that they have a right, or an opportunity to participate in the world. Rose (PL)

there is a real risk of you getting left behind or a real risk of you not being a citizen in the current mode... the divides got bigger... whether that is due to fear, knowledge, money. Marmite (PL)

One of the ways of mitigating against some of the negative impacts of technology is to have people with lived experience co-produce it:

If it is a system that is designed with a level of humanity, with that kind of social justice kind of element to it...So yes, I think that, again, people helping design that would be a marvellous thing especially people who would access the services in the future. Primate 10 (PL)

Co-production in relation to digital technology involving those with lived experience does not feature strongly in the literature (Hariman et al. 2019).

Participation and being an 'active citizen' fits well with 'acts of citizenship' (Isin and Turner 2008) and the call for mental health professionals to be allies is a key part in creating more inclusive futures (Brannelly 2018a; Hamer and Finlayson 2015). There is scope for people with lived experience to shape their own citizenship, not just by participating and co-producing mental health technological solutions and future mental health services, but by leading them with professionals campaigning alongside them. A key element within that is people having choices over the extent they engage in digital supports or treatment, particularly with the relationship between risk and surveillance.

#### 10.6.4 Risk and Surveillance

Concerns were raised that future treatment pathways would be rigid algorithms and **risk driven** (especially if privatised), and that people could be forced into receiving treatment they did not want/need. This was a particular concern if a biomedical stance continued to have dominance. The citizenship literature acknowledges that when mental health is associated with dangerousness, this compounds people's experience of exclusion (Hamer 2012; Hamer 2014; Hamer and Finlayson 2015; Hamer et al. 2017; Harper et al. 2017; Vervliet et al. 2019; Hamer et al. 2019; Cogan et al. 2021). Whilst participants did not talk about being perceived as dangerous, they highlighted the impact of the Mental Health Act 1983 on citizenship. This reinforces the biomedical framing of mental illness and how technology, if unchecked, could potentially reinforce this. Linked to this is the role of digital mental health monitoring for support vs **surveillance** and vulnerability to exploitation:

There could be lots of things that are automated that happen without you necessarily having choice and control...So everything that you considered to be your basic needs, maybe kind of pulled out [of your wages or welfare] ...maybe it could potentially be defined for you as opposed to by you if you were in a particular class... part of society...You know, everything can be tracked in terms of, of what interactions you have... I think that that is has potential...to reduce people's rights or opportunities to have choice and control. Rose (PL)

Concerns were raised about the impact and future extensions of the Mental Health Act:

The fact is, that if the risk levels on a given device are set to a certain level then, actually, that is just about automating a response, rather than making a human response and where that means a call for help goes out whether somebody arrives or, you know, you get a message to report to this place here so that you can be treated by somebody that's you know that for me just feels it's going to be dictated by whoever creates a system...It's almost like having the Mental Health Act on tap. That would scare me brutally to death. Primate 10 (PL)

Several participants called for further reform of the Mental Health Act 1983 in order to promote future citizenship:

The Mental Health Act has to be completely changed and the whole ethics and the way it's designed and set up has to take into consideration the human being at the end of it, not what the desired effect and the control of it is. So, if you wrote it again, it should be coming from a place of inclusion, of compassion, of transparency, of tolerance, of understanding. Auba (PL)

Emejulu and McGregor (2019) call for radical exposure of power structures in the digital world and greater levels of transparency. It is clear from the experience of the participants in this study that there is a desire to totally redesign the Mental Health Act (1983) in line with a more compassionate personcentred approach to mental health. This is a step further than the current proposed UK Government (Department of Health and Social Care [DHSC] 2021b) reforms of the Mental Health Act 1983. It is a plea for wholesale change. There is concern about the risk of greater control and surveillance implemented through technological approaches without reforms and understanding:

It's a system that is created because the Mental Health Act and... because of the way society treats mental health. It isn't about keeping the person well; it's about managing of behaviour and the behaviours connected to the absence of actual support and human connection. The system is necessary because of the system. It's self-perpetuating...It isn't about making people feel safe it isn't even about safety. It's about control. If it was about safety you'd be asking people what happened to you to make you feel like this...what is the pain? Aspienaut (PL)

Mary O'Hagan (2013) provides a blueprint for a more inclusive approach to the Mental Health Act, although she does not include technological solutions or elements. Much of the Future Studies Mental Health literature calls for a more rights-based approach with a reduction of coercive approaches. In the UK there has recently been a consultation on proposed changes to the Mental Health Act 1983. The findings of this consultation propose a strengthening of the right for people detained to overturn their detention, strengthen their rights to refuse treatment, and create a higher threshold for the use of Community Treatment Orders. Interestingly, the use of remote technology to undertake assessment was rejected. However, despite this there are concerns from NSUN (2023) that technology is being used to increase intrusive blanket surveillance within inpatient settings, such as the use of Oxevision, a patient monitoring system consisting of a camera and infrared sensor. This highlights the importance of considerations of rights and privacy in relation to technology and the Mental Health Act 1983, which are not explored in depth within the DHSC (2021) review.

Within the DHSC (2021b) consultation there is also greater consideration of the needs of people with learning disabilities, autism, and people from black and minority ethnic communities. National Survivor User Network (NSUN, 2022) describe the findings as having the potential to improve the experience of people who are detained if sufficient funding and focus is given to the reforms. However, NSUN (2022) claim that, fundamentally, the reforms do not go far enough in replacing the existing legislation with a rights-based framework which is concordant with the spirit of the UNCRDP, nor does it go far enough in addressing the institutional racism inherent within the Mental Health Act 1983.

The participants in this study call for an overhaul of the Mental Health Act and not an adaptation of the existing legislation; there are real concerns of creeping surveillance and control if reform is not wholesale. These demands sit alongside those such as King and Jeynes (2021) who claim the Mental Health Act is inherently racist and not fit for purpose. There is a clear need for further specific work on the direction of the legislation, ensuring that any future use of technology is designed with people with lived experience, and particularly those more likely to be subject to the most coercive elements, such as people of colour.

#### 10.6.5 Power and Activism

This raises questions about how change can be enacted, who will have power and access to decision making, who will define citizenship, and who will make decisions about society?

Whose power and control is it? And who is shaping citizenship... and if it is being equal and fair across the rest of the citizens. Probably not... Who's legal, who is shaping legal who is shaping what citizenship should look like, who's doing that, is it you, is it I or is it the institutions or the government or whatever? So, transparency that is what I would look for. Auba (PL)

This raises concerns about the checks and balances, ensuring transparency, and the role of protest and activism. Primate 10 (PL) uses the example of GDPR to highlight the possibility to change things and how governments/democratic institutions can have control over corporations:

Actually, having the ability to pressurise governments in order to be able to make sure that companies don't have that power; I think is one of the most important things. So that is actually something where actually the activism and the citizenship again can kind of be used in order to be able to kind of inform how that goes.

Auba highlights the relationship between human rights and struggle:

...Citizenship is... it's been trying to be attained for certain groups of people who believe that they should have it, and never had it, and human rights and all that issues around that side of it. You know that it's a major human right and who is shaping citizenship? And what does that look like and whose citizenship is it?

This links to the importance of having a voice and being able to campaign for change as a fundamental part of citizenship and shaping the future. These themes were taken forward for further analysis with the peer researchers, which informed the development of the film.

#### 10.7 Conclusion

This chapter has explored how data from the first phase of the research was integrated with some of the findings from the literature review in creating a coproduced film to stimulate discussion. The film covers key factors that will shape future citizenship for people with mental health challenges and tackles the main challenges and opportunities to promoting inclusive futures. The film created an engaging way to convey the complexity of exploring future citizenship whilst enabling the viewer to take a reflective position in thinking about key issues and ethical dilemmas.

In the second phase of the research the film was shown to participants with a view to examining the most important themes in addressing inclusive future citizenship for people with mental health challenges. It was anticipated that the film would also work as a standalone piece of work in the dissemination of this PhD. The next step within this research was to share the film with participants and explore what, if any, action it would engender in promoting inclusive future citizenship with the existing participants (Kindon et al. 2007). The participants' experience of watching the film and value of Future Studies will be discussed in chapter 11 alongside the key themes generated in exploring how to enact inclusive future citizenship for people with mental health challenges. The themes from both of the findings chapters and the literature review will be analysed in chapter 13, alongside the round table discussion between the members of the research team (appendix 16).

## Chapter 11: 'Citizenship, it's about having a voice' Findings Phase 2

The primary research objective within phase two was to address what could be done to promote *inclusive future opportunities for citizenship for people with mental health challenges.* The emphasis was on *Action*, as part of the cycle of CBPR (Kindon et al. 2007), through exploring the key areas of importance to take forward. This was achieved via a focus group that involved discussions between the participants, peer researchers and academic researcher. This blurring between participants and researchers was important as part of the coproductive approach of the study.

Chapter 10 explored phase one: the co-production of the film based on data from the interviews and co-production workshop. In this second phase, participants were asked to watch the film ahead of attending the focus group. In the focus group they were asked to reflect on the impact of the film and their participation in the research. They were also asked what they thought the main issues were in promoting future citizenship for people with mental health challenges and what, if any, actions they were prepared to take. As described in chapter 9, the digital technology company were unable to participate in this phase, so only the peer-led organisation was available to attend. The knowledge exchange was therefore between the participants and researchers.

The transcript of the focus group was co-analysed with the peer researchers. Braun and Clarke's (2006; 2019) reflexive six stage thematic analysis was used. This chapter has tried to use the voice of the participants as far as possible to describe the rationale for and content of the themes. The four key themes that were identified were:

- 'Who holds the power?'
- 'Divide'
- 'What it means to be human?'
- 'Having a voice' ('and caring about it')

This chapter opens by looking at the value of the film and role of Future Studies as an approach to explore issues of citizenship for people with mental health challenges from participant perspectives. It then explores four key themes in depth and how they relate to the literature and previous stages of research. The chapter closes with an overview of the actions identified through the focus group. These actions are not set against the themes, as often they address more than one theme but rather as local/regional and national/international actions.

### 11.1 Value of the Film

Overall, the peer-led organisation demonstrated a strong commitment to the study and one participant summed up the process of watching the film and the focus group providing an underpinning to the future direction of their work:

This session and the film, you know, I think there'll be quite a lot of impact from this and then it will affect everything that we are doing moving forward, I see this as something that will build in terms of momentum. Marmite

It would be interesting to explore what the impact of viewing the film alone (without the interviews and workshops) would have on a viewer and whether it was effective in stimulating discussions on future thinking.

Participants engaged with the film in the way that we had hoped; for example, they made emotional connections to the characters that Bex played, and this supported their engagement with the topic (Baumann et al. 2020). Some people used the word 'powerful' to describe the impact of the film:

I thought the film was very clever... I could imagine ... Juniper's life her network, how, what her life looks like, what her social interactions were, what her reality was.... Marmite Thinking about Bex's character and you know that that sense of autonomy and what it means to be a human being with choices and options how that might be fundamentally changed in that futuristic view really, really came across quite powerfully to me. Laurel

People had a visceral response to the film and described feeling concerned, or even terrified about the more dystopian futures presented in the film:

a really terrifying thought. Rose

really terrifying Laurel

lots of concerns and worries Janet

One participant felt that the film enabled them to see some positives when previously they had been against more technology:

I'm definitely seeing some positives after watching the film. Colin

### **11.2 Value of the Future Studies Approach**

It was useful to explicitly ask about people's experience of the Future Studies approach. During the first phase of interviews, participants reflected to the academic researcher how useful and interesting it had been to discuss the future. However, these conversations took place after the recording had finished rather than forming part of the interview. In future research, it would be good to consider including questions and data on the experience of the interview to develop the practice of Future Studies.

Participants described the value of Future Studies as giving them a sense of agency, which links to the themes in the data around 'power' and 'having a voice.' This chimes with the Future Studies climate change research that demonstrates people feel like they have a greater sense of hope for the future and more control after participating in Future Studies workshops (Ojala 2015).

In the short-term some participants spoke of a sense of agency that was motivating:

It's a reminder that we have a role to play and potentially some agency in creating what that future looks like. Rose

I think sometimes you need to feel that you still have agency over what might happen in the future, that the pitch is not set. Janet

Janet goes on to state, *'It gives you a sense of motivation and a sense of actually we can, as activists, kind of work with that'.* This adds to the argument that Future Studies has a useful role in promoting citizenship, especially in relation to Isin's concept of 'acts of citizenship'. This links to the importance of being able to imagine more inclusive approaches to enact change (Isin and Ruppert, 2020)

However, without that activist element or ability to influence the future it can potentially have a negative impact:

It's useful looking to the future, as long as you're not seeing it as a runaway train that can't be changed because, if you do look at the future and you're in that mindset then it's just going to stress you out. Colin

This led to a discussion on what influence you can have locally and then nationally or globally. This needs more planning and courage. Other participants found using a future thinking approach enabled a different perspective on the present:

I think it's been really important to stimulate the conversation...So without having gone to the future I'm not sure it would have been the same type of conversation and therefore kind of stimulated us to think as clearly about what it means for us now. Rose

Within the session, participants moved between the past, present and the future. This was particularly stimulated by the Covid-19 pandemic which brought a rapid uptake in the use of technology, an increase in inequality and a radical

change to our lives (Beresford et al. 2021). Therefore, by exploring the impact of the present, people reflected on the future and vice-versa. People reflected, as evidenced in the themes below, on access to WiFi, technologies that are already here, conversations about technology that are currently taking place and opportunities to campaign and shape them.

The feedback people gave on the value of Future Studies, reflects the discussions within the discipline of Future Studies about its value to participatory social movements. As themes are explored, the role of power is highlighted, as an important part of critical futures and a way to challenge dominant discourses (Inayatullah 2013). The primary purpose of this study was to explore the possible (Fischer and Dannenberg 2021), and through the co-productive participatory process enable people to define citizenship (as participants did in the first phase of the research) and explore different possible futures to identify steps towards preferable futures (Amara 1991). These central areas are identified through the four themes and the analysis of the focus group. These themes are explored in this chapter (see table 12 for themes and subthemes)

Theme:	Sub Themes
11.3 Who Holds the Power?	11.3.1 Knowledge is power/Data is Power
	11.3.2 Agency
	11.3.3 Democracy
	11.3.4 Opting-out
11.4 Divide	11.4.1 Digital Poverty
	11.4.2 Generational Divide
	11.4.3 Addressing the Divide
11.5 What it means to be human	11.5.1 Connection
	11.5.2 Uncertainty
	11.5.3 Promoting Understanding
11.6 Having a voice	11.6.1 Collective Action and Activism
	11.6.2 Dissent
	11.6.3 Co-production

### Table 12: Phase 2 themes and subthemes

### 11.3 Theme: 'Who holds the power?'

One of the most prominent themes that reoccurred through the session was one of power: Who has it? What gives people power? How can people with mental health challenges claim some additional power? Building on the discussions in the first part of data collection, and in line with the literature on citizenship, Janet set the context for the discussion highlighting the existing lack of power and discrimination that people with mental health challenges experience through bias and exclusion *"Isn't there bias already…people make decisions about us, without us."* 

### 11.3.1 'Knowledge is Power'/ 'Data is Power'

Initially the discussions on power focused on the role of knowledge, with Rose stating one of the impacts of watching the film was *"The concept of knowledge is power and, actually, that came screaming lough."* She later expanded on this, *"If you don't have access to that knowledge... by default you have less power and less control".* She also described that having access to knowledge was linked to participation, but even knowing what to know was oblique and therefore even more exclusionary, *"It's the broader knowledge, it's the knowing what I need to know in order to be able to participate."* 

In the literature people with mental health challenges talk about the difficulties of knowing the rules, which are often hidden, and the challenge of doing this when managing exclusion due to mental health (Hamer and Finlayson 2015; Vervliet et al. 2019; Cogan et al. 2021)

Marmite saw access to knowledge about making informed decisions as fundamental to future citizenship and creating spaces to enact this as being key:

If we're talking about citizenship then, and obviously there are payoffs for all the decisions that we make in life, but actually being able to make the decisions and choices in an informed way and in an inclusive way, so that we don't pay the price of being citizens and our citizenship and our rights and all the things that go with being human.

In terms of thinking about actions for the peer-led organisation, Marmite reflects on the point raised by Rose about the importance of creating spaces for people to learn about their personal power and citizenship:

I think it's Rose's point around knowledge really, about being able to make informed choices and creating the spaces for that to happen, that would be the priority for me. Marmite This highlights projects in the mental health citizenship literature, whether that is the structured citizen programme that Rowe and colleagues offer (Clayton et al. 2017), or the participatory projects proposed by workshops or community projects (Quinn et al. 2020; Reis et al. 2022). These programmes currently lack a focus on digital citizenship and the impact of technology. If the peer-led organisation is to take this forward, there needs to be a discussion about whether they wish to join or try to influence an existing programme or (co)create their own.

The discussion on knowledge and power moved into a conversation about data and power. Colin identified societal split:

A split between those who provide data and those who exploit that data for financial gain, or whatever. You know there's going to be less jobs in the future...a huge unemployed class whose job it is just to provide data to people who will then use that data to make money from in their business.

In response to this Rose raised the question of *who holds the power?* Colin expanded on this by stating some people's 'job' will be to provide data and those receiving it or *mining the data get the benefits from that*. This highlights the issue that it is not just government and individuals/groups that shape citizenship, but it is also a question of who controls the internet (Isin and Ruppert 2020).

It is important to understand discussions on citizenship in the context of neoliberalism and hyper-capitalism, where citizens become subject to new 'technologies of citizenship' (Cruikshank, 1999, p2). These new technologies are where people are directed to consumerism and people's participation in society is monetised. Zuboff (2019) suggests that citizens as participants become commodities as they increasingly allow their lives to be under surveillance, allowing increasing individualised marketing opportunities and increased potential for manipulation. Eiroa-Orosa and Tormo Clemente (2022) describe the current state of citizenship for people with mental health challenges as a 'crisis of values' (p9).

As Rose described, people with mental health challenges, or other marginalised groups excluded from access to knowledge, are more vulnerable to exploitation by groups, corporations, and governments. To counter-balance potential exploitation the focus group discussed people's opportunities to exercise their collective or individual power as citizens through promoting an ethical rights-based framework focused on promoting agency and democracy. These two sub-themes are explored next.

### 11.3.2 Agency

Janet suggests that, if data is power, it is a way that people can claim some influence:

It's about where we have agency over some of this stuff & agency over our data if data is power, how can we take that back in a way?

Participants reflected on the character XA754 and concerns about the role of automation and surveillance algorithms further eroding people's sense of independence:

How that then looks for people who are having decisions made for them by machines, you know thinking about Bex's character [XA754] and you know, that sense of autonomy. Laurel

This links to concerns about people's personal agency collapsing due to biomedical framing of people's distress (Hamer and Finlayson 2015) and the potential extension of this through automation. In addition, consideration of who initiates programmes is important as studies expose gender and racial bias in algorithmic programming which have real life consequences (McQuillan 2023). The specific danger with technology is it being described as value neutral and so discriminatory attitudes can become hard-wired into society (Isin and Ruppert 2020).

In the first Findings section, repeal of the Mental Health Act 1983 came across as a key theme. Interestingly, it did not feature heavily in the second part of the findings. This may be because there was no specific focus on the Mental Health Act in the film. It may have been assumed by the participants that it would be part of the activism work and part of having a voice. Either way it is an important consideration for Future Studies in mental health, particularly relating to the use of technology, citizenship, and the reduction of coercive practices. The use of technology within the UK government's review of the Mental Health Act 1983 (DSHC 2021) was rather narrow and did not address the use of technology as surveillance (NSUN 2023). As it was such a strong theme in the first Findings section it would be beneficial to undertake further research looking at this specifically, especially because of the implications of increased surveillance and monitoring through technology. Janet stressed the importance of digital ethics: 'We also need to think about the ethics of this, think around the ethics of digital *citizenship.*' This was not just a future consideration but a present concern as 'people are being surveyed already without their knowledge'. It is for this reason that it is important a discussion of the impact of technology takes place in the context of current mental health citizenship and it is recommended that other authors looking at citizenship and mental health address this consideration in studies they undertake in the future. Janet also describes how as an organisation they already uphold people's "digital rights."

Rose described how following the previous workshop there had been an increased focus on digital rights and how this had been promoted within their organisation's advocacy service and recovery college. This demonstrates a tangible outcome from this study and may be worth evaluating and, if successful, promoting to other recovery colleges and advocacy services.

Having agency and being able to influence and enact change as citizens was an important part of the discussion and much of this is picked up in the theme of *'having a voice'.* Within the theme of *'who holds the power'* the discussion on personal power or 'power as a peer-led organisation' came to the fore. By being a collective within an organisation participants felt they were accountable in challenging existing power structures:

I think we do have a responsibility to hold to account to speak up for people that are left behind or not being included and make sure because we have privilege as an organisation and position, we have influence. Marmite

#### 11.3.3 Democracy

On the macro-level democracy was seen as key in giving people power and promoting more equal societies:

How do we as a society, a global society try and keep those things equal and inclusive and hold people to account on that as well? Marmite

Janet raised the question about the extent the UK was democratic currently, but also the future possibilities of more digitally enabled direct democracy:

I think it's about our definition of democracy and actually, at the moment are we truly a democratic society?...in 30 years... how would citizens create some of their own DIY democracy, how would they take control of some of the core bits of society to help themselves? Janet

Isin and Ruppert (2020) highlight how neoliberalism undermines democracy in the UK and US with steps made to discourage people from voting. The UK government are making it more difficult to protest (Mason et al. 2022). In the previous Findings section Primate 10 highlighted how democratic bodies, such as the European Union, can provide a counterbalance to the power of corporations through General Data Protection Regulation (GDPR). The fight for rights is reflected further in the 'having a voice' section. Promoting democracy is integral to citizenship in counteracting authoritarian tendencies of governments and the power of corporations.

# 11.3.4 Opting Out

An important element in having power and agency is the ability to opt out or not choose to participate. Laurel identifies that there are those who have *'no desire or wish to even partake in a kind of digital community.* 

Janet argues that it is key to how they work as an organisation, particularly in engaging people from marginalised communities:

How do we work with people that want to dissent, don't have equal access. We ourselves are listened to and you know I'm really interested in working with seldom listened to groups and actually how do we think about future ways of working.

This overlaps with the role of intersectionality and reasons why people may not wish to engage in technology or participate as citizens. An important role for the peer-led organisation is listening, understanding, and supporting people to dissent. However, this discussion was held in tension with the impact of people being further divided or left behind which feeds into the next theme.

## 11.4 Theme: 'Divide'

The biggest concern was the divide in society, particularly people being left behind:

The implication of a massive divide in society or the world...makes me think of some kind of Sci-fi film and a real kind of dystopia, really just a world I don't want to think about in lots of ways. Marmite

Other participants raised concerns and fears about the current and potential future directions of society:

...scared of the future... how it [technology] will drive division Colin

The divisions were described on several levels: between '*the educated*' and '*the people with money* and the rest of society' (Colin); between those with access to technology and the skills to engage in it; and these divisions are across the ages, as well as geographical divisions, also those related to privilege and status. Understanding the context of someone's citizenship is important and the Resources part of 5Rs is key to understanding and should potentially be understood as knowledge (or social capital (Tew 2013) as well as material resources (Rowe and Atterbury 2012)).

The Covid-19 pandemic was seen as pivotal in increasing health inequality and the rapid uptake in technology:

### It's created more of a kind of gap, more inequality. Rose

Concern was expressed about the speed of change and how this could lead to a greater sense of division:

feels like it is already moving away from you... for a lot of people, it can whoosh past them. Marmite

These themes were reflected on in the first Findings section and are related to discussions in the future mental health literature about the importance on the social determinants of health, and to how people with mental health challenges are feeling left behind as citizens (Hamer et al. 2014; Hamer and Finlayson 2015; Vervliet et al. 2019, Cogan et al. 2021; Eiroa-Orosa and Tormo Clemente 2022).

However, a new sub-theme emerged in this focus group. Marmite described a divide in reality:

the two characters that Bex plays were so different and from completely different realities... the reason it made me think of a dystopian reality kind of film is because I, in my mind I could imagine Juniper's life... her reality was as being completely different and in almost like in a, I want to say a kind of you know underworld, if you like, from this other world where there's all this digital activity and everything is digitally enabled.

This is profound and has serious implications for people with mental health challenges if they are further hidden from view and from people's world view, especially if that divide is exercised by those who have power. It echoes back to the asylums and alienation where people with mental health challenges were separated from society. However, the current reality is that people with mental health challenges are not accommodated by reasonable adjustments and can also be detained under the Mental Health Act (Hamer et al. 2017).

### 11.4.1 Digital Poverty

Digital poverty was seen as a key issue, whether due to a lack of access to technology, due to costs, access to infrastructure, or lack of knowledge of how to utilise technology (Eiroa-Orosa and Tormo Clemente 2022).

Look at the current situation, during lockdown we moved a lot of activities online and they excluded a lot of people. You know the phrase is banded around, but digital poverty is an issue now, and as the technology advances that will mean you'll need better hardware that would cost more money, and you know what I mean it's like at some point that's going to rule people out. Colin

Ian describes his home Wi-Fi in a semi-rural part of the country and how this limited his accessibility to connect with others at times. Janet talked about a recent stay in a psychiatric hospital and how poor the Wi-Fi was. She saw this as an important campaign for the peer-led organisation.

Locally access in hospital to Wi-Fi is really poor in this county, so I think it's like there's different levels and the drive is on access that we have.

There was acknowledgement digital access is not just a local or UK issue, and globally digital access is a much larger issue that goes beyond mental health:

You know whether they've got mental health issues or not, how that fits in with citizenship or not, you know there's a lot of people out there who are in complete digital poverty and they're scratching the surface just to make a telephone call in some regions and countries. And I think we're quite lucky in the western world, as we would describe it, that we accept these technologies and like kind of part of our lives. IW

This raises important questions about how we consider citizenship on a global level and how digital citizenship can include and exclude, especially if some of the future mental health conversations are focused on offering global services. Digital citizenship approaches can be useful in mapping who has access and who does not (Mossberger et al. 2008). As with global citizenship, it is important that critical perspectives are utilised so that technology is not viewed as neutral. and that communities are not further marginalised whilst existing power structures are reinforced (Isin and Rupport 2020; Emejulu and McGregor 2019).

#### 11.4.2 Generational Divide

Laurel talked about her concerns about the different impacts on different generations, on young people and on the older generation:

With our young people, predominantly having this presence online I really worry about their safety and their mental health in terms of not knowing what they're facing and not knowing what they're up against and not knowing where criticism or bullying is coming from... My parents-in-law, you know, being as an elderly population as people in their 80s, who have no desire or wish to be part of this at all.

Laurel gives the example of her parents-in-law trying to access the Covid vaccine and how it was impossible to book the jab without internet access:

If they didn't have us, who were able to do that, they would have slipped through the net for things that they need in order to keep themselves safe. She raised concerns about what happens to people without support to access the internet, especially those being forced to access public services via the internet (Jæger 2021). This means some people with mental health challenges are potentially going to lose social rights as they may not have access to, or chose not to access, technology.

#### 11.4.3 Addressing the Divide

Marmite highlights the urgency of addressing the digital divide and inequalities that have been exacerbated by the pandemic, reflecting on actions they should take as an organisation:

Are we being proactive enough around saying hang on a minute, it might be where we are today because of two years of pandemic, but what about everybody else, and where you know those people that aren't able to be part of this, and what are the implications for those people today, in six months time, in two years time, in 10 years time? we know that the world's not going to go back to where it was before, but actually are we intentional as a system in [local area] and beyond? Are we actually having intentional conversations about what we do about the inequalities for people

Rose highlights the importance of 'how we upskill people'. In developing any skills programmes Choi and Critiol (2021) advocate an emancipatory approach to education, tackling discrimination and inequality through amplifying the voices of people from marginalised communities. This fits with the 'acts of citizenship' approach were people or groups are empowered to rupture norms (Isin and Neilsen 2008). It could be a role for recovery colleges to support people around their rights, digital or otherwise. It could also form part of training for peer workers and mental health professionals.

## 11.5 Theme: 'What it Means to be Human?'

What it means to be a human being with choices and options. How that might be fundamentally changed in that futuristic view...came across quite powerfully to me. Laurel

One of the strongest themes and possibly the most profound question raised was what it means to be human. This has already been touched upon when reporting Marmite's reflections on Juniper and XA754 living in different realities. With the development of technology, a question philosophers wrestle with concerns the extent to which the virtual world constitutes reality (Chambers 2021). Whilst this is an important question for us all, the focus of this PhD is the meaning of citizenship for people with mental health challenges. Rather than a philosophical perspective the fundamental concern for participants was maintaining the importance of human-human connection.

### 11.5.1 Connection

There was real concern that human touch and the use of the '5 senses' would be lost and that this would mean a loss of something fundamental:

When you said that you lose that human touch, you know robots are not going to provide you that human touch. That made me feel really sad and you know, having robots and technology around is great in one respect, but that face-toface person to person thing is that's like embedded in us. How can you recreate that? You can't. Poppy

This is a key issue, particularly as the future mental health literature is advocating further use of AI and automated Mental Health staff. CHATBOTs are currently being used within mental health services and people are talking to personal assistants such as 'Alexa' about their mental health (Luxton et al. 2016; Poulin et al. 2016; Miner et al. 2017). There is some evidence that some people prefer talking to AI as they do not feel judged (Luxton et al. 2016). This highlights the potential issue of people working in services being judgemental, which perhaps is more of a concern than the digital solution on offer. There are also potentially unknown longer-term implications of people talking to AI to support their mental health; for example, there were concerns about the costs of meeting predominantly online. Laurel, who described not being able to meet people physically, due to her health conditions, explained how this has made it difficult seeing people in the physical world:

Over the last two years, where you know, for me, in particular, our contact has been digital and how it's now made me quite fearful of human-to-human contact because of the messages [from health providers] I've been given over the year.

This is something to consider, as people may increasingly find it more difficult to interact in real life and this will impact on people's mental health, particularly for those with mental health challenges. There are clear advantages for increased connection, but it is unclear what the consequences of this will be. There are concerns that the negative impacts of social media have increased social division (Dixon 2016) and negatively impacted the mental health of some groups in society (e.g. adolescents, particularly teenage girls (Saurwein et al. 2021; Santos et al. 2023)). Social media companies have taken action to avoid enacting change through protracted legal proceedings (Zuboff 2019). With virtual spaces, such as the Metaverse, being promoted, issues of public health are increasingly important from a mental health perspective, including through more online protections.

People also reflected on their experiences through the Covid-19 pandemic and greater use of technology to stay in touch and the benefits of this. Janet stated *"I've had a terrible couple of years, but I've been able to connect to people and keep connected* [online] *and as a human that was really important to me"*.

#### 11.5.2 Uncertainty

The disruption of connection through the pandemic, and reflections on the film, made people question the longer-term impacts on the mental health of all citizens:

Is it going to be a massive payoff in 10 years' time? When this AI, suddenly there's, you know, people start becoming more unwell because they are finally realising that human connection is really important for us? Or is it important for us? Colin

Or as Colin questions, *Is it important?* Laurel wonders what the impact will be on relationships and how that will impact peer-support:

that interaction through technology, will that be fundamentally changed and how we form relationships and how we relate to one another, will that be kind of pulled apart and changed and twisted about and look really different? I find that really, really terrifying in the, you know, the work that we do and supporting each other.

This is particularly pertinent in relation to citizenship and the importance of peer support and shared identity for those excluded or disconnected from the mainstream (Cogan et al. 2021).

Janet described the issue as beyond citizenship to considerations of what it means to be a human:

I think, quite often we have this thing that we think about what citizenship is that, actually, what does it mean to be a human being, now, what does it mean in 10 years' time and how do we frame that.

In the first Findings section Aspienaut raised how this impacts on mental health, how it is understood, and is affected in the future with the possible development of new forms of emotional distress. Looking at this through a Future Studies lens highlights the importance of promoting conversations about what sort of future society we want and how we build societies that connect us to 'being human'. This could be a global conversation.

# 11.5.3 Promoting Understanding

Participants thought their organisation had a role in promoting understanding of 'what it means to be human' and valuing a plurality of positions based on people's experiences, as demonstrated by this conversation between Rose and Marmite:

Rose: ...what does it mean to be human in a digital world? And I think what's coming through is we don't actually know the answer to that question. We've got a lot of kind of ideas about what that might be, but there is something around enabling mechanisms for people to share their experiences of...

Marmite [interrupts]: and it will be different for everybody.

Rose: yeah completely.

Marmite: And that's okay

This pluralism links with the feminist future approaches of Bergman et al. (2014). It is not about creating one desirable future but rather having different voices and different perspectives.

Primate10 in the first Findings section highlighted the impact of trauma for many people with mental health challenges and the impact on relationships, trust and citizenship. In the focus group Janet drew on the importance of relational working to support trauma-informed ways of engaging with people online:

I think we all have to be mindful of, that we all relate in different ways and for some people doing that through a screen is really useful. And how do we think about relational approaches<sup>4</sup> in our digital work, if that's the case.

<sup>&</sup>lt;sup>4</sup> \*relational approaches (refers to trauma-informed approaches to engagement which focus on openness, transparency and avoiding re-traumatisation) (Sweeney et al. 2016).

Janet also addressed how face-to-face and digital can be integrated to enhance people's experience in mental health treatment:

We are using augmented reality in lots of therapeutic approaches at the moment, and it seems to be very successful and new ways of working, that's not negating relationships and being alongside somebody is really important. It's really important to think, actually, being able to think, about different ways of working with people in mental health is really important, as well.

Janet highlights the importance of integrating the digital and non-digital and that there is a role to support and understand new ways of working in mental health. Currently, in the Future Studies mental health literature, there is little call for people with lived experience to be involved in digital developments (Hariman et al. 2019), but for concerns raised in this study to be addressed it is essential for people to have a voice in these plans and discussions.

# 11.6 Theme: 'Having a Voice' ('and caring about it')

I think it's... in my opinion quite simple, and you know citizenship...it's actually about using your voice and caring about it and that's what I'm going to take forward. Bex

In the first phase of the research, there was a distinction between those from the peer-led organisation and the digital technology company, where both saw citizenship being linked to 'belonging'. Those from a peer-led organisation also saw a responsibility to have a voice and be active in using it. This theme carried through as fundamental to future and current citizenship in trying to influence change.

There were three elements to this: a sense of activism or collective action; the importance of supporting dissent or allowing people to dissent or opt-out; and the role of co-production.

# 11.6.1 Collective action and Activism

There are two important elements of taking collective action; on the one hand building existing practice and opportunities to influence; the other was continuing to have conversations focused on citizenship and exploring what is possible.

Marmite committed to promoting collective action regarding future citizenship and suggested that as an organisation they would need to explore further the extent of their activism in this area:

As an organisation that would be our commitment, I think as a collective we take that and how far we move with our activism is something we need to decide.

This approach to activism links directly to 'acts of citizenship' and participatory collective citizenship. Within the literature various authors look at different approaches, from self-organisation, co-production and direct action, where there is a call for mental health professionals to show solidarity (Beresford 2013; Quinn et al. 2020; Bromage et al. 2021). Interestingly, the role of mental health professionals did not arise in this conversation.

A fundamental starting point for activism is building on existing opportunities to challenge and influence.

On a local level we advocate already if you think people's digital rights are being restrained or data being used inappropriately. Janet

A key element of activism is speaking up but also creating space for others and space for people to dissent:

Think that is something that we have a responsibility to do in terms of that kind of activism element of our work... I think it is around just challenging in every
context that we're in, what do we actually mean? How do we keep people connected and keep people having a voice? How do we enable those voices that are missing, within the context of this particular work stream or this particular community? Janet

Marmite described using the organisation's influence to support change:

I think we do have a responsibility to hold to account to speak up for people that are left behind or not being included and make sure because we have privilege as an organisation and position, we have influence.

Both GR and Rose saw a key part of promoting future citizenship and 'voice' is to continue to have conversations about citizenship. The approach to defining citizenship here is a discursive iterative one rather than linear. This is like the CBPR approach promoted by MacIntyre et al. (2021) and Rowe et al. (2012):

It's about asking that question around citizenship and within the context of the different conversations that we're having in the work...how do we enable citizenship? Rose

I've had more of an opportunity to spend time thinking about this stuff and I think what the conclusion I've come to is that it's not about having the answers it's about having a conversation or asking those questions so that that's the positive thing I take. GR

It was identified these conversations took place not just in the health or governmental sphere but also with corporations. There was recognition that the activism or collective action needed to focus on challenging and *lobbying* (Rose) global corporations:

Rather than the agenda being set by Meta or Twitter or global organizations, it's about how do you come together? Janet

In relation to global corporations or global challenges Marmite and Janet describe the opportunity to come together as a global mental health movement or together with other movements to promote inclusion:

.. If you think what's happening globally in terms of people coming together across digital processes? Janet

How do we as a society, a global society, try and keep those things equal and inclusive and hold people to account on that as well? Marmite

This highlights the importance of intersectionality and connects with calls within the mental health citizenship literature for people promoting citizenship for people with mental health challenges to join with other marginalised groups to create a collective voice and show solidarity (Davidson and Rowe 2016; Quinn et al. 2020).

#### 11.6.2 Dissent

Within the space for conversations there was an acknowledgement of the importance of different perspectives, especially those who may dissent or wish to opt out and that this was a 'valid' response to have:

I think what's been great about this and co-productive process is that we all have slightly different perspectives and the slight concern that percolates is, in a world which is around progress and is around future and moving forward, do we lose the opportunity to listen to dissent and to have space to be able to share fears and concerns and worries without feeling that you're not progressive or you're not open to new ways of working and to new challenges? Rose

There were discussions on supporting people with skills, but also to give voice to people's fears and concerns about choosing not to engage with technology. People should not be forced to opt into technological approaches to citizenship or participation, and strengths-focused approaches offer a way of engaging people in these conversations.

# 11.7 Co-Production

Whilst collective action and activism was seen as important in raising awareness, the consensus was that co-production is the best way to address future citizenship. Participating in the study offered pre-co-production work before engaging with wider stakeholders. Rose states:

I think for me one of the things that this conversation is really bringing home to me, is the focus around co-producing that kind of future citizenship.

She then goes on to talk about the importance of valuing different forms of expertise and involving industry or the commercial sector in these conversations:

Thinking about from a co productive process what we do know is this isn't about us having all the expertise and tech companies or corporate organizations not having that [expertise in mental health citizenship].

This call for a wider participation in co-productive processes goes hand in hand with lobbying governments and tapping into the social responsibility of corporations. The consideration of co-production in partnership with corporations to promote citizenship is not something that has been mentioned in previous literature. It needs to go hand in hand with activism and attention to power dynamics to avoid exploitation. Exploration of what this would look like and how it could be achieved is worthy of further research.

# 11.8 Summary of the Actions Discussed

The focus of this phase of the research was the action phase of CBPR (Kindon et al. 2007). Therefore, this section highlights the actions that participants talked to directly or emphasised as important. In looking at actions that promote future

citizenship for people with mental health challenges it is important to look at local/regional actions, and then national/global actions.

# 11.8.1 Local/Regional Actions:

These were largely actions that the peer-led organisation could undertake themselves within their current context.

Some focused on having further conversations and promoting their voice and the voice of others:

- To promote citizenship by continuing to have conversations about citizenship.
- To create spaces to raise awareness and acknowledge people's reality in relation to social disadvantage.
- To create spaces for seldom heard voices to discuss citizenship and access to digital technology.
- To develop nuanced ways of engaging and supporting with those who wish to opt out of digital futures.

Other local actions were more explicit ways of challenging and shaping local mental health provision using existing influence:

- To promote ethical decision-making relating to the use of technology in the mental health sphere. Increasingly work to understand, critique and support access to digital mental health supports
- To explore trauma-informed approaches to the use of digital technology.
- To have a voice as a peer-led organisation in digital mental health and citizenship developments.
- To renew commitment to work in local health and social care system challenging inequality and working for diverse voices.

- To expand existing opportunities for people to access knowledge on citizenship (including digital citizenship). Some of this work has already started since the first phase via awareness raising within the advocacy service and Recovery College.
- To decide as an organisation the approach and extent of future activism
- To promote more direct or D-I-Y democracy. This issue straddles both local and national/global action, but there could be calls for local accountability and increased role for people with lived experience in the delivery of health and social care and local government.

# 11.8.2 National/Global Actions:

The peer-led organisation is a locally based organisation therefore these actions may be longer term and will require wider collaboration. Co-production and Activism were seen as key in promoting action.

- To facilitate conversations with people about what it means to be a human in the digital world.
- To promote an ethical rights-based framework based on agency and democracy.
- To explore how people can take further control of their data and use this to influence their personal and collective power.
- To lobby governments and corporations to promote the rights and citizenship of people with mental health challenges.
- To work with other movements and form local, national, and global networks of marginalised groups to promote citizenship and inclusion.

# 11.9 Conclusion

Across the two Findings chapters, the importance of having a voice was key in determining citizenship, and participants valued a discursive and pluralistic approach to citizenship. Having a voice, alongside having access to education to make informed choices was important to be able to enact power as citizens.

However, having the power to influence decisions was key for those decisions made by corporations as well as government. To understand the dynamics of power it is important to see the discussions in their social and political context. This relates to the importance of democracy and social rights to ensure people have equal access to citizenship and this applies for all marginalised groups (Hamer 2012).

People felt that the role of the Mental Health Act 1983 created a unique barrier to citizenship for people with mental health challenges. The importance to citizenship of replacing it with something more compassionate, shaped by people with lived experience was something that clearly came through, particularly in the first phase. Interestingly, other than the focus on the Mental Health Act 1983 and the more coercive practice and restrictive care pathways there was little discussion on mental health services themselves. The discussions were more about how mental health is conceptualised and the importance of understanding the social context and psychological context (the impact of trauma) and how this relates to citizenship. The implications of this require further discussion. However, a broader understanding of mental health was seen as valuable in promoting a more compassionate and inclusive society for all.

A new finding was, 'what it means to be human in a digital world' and whether the direction of technology will fundamentally change this for people with mental health challenges. There were real fears that something human was being lost, that people would be even further excluded and 'left behind' and were described as living in an 'underworld' or in a different reality. There were implications about what this means for how we understand mental health and whether there will be different forms of emotional distress, particularly in relation to the use of digital technology in mental health services.

For the peer-led organisation, there was evidence that there was value in exploring the future. There were key actions identified to act in the here and now in promoting future citizenship. Some of the actions were longer-term and beyond the scope solely of a peer-led organisation. Co-production was seen as a central approach in moving these conversations forward. In particular, the importance of bringing seldom heard or marginalised voices to the table but also engaging with other partners, such as industry or the commercial sector and tapping into the corporate social responsibility agenda. However, as with *Recovery*, this brings another set of risks around co-option and another set of power dynamics to negotiate but is crucial in thinking about future citizenship, especially with the ever-growing role of technology. These discussions about co-production will be taken forward in both chapters 12 and 13, the Reflections on Co-production chapter and Discussion chapter respectively. They will draw out the learning regarding co-production in relation to a PhD and how coproduction can influence future citizenship.

# Chapter 12: 'Lived experience is a unique source of knowledge about people in the world' Reflections on Co-Production as a Research Method

# **12.1 Introduction**

One of the research objectives of this project was to *undertake a critical exploration of the use of co-production and participatory research methods within a PhD*. Although there is literature on co-production as a research method (as described in chapter 9) there is not any specific guidance on how to apply co-production principles to a PhD. Therefore, this study was an experiment drawing on the peer researchers' and academic researcher's experience of co-production whilst drawing on the literature. This chapter is a critical reflection of the above stated research objective. It should be considered the discussion chapter in relation to this aim.

To provide a rounded reflection, this chapter will be structured using the NIHR 5 Key principles of co-production (Hickey et al. 2018):

- Sharing power
- Including all perspectives and skills
- Respecting and valuing the knowledge of all
- Reciprocity
- Building and maintaining relationships

Whilst there is overlap between each of these areas, to guide the reader through this chapter they will be taken in turn. There were two strands of coproduction in this study: one, co-production of knowledge with the participants and to some extent with the peer researchers and two, co-production of the research process alongside the peer researchers. In chapter 9 I laid out my position - that it was better to engage in the 'messy' process of real-world coproduction and attempt an imperfect approach, if attention was paid to the dynamics of power (Farr et al. 2021). Therefore, it was important to avoid any exploitation of the participants and peer researchers. It was also thought to be of value to share learning from this process to contribute to the broader understanding of co-productive research methods, particularly in the context of a PhD. This chapter should be read in conjunction with, and builds on the discussions within, the methodology (chapter 9), where I describe which elements of the study were co-produced (table 6) and includes a social realist critique of the approach to co-production in this research (Farr 2018) (section 9.11).

The reflections in this chapter are based on: the reflections of participants and peer researchers in the focus group, described in chapter 12 (which was co-analysed by the peer researchers and myself); notes from my reflective diary; the transcript of a session held by the peer researchers about their experience of co-production<sup>5</sup>; the research literature on co-production as a methodology, and my further reflections based on my overall experience of co-production within this study. Before reflecting on the 5 key principles of co-production (Hickey et al. 2018), it is important to address whether this research was recognisable as co-production.

<sup>&</sup>lt;sup>5</sup> The peer researchers held a session to independently discuss whether they wished to publish a paper related to the role of lived experience within research and in particular their experiences within a PhD. They recorded this session. This session took place after the focus group but prior to the roundtable discussion meeting. Their reflection was they did not wish to write a paper but felt that they had a useful discussion and wished to share it with me as part of my thesis. It is with incredible generosity that the peer researchers volunteered to share their transcript and gave me permission to use extracts within this thesis. The additional value of this as it gave an unfiltered insight into the views of the peer researchers as they had not initially planned to share it with me. To address the ethics around this I discussed and revisited this decision when we met to record the roundtable discussion. I explained how I was planning to do this and again they reiterated that they felt it was important to share the transcript.



# Figure 9: Sources of data for reflections on co-production chapter

# 12.2 Was it Co-Production?

Acknowledging the tension of undertaking a PhD using co-production as a methodology, it is important to reflect upon whether it was co-production from the perspective of participants and peer researchers. Within the focus group there was an explicit conversation about people's experience of the research process. From the perspective of the participants who engaged in this discussion, they felt that within the research process there had been a degree of co-production:

This has felt co-produced, very different from how it could possibly have been if it had been a traditional research approach, which wouldn't work for me... (Marmite)

for me that's been the focus on the process so that's really helped me...feel that it's co-produced. (Rose)

Interestingly, Rose highlights it is the focus on the process that has helped the feelings of co-production, and that transparency has been helpful for the participants. King and Gillard (2018) identified that CBPR may have supported the participants involved in their study and therefore this may have supported the sense of co-production in this study as well.

The notion of evolution was picked up by the peer researchers, identifying that the study had become increasingly co-produced. Interestingly GR, in the focus group, highlighted how it was not just the peer researchers that helped shape the study but also the data (knowledge exchange) from the first phase.

The element of co production's kind of developed and got more interesting what I found, yeah, what I found interesting was how from the phase one you managed to consult, interview people and then that actively shaped the direction of the next phase of research, so the script for the film was based on what people had said in the previous phase of research it wasn't something you'd come up with it's taken is gradually started to take on a life of its own and the direction that the research is going is less down to you and more to that coproductive process (GR)

This was also reflected by one of the participants, with an acknowledgement it is not always possible to start at the top of the ladder of co-production:

I suppose it's just thinking about that ladder of co-production isn't it and you started off with a thing that you had to ask questions about. That you've gone on that ladder and added more assets and more people's views in as you've gone along and that's what sometimes we have to do. Co-production, we don't actually start right at the top, we work ourselves up and bring more views in as we go along the process. (Janet)

Hickey et al. (2018) defines co-production as being at every stage in the process, but as explained previously this was not the case in this study. It also took longer than I anticipated for the peer researchers to be able to effectively co-produce alongside development of their research skills (Farr et al. 2021). I

think this is a limitation of not jointly conceiving the idea and co-developing the research question. Certainly, these initial stages were not co-produced. Therefore, by the NIHR definition this would not be co-production.

I have wrestled at different stages of the PhD on whether it is or should be called co-production. Oakley et al. (2022) describe researcher guilt in relation to power and privilege in participatory research. I certainly experienced this sense of guilt, less so directly with the peer researchers and participants, but more widely in respect to seldom heard communities and claiming research as co-production when it was not conceived by the community itself.

Ultimately, I was guided by Farr et al.'s (2021) pragmatic approach arguing that co-production is a process to be worked with. The risks with this pragmatic approach are that co-production becomes co-opted, its transformation potential lost and it might even become harmful due to exploitation (Bell and Pahl 2016). However, the decision to be pragmatic may be another expression of privilege in having the power to call something co-production. To counter this, I have continually weighed up the rationale, costs, and benefits for co-production in relation to risks to participants, peer researchers, myself, and the research itself (Oliver et al. 2019). I have engaged in constant critically reflective practice and dialogue to facilitate more equal relational approaches across individual, community and organisational levels (Farr 2018). It is these reflections that are shared within this chapter.

To promote full co-production as a method within a PhD there would need to be organisational change within universities alongside the approach used within this study. However, I am not sure how this would be possible within a PhD, or indeed possible in most forms of research due to inherent power structures (Rose and Kalathil 2019; Bell and Pahl 2016). Therefore, there is always a power imbalance. This poses the question whether co-production is about equalising power or pragmatically working with the tension and dynamics to challenge them; for example, for ethics committees to support more advanced approaches to co-production. I would argue that within this research we worked towards co-production, and this varied across the study as it developed and became increasingly co-produced.

#### 12.3 Sharing Power

The key component of co-production is sharing power. However, I would argue it is as much about acknowledging and being transparent about the dynamics of power and working to disrupt them (as an 'act of citizenship' perhaps) rather than trying to create some utopian approach to research (Bell and Pahl 2016). This is particularly important when acknowledging the structural disadvantages people with mental health challenges experience and how this can intersect with other forms of discrimination and disadvantage (Beresford et al. 2021).

This is even more pertinent in the context of a PhD where there are academic requirements, and academic structures within which the PhD sits (Farr et al. 2021), where only one person is receiving a Doctorate and therefore leading the research. This is where, through discussion with my supervisors and peer-researchers, we agreed to describe the research as being co-produced but the thesis being my work. It is important to note the peers were not expecting to be awarded a doctorate and were aware of the limitations of their input due to the funding available (180 hours between the three peer researchers). The expectations were clearly outlined in the introductory workshop. However, co-production as a research method in this context also becomes increasingly blurred and potentially problematic when using co-productive approaches to analysis, discussion, and co-produced knowledge and learning. This highlights questions of ownership and decision-making; ultimately, I led the research team.

Despite leading the co-production approach, I was very aware of having to give up power, which was a personal challenge, and more difficult than I anticipated. I think this is fundamental for any PhD candidate to consider and reflect on when engaging in co-production. After the initial peer workshop, when I recruited the peer researchers, I made the following note in my reflective diary: It was interesting doing the peer workshop. It brought the study to life and it was great to share it with others. However, it also made me realise I would have to share power and it was no longer completely my study. Especially if I was going to do this properly (notes from reflective diary).

I shared my reflections on power in the focus group and my desire for the project to go in certain directions and how I have managed myself:

I feel quite anxious about it because I feel I hold a whole bunch of the power in the direction of it and have a, you know... it wasn't like co-created from the very start, so you know, whilst you say that I haven't got an agenda, I feel that I have, and I have to suppress it... and pay attention to it. (Phil)

Part of GR's role within the methodology was to provide challenge and watch out for this:

I think you probably have had an idea about how you wanted the research to go and had an agenda, I think, because we all do, and I think it's been my job to make it difficult for you. (GR)

BS in the focus group provided some re-assurance:

I think you've done a really good job Phil, because I feel very much that you've always asked or spoken with us and discussed it, and come up, we know with different ways we could take things like you've hidden your inner wants very well. (BS)

IW reflected again the focus group that the process had been co-produced:

I think, as a researcher Phil we've all been given the equal platform to actually influence or discuss at each stage. So, I think in terms of true co production, you know there's been three of us kind of outweigh you sometimes and you've had to go well okay well we'll look at this from a different angle. (IW) However, in their reflective session, the peers were a little more candid, and whilst they acknowledged with each other that co-production increased as the study went on, they shared some of their frustrations around the early part of the study which was less co-produced. BS acknowledged that ultimately this was still my PhD, and this influenced how the peer researchers engaged and were at times tentative in giving feedback:

So, to some extent because it's Phil's PhD, there has been a level I've tried to be respectful if I've thought otherwise. Whereas, perhaps, if it was my show, I'd be a bit, you know, probably a little bit more now I would like us to go this way.

Interestingly there was one occasion that highlighted an area where I was concerned that I had led the peers. In my reflective diary I wrote:

Interesting dynamics when digital media company pulled out – I had initially wanted to find another one and then came round [following a discussion with the research supervisors] with going ahead without. When shared with peer researchers they all wanted a new digital media company – then I felt I was just trying to get them to agree so we decided all to reflect and discuss reflections via email and then meet again.

Through this process everyone agreed that it was best to go ahead without, however, it would have been easy to miss this reflective stage in the decision making:

Power is key in research and discussing it openly (notes from reflective diary)

The peers discussed the same scenario and identified that at times they had felt led, although they equally reflected that they had the chance to explore different choices and options. This compromise may have related to the tentativeness described by BS, as it was my PhD and the sense of ownership that comes with that. Whilst in my reflection I was highlighting power is the key, I am not sure we effectively and transparently discussed what had happened in this situation rather than just moved on to the next step of the research process.

In future I think it would be essential to be more explicit about the parameters of co-production i.e., what are the constraints and what is moveable. This would help in being more transparent about the power dynamics; for example, the parameters of what co-production means in the context of a PhD, time, finance, knowledge of research process. Also, it would be useful to have further conversations to discuss the value of lived experience, the role of the literature and technical or academic expertise. It would have also been useful to explore the more psychological aspects of the parameters in terms of how people felt about the process and challenging each other. It may be worth considering a more explicit conversation about our feelings as a research team and that openness. I wonder, bearing in mind BS' comments, whether she (and the other peer researchers and participants) felt able to say how she felt rather than needing to protect my feelings. So, whilst we would have conversations about how it was going, and the extent people felt involved, it may have been useful to have facilitated sessions with the research supervisors to explore these elements to create more challenge and more balance. On reflection, the transparency around parameters is probably as important as the transparency around the ladder of co-production and in future is worth examining. From a social realist perspective this should also involve discussions of structural power and inequality (Farr 2018).

Within the facilitated roundtable discussion (appendix 16) the peers seemed to experience the most equality. It was facilitated by one of the supervisors and I was a participant. Being a facilitated session enabled me to have a sole focus on the data and discussions on the data, whereas at all other stages I was both present but also thinking how it would fit, what we would need to do next, how I would write it up. In future, if work is to be fully co-produced, there needs to be a sense of equalisation and a potential role for facilitation or having agreed joint facilitation. Interestingly and unsurprisingly, my ownership of the overall project was also reflected in the roundtable discussion, where the peer researchers still named me as the person to follow up or take forward further actions, so power dynamics persist.

When considering sharing power, it is important to understand the possibility of co-option and exploitation (Rose and Kalathil 2019; Colder Carras et al. 2023). This is particularly important when examining the wider neoliberal contexts within which this research is being undertaken. As neoliberalism does not just work top down from government but through its 'common sense' approach, it can capture bottom-up initiatives which are distorted into benefiting the state and capital (Bell and Pahl 2019); for example, creating an illusion of co-production that only maintains the status quo and repression.

Beresford (2019) argues that any co-production needs to be understood in the wider political context; it is too narrow to solely look at it in the context of health and social care research but rather it needs to be understood in terms of wider oppression and the struggle for participatory democracy and equality for people from seldom heard groups. This is where the relationship between citizenship (in particular 'acts of citizenship' and participatory citizenship) intertwine with co-production in research. This relates to Farr's (2018) social realist frame in terms of acknowledging structural inequalities but recognising that actions can disrupt. It is important to judge the outcomes of this research as to whether they disrupt in a way that promotes greater inclusivity of people with mental health challenges.

# 12.4 Including All Perspectives and Skills

This principle is defined as making sure the research team includes those with necessary skills, knowledge and experience and recognises people have multiple identities and can contribute from multiple positions (Hickey et al. 2018).

Regarding multiple identities, this occurred within the study with people from the digital technology company sharing their lived experience of mental health

challenges and people from the peer-led organisation sharing in-depth technical knowledge. This added a richness to the themes within the co-production workshop.

However, when the digital technology company withdrew, it changed the nature of the research as it was more co-produced with peer researchers and the peerled organisation and the action phase focused solely on the actions of the peerled organisations, rather than co-produced solutions with a digital technology company. As described above, the purpose of this research was not to create the definitive guide to future citizenship, but rather promote discussion. Therefore, the lack of involvement from the digital media company did not devalue the work but rather gave it a different focus, enabling us to go into more depth from a peer-led organisation's perspective.

BS and IW specifically talked about how their lived experience had shaped their desire to get involved, whereas GR described his previous academic experience, alongside lived experience, as being central to why he wished to be involved. Therefore, there was an attempt to draw on both skill sets. As GR had previous research experience it felt important for him to be able to utilise this and share his expertise. This meant co-creating a slightly separate role for him from the other peer researchers. As described previously, GR had a role critiquing the methodology as part of supporting the co-production.

From my perspective, and from BS and IW's perspective, GR played an invaluable role. He could cross-translate between the academic language and as a peer asking challenging questions that supported peer researcher understanding. From my perspective he offered valuable challenge and a critique of the whole process, including the philosophical standpoint. However, he reported feeling out of the loop, as his involvement wa218elations more intermittent; so, whilst his skills were incorporated, there was not enough attention paid to the relationship and reciprocity, which will be discussed further below.

Whilst GR's role was integral, on reflection it was misaligned; in future I would advocate having someone with a specific lived experience perspective as part of the supervisory team. This would help address the power balance, especially if there were to be facilitated conversations between the academic researcher and peer researchers, as recommended in the previous section.

This argument is strengthened by one of the conversations within the reflective piece shared by the peer researchers. They discussed feeling that there were almost two research teams: the peer researchers, as one team; and the supervision team and me as the other; that the two were entirely separate. This draws out interesting dynamics in assumptions about the supervisory team, and whilst they may have professional health and social care qualifications, it was assumed they did not have lived experience. It does highlight a limitation in the co-production approach in relation to the separation of the supervision team and peer researchers, which as previously discussed could have been strengthened by an intentionally employed lived experience supervisor.

Conversely, whilst GR had significant academic understanding and experience, BS and IW were new to research. So, a key component of addressing this principle was upskilling people:

There was also the challenge of giving people a say, and co-producing, but also people not having the same awareness of the study or the research process. (notes from reflective diary- after recruitment workshop)

Farr et al. (2021) acknowledged the challenge around people needing to be orientated to a project and given research skills as part of the move towards coproduction. This was balanced by the importance of recruiting people because of their 'lived experience' rather than knowledge of research. In my mind, as I brought the research knowledge, supported by my supervisors, it was more important to prioritise the lived experience perspective of the peer researchers. We could then co-produce how we would approach the study as we worked together. This is essentially what happened. However, I had not anticipated how much time it would take people to feel confident in their understanding of the topic and therefore the challenge of moving through the ladder of co-production was greater than anticipated.

Ideally, we would have co-created the idea, the approach, and undertaken all stages together and this would have included an upskilling of the whole research team (including myself) in understanding each other's roles and the research skills required. Within this PhD, as I was new to this level of research and applying co-production in this context, it was very much an evolution. In future I would encourage anyone considering this route to anticipate and take additional steps to for further discussion of this and consideration of sufficient and robust training for the peer researchers (or a co-produced agreement on the level of training required, including understanding the dynamics of power).

The key in this study was valuing people's expertise in what they brought from their own lived and learned experience and acknowledging people's changing expertise as the study moved forward. As IW and BS had knowledge of the subject of research, I had to learn to share' the project and direction. BS describes her journey through the study:

The research bit, I must admit, probably terrified me at that point, not knowing what it 'as about. And just to be involved, as a peer, was the first kind of string I was looking at like because I didn't go to uni, so I didn't have any kind of higher education qualifications. So I was a little bit apprehensive about that. But once it got into the project that was, kind of, not an issue.

The New Economics Foundation (Slay and Stephens 2013) principles of coproduction describe *building on existing capabilities* and being *asset-focused*, which I believe are key in supporting effective working. This provides a framework for valuing lived experience expertise as much as academic or clinical perspectives and enables all people to see what they bring to the process. These two principles are central to co-production in research and, whilst acknowledged within Hickey et al. (2018), are perhaps not as explicit as they could be.

# 12.5 Respecting and Valuing the Knowledge of All (and giving weight to different forms of knowledge.)

This is the most fundamental principle in shaping the outcomes of this study, as if it had not had the peer researchers, or peer-led organisation, involved the whole feel of the study and outcome would have potentially gone in a totally different direction and would have lacked authenticity.

Speculating about the future shouldn't be left to people who haven't got that present lived experience because it is hypothetical, it is speculative, and it needs to be constrained and informed by real-life experience for it to be a true examination of the future GR

This is also challenging within a PhD, where there is a primacy put on academic knowledge; for example, when I came to write up the findings, having done the co-analysis, it felt strange to then write a discussion chapter on my own. Following a discussion with my supervisors and the peer researchers we decided to do a round table discussion which we would use verbatim without additional analysis (other than a basic edit) and include in the appendix. I had noted that some of the later participatory citizenship literature had been presented this way (Reiss et al. 2022) and therefore this would not only sit well with a co-productive methodology but also as participatory citizenship.

This became important to do, but I was uncertain how it would work. Taking risks and being supported to do so is key in trying to co-produce a PhD. Therefore, it was imperative the supervisory team were committed to valuing lived experience and holding on to the uncertainty that co-production can bring, whilst simultaneously providing the guidance so that the thesis met the requirements of a PhD.

Another intrinsic part of valuing and respecting the knowledge of all, is acknowledging whose voices were missing in the study. As discussed in the methodology chapter, whilst most participants had lived experience of mental health challenges, the participants, academic researcher and peer researchers were predominately cis, white and heterosexual. Therefore, it is important to acknowledge that the findings have been shaped by a discourse informed by 'whiteness' (King and Gilllard 2019) and enlightenment rationalism (Rose and Kalathil 2019). Unwittingly, the analysis may have been subconsciously informed by colonial patriarchal perspectives. The feminist and post-colonial perspective of the Ethics of Care framework (Brannelly 2018b) has been important in opening-up dialogue around intersectionality and the nature of mental illness. Hopefully, this is represented both in the film and the thesis. In future research it would be important to review the recruitment strategy and look to engage more diverse participants and peer researcher cohorts.

It is important to state that the purpose of this research is to stimulate debate, not provide a definitive answer. I have tried to be as transparent as possible on how the process can be viewed and critiqued regarding co-option of the coproductive process (Hughes and Duffy 2018; Colder Carras et al. 2023) and to show whose voices are included and excluded.

#### 12.6 Reciprocity

This principle is that "*everyone benefits from working together*" (Hickey et al. 2018).

Rose summarises her experience of the project within the focus group:

I think the other thing that's been really good about it is, given the complexity of the topic and the different ways that that can be explored, there is open space for people to participate on their terms and it feels very, very balanced and there's not one part of the conversations that we've had, where you felt, well I have felt lacking in knowledge or understanding. (Rose)

One of the most interesting elements of the reflective piece from the peer researchers was based around their reasons for wanting to participate, which was based around their lived experience and being able to make that contribution. Participating in academia was seen as a means to an end in sharing their lived experience more broadly rather than valuing academic knowledge in itself.

IW: I left school with basically nothing and that was me. So, when it came up and it was a kind of peer researcher, the peer bit, kind of exciting, which is to say, OK, we can steer this in a certain direction if we need to. It's from our own perspective.

For GR the rationale was slightly different and focused on trying to integrate his academic experience with his lived experience and wanting to explore how lived experience expertise in mental health is understood. He was interested epistemologically in lived experience and how it could be understood on a par with professional expertise:

How do we justify or explain the value of lived experience? And the view that I tend towards is lived experience is a unique source of knowledge about people in the world.

It was interesting to explore further the valuing, or not, of academic knowledge and why people wanted to get involved. The peer researchers only met (when they recorded their reflective discussion) to discuss writing a paper because they felt it was what I had wanted them to do. In the interests of my perception of reciprocity I had wanted them to be able to publish something, as I valued that academic recognition. However, this was not important to the peer researchers at this point. This was significant learning concerning making assumptions about what people may or may not wish to get from their participation.

It was interesting what the peer researchers, particularly BS and IW, took from participating in the study, as their knowledge deepened and the topic itself became more important and relevant: The more I was able to think, how would this affect me? How would this affect my son? The more passionate I became. BS

Both BS and IW refer to being citizens in the round table discussion and also in the reflective conversation they had:

IW: Yeah, I was gonna say it's got me thinking more about me: what I stand for, both as a peer and as a citizen. And then looking forward, to say well, technology is already being used in this kind of way, you know in my own lifetime now. My own experience of seeing CMHT is now via this kind of Teams approach. You know, the prescribers can change drugs without actually having to go and see them face to face. And it's all kinds of stuff that's happening now. And it's how far do I challenge? Say, hang on a minute! This is not right! Or how far do I say, well, actually this can benefit me, I don't have to drive 20 minutes to go and sit in a room for 15 minutes waiting, then I don't have to, you know, sit in front of somebody for a full hour? When I've got 1/2 an hour on teams so you can see the positives and the negatives coming out from the project, actually in real life now.

BS: It's in contributing as a citizen and I think that's been a big change for me. It's so many things came up with that and again that the activist side. Yes, I have mental health challenges, but that doesn't mean I'm not capable, and wanting to fight that fight. Remember, you know, Jetson [sic -Juniper] whatever it was, and then you know, it became more accessible, and I was starting to think, holy moly, I don't, I wouldn't want that to happen. I wouldn't want my meds to be able to be adjusted without my say.

Whilst GR may have experienced less reciprocity in terms of what he had hoped to gain from being involved in the project, the sense of activism also engaged him:

One of the breakthroughs for me, I suppose, was that really getting the activist element of what Phil wanted to achieve by thinking about the future, you can imagine this future you'd like to bring about and then you can work back from that to the present to see what we have to do now.

IW described a sense of responsibility for others in his role as a peer:

And I think as technology changes, it's gonna be one of those where we're standing up for more and more people.

The participants also appeared to value thinking about future citizenship, as reflected by Rose in the focus group:

When we start to understand kind of co-production in future citizenship because it's about what's our current, competency, capability, where are we starting from, what our assets are now it's been a really helpful conversation to bring to the fore.

Unfortunately, due to the digital technology company withdrawing in the second phase, it is difficult to assess the extent they gained from participating in the research. From my correspondence with them it appeared that happenstance was the barrier rather than a lack of commitment to the project. However, only one of their staff was available for the co-production workshop, despite three staff stating they would attend. So, it is necessary to acknowledge they may not have felt as engaged, despite email correspondence to the contrary.

I see my responsibility in relation to reciprocity as to carry this forward and continue to promote opportunities for people to have their voices heard. One of the main reasons for using co-production was to build on existing relationships, so that the work coming from the research can be continued. A key element will be dissemination, starting with the Digital Technology company and Peer-led Organisation.

# 12.7 Building and Maintaining Relationships

Despite the challenges with engaging the digital media company, this was largely successful for both participants and peer researchers. Informed by the Ethics of Care approach, I tried to engage with the individuals and organisations in a sensitive way based on attentiveness, responsibility, competence, responsiveness, and solidarity. I also tried to be vulnerable, to listen and negotiate the research process (Brannelly 2018b).

There were definite benefits of working with organisations that I had an existing relationship with, in building that initial engagement and through the existing relationships I had with the peer researchers. Whilst I had not worked closely with them previously, we did know each other, and they knew of my work as part of the Wellbeing and Recovery Partnership, which helped build trust more quickly. It is important to note that co-production is often slow and takes place over a long period of time (Hickey et al. 2018). Therefore, pre-existing relationships can speed up the process and support lasting change (Brannelly 2018b).

The relationships were strong despite the challenges of dealing with the impact of the Covid-19 Pandemic and having to adapt to undertaking research online. Through my work I learnt how to facilitate mental health courses on-line, so was able to utilise those skills to support the engagement that was crucial for the study.

As previously discussed, GR probably had the most difficult time in terms of what he had hoped to get out of the study and relationships. However, his role did enhance the relationship between myself and the peer researchers due to his ability to cross-translate what I was trying to communicate as an academic researcher.

BS- Your [GR's] perspective definitely helped me. You were like a conduit in a way between Phil and me.

In future it would be useful to continually feedback on the relationship as well as the progress on the study. In terms of *attentiveness* and *responsiveness* I could have been more aware of GR's needs. Within the discussion workshop we had the opportunity to discuss this and share the learning with each other. Regarding Future Studies, this is where having a supervisor specifically employed for their lived experience potentially would have also strengthened the relationships, as well as supporting the *valuing all forms of knowledge* and *sharing of power*.

#### 12.8 Conclusion

The experience of using co-production as a research method has been a huge learning experience. It has been useful to reflect both on this process and my previous experience of co-production. Whilst I was aware of the importance of paying attention to structural and social inequalities, this process has given me a deeper understanding. In clinical practice it is challenging, due to the pace of work, to take the time to engage with the literature and to reflect on what could be done differently on a deeper level. It has been useful to understand tools such as the social realist critique of co-production (Farr 2018) and the importance of situating co-production within its political context (Beresford 2019). The shift in title, from Co-producing Future Citizenship Alongside People with Mental Health Challenges, is a fundamentally important change and the notion of striving towards co-production and that being an 'act of citizenship' in disrupting social norms and being able to describe that process (including its limitations) is fundamental. Working towards, and using a social realist framing, acknowledges there are inequalities outside of the process of co-production that limit and constrict what is achievable, but also that there are individual and collective actions that can influence shifts or changes.

The NIHR definitions of co-production do not engage enough with the realities and complexities of trying to co-produce, nor appreciate the structures that constrain it. For example, there are significant changes required to the academic structures (let alone with wider social constraints), including the role and value of the knowledge of lived experience, how knowledge is constructed through a lens of 'whiteness' and rationality, to be able to truly co-produce (Rose and Kalathil 2019). By engaging in the messy process of co-production (Farr et al. 2021), undertaken with integrity and transparency (Colder Carras et al. 2023), and whilst giving attention to co-option and exploitation (Brannely 2018), there is learning. Disruption can influence the potential to create change. The value of the co-construction of knowledge and research in this study has been invaluable in being able to effectively address the research aims and objectives, especially when using a CBPR approach to engage both participants and peer researchers in this process.

Within this study participants viewed co-production as key in promoting inclusive citizenship. I would argue that the learning from co-production and participatory research methods are valuable in thinking about applying coproductive principles to citizenship. This is an important finding in terms of both the research and co-production and to the application of approaches to citizenship. As with Higgs et al. (2023) who reflected on their experience as working as a team of academics and peer researchers: they describe how they explored their journeys of citizenship and the barriers and opportunities they had faced and, by working this through, it enhanced their understanding of how to work effectively together in sharing power and understanding structural inequalities. This approach, if adopted more widely, may help with reflections and discussions on power. Ultimately, Higgs et al. (2023) saw working and contributing together to research as being a core element of expressing citizenship and this highlights the potential benefits of using citizenship as a frame, not just for the content of the research, but the process itself. This discussion is developed further in my examination of the research objectives and in section 13.6.8, which considers the role of co-production and future citizenship. Before moving on to discussing the wider research objectives, this chapter concludes with a series of recommendations concerning the use of coproduction and participatory research methods within a PhD.

# **12.9 Recommendations**

- To promote an understanding of the importance of 'acts of citizenship' or participatory citizenship within participatory and co-productive research to support inclusion of researchers with lived experience.
- Consider the make-up of the supervisory team with consideration to having a supervisor primarily recruited for their lived experience.
- To build time to explore the parameters of co-production, clarity around decision-making, the value and experience everyone brings, and for people to develop the relevant skills to co-produce the research effectively (Farr et al. 2021).
- Have regular supervision with supervisors, which includes peer researchers and focuses on the relationship and dynamics of power.
- Co-produced research to be as transparent and self-critical about the process as possible (Colder Carras et al. 2023); to use tools to aid this transparency, such as Farr's (2018) social realist critique.
- For academic institutions to consider and engage in radical solutions that would support co-production within research in general, but specifically PhDs and consider co-produced PhDs (e.g. joint awards, addressing the epistemological value of lived experience).
- Ethics committees to strengthen their involvement of people representing lived experience perspectives.

# Chapter 13: Discussion, Recommendations and Conclusion

# **13.1 Introduction**

In this final chapter I return to the research questions, which are as follows:

**Aim:** To explore how future developments in technology will impact on citizenship for people with mental health challenges

# **Objectives:**

- What do participants think are the key factors that will shape citizenship in the future?
- What are the perceived challenges and opportunities for people with mental health challenges in relation to future citizenship?
- To examine the key areas for development to contribute to inclusive future opportunities for citizenship for people with mental health challenges.
- To undertake a critical exploration of use of co-production and participatory research methods within a PhD

This thesis has a slightly unusual structure in that there are two other elements that have formed part of the discussion. The first was the Reflections on coproduction chapter 11, which addressed the research objective *to undertake a critical exploration of use of co-production and participatory research methods within a PhD*. This objective will not be revisited within this chapter, but the learning will be integrated in the conclusion. The second element is the transcript of a roundtable discussion with the peer researchers (appendix 16); this discussion has been synthesised into this chapter alongside the literature review and research findings.

This chapter will provide an overview of the thesis, followed by an exploration of the limitations of the research. This leads into an examination of how this research contributes to the body of literature on citizenship, mental health, the role of technology and the future. These are discussed in relation to the research objectives. The key themes identified through the findings, including the film, literature review, findings and roundtable discussion have been synthesised and presented alongside each research objective (see Figure 10). After the thematic discussion and the identification of actions to promote inclusive citizenship, a series of recommendations highlight the implications for research, education, practice, and policy. This is followed by a conclusion which brings together the outcomes from this chapter, and the thesis.



Figure 10: Reseach objectives and corresponding themes

#### **13.2 Overview of Thesis and Research Aims**

Despite increased focus on citizenship (Rowe and Davidson 2016; Hamer et al. 2019; Morgan et al. 2020; Davidson et al. 2021; MacIntryre et al. 2021) and some limited interest in Future Studies and mental health (Bhugra et al. 2017; Giacco et al. 2017; Priebe et al. 2019) very little has been written on Future Studies, citizenship, and mental health (Morgan et al. 2020). This thesis therefore makes a significant contribution to the field. The Covid-19 Pandemic led to a rapid uptake of technology and the use of artificial intelligence has grown exponentially, to the extent that I could ask AI to write this thesis. Therefore, this study feels even more relevant than first anticipated and asks important questions about how we understand technology and its impact on citizenship for people with mental health challenges.

Co-production was identified as the research method. This was informed both by my clinical practice and by the literature, in that it was fundamental to have the views of people with lived experience central to understanding what citizenship and future citizenship meant to people with mental health challenges. A peer-led mental health organisation and digital technology company were identified as participants. It was important to have lived experience involvement in shaping the research; therefore, funding was found, and peer researchers were recruited to support the development of the study. From my perspective this was invaluable to the quality of the research but also led to several ethical tensions, as discussed in chapter 12.

The first phase of the research explored how people with mental health challenges understood citizenship, the factors they thought would shape citizenship in the future and the challenges and opportunities this may bring. The findings from this phase were co-analysed and a short film was co-created with the peer researchers. This film was then shown to participants from the peer-led mental health organisation and discussed with them in a focus group. The focus group, as the action part of CBPR (Kindon et al. 2007), examined key

areas for the development of inclusive future opportunities for citizenship for people with mental health challenges. These findings were then co-analysed with the peer researchers. Finally, the implications of the findings were discussed in a round table discussion between myself and the peer researchers (appendix 16), and are also integrated in this chapter.

In parallel to this, a range of sources (see figure 9) were used to reflect on the process of co-production within this research. The primary outcome of these considerations was a change of title. The original title was Co-producing Future Citizenship Alongside People with Mental Health Challenges. However, reflecting on the complexities of co-production, the level of inequality and power imbalance across the academic structure of a PhD and full citizenship for people with mental health challenges, the title was changed to Towards Co-Production: An Exploration of the Impact of Technology on Future Citizenship for People with Mental Health Challenges.<sup>6</sup> This demonstrates both the striving towards co-production, as well as incorporating the active part of citizenship; it highlights that the study is not trying to create a definitive description of future citizenship but rather interpretations that promote further discussions. It is also recognition of the political and social context, in particular the impact of neoliberalism, within which discussions about citizenship and co-production are taking place (Beresford et al. 2021). One of the core messages from the round table was the importance of not defining future citizenship but promoting and creating spaces for further discussion and action. The significance of this will be explored further in this chapter. Before addressing each of the three research objectives, the limitations of this research are explored.

#### **13.3 Limitations**

It is important to describe the limitations of the study so the reader can understand the discussion in the context of the constraints of what the research

<sup>&</sup>lt;sup>6</sup> Note, following Viva Voce and suggestion by the Examiners, the title was additionally amended to include 'the impact of technology' to reflect the focus on digital technology.

was able to achieve. The first limitation is the use of Future Studies itself, as the future is in essence unknowable or a least unpredictable. This has been demonstrated by the societal changes which occurred during the period of this PhD. Probably the most profound change was the speed and intensity of the development of AI. The speed has been such that in March 2023 several scientists, including two of the 'godfathers of AI,' have written an open letter calling for a pause on the development of AI due to fears of the impact on civilisation (Future of Life Institute 2023).

However, the purpose of Future Studies, and certainly the approach used in this study, is not to accurately predict the future but rather examine possible, probable, and preferable futures (Amara 1991; Inayatullah 2013,); nor is it to try and define a single version of the future (Bergman et al. 2014.) Whilst there are things that have not been anticipated, what has been discussed examines the possible, probable, and preferable to a high enough degree to still have value. The 'probable' and possible' was particularly aided by the involvement of those from the digital technology company and some of those within the peer-led organisation who had a strong understanding of technology and its capabilities.

At the beginning of the study there was a plan to describe preferable or desirable futures in more depth but as the study evolved it became more about the mechanics to create desirable futures rather than what they are. This led to some assumptions around what people understood as desirable, through their definitions of citizenship, but not necessarily what this would look like. Therefore, there is potentially some future research that involves, or is led by, people with lived experience that explores desirable futures.

Another limitation is the diversity of the research cohort (including the peer researchers and myself). The cohort were a small and relatively un-diverse group (particularly in terms of ethnicity), resulting in limited reflection on intersectional perspectives. This is significant as intersectionality plays a key role in inclusive future citizenship. The implication of the lack of ethnic and racial diversity within the participants and peer researchers in relation to the

construction of knowledge and dominant 'white' perspectives were discussed in chapter 12. It is important to recognise that citizenship, mental health and Recovery all have their own cultural contexts and meanings (Eiroa-Orasa and Rowe 2017), and this research (and my professional practice) is located in England and this context has shaped the findings, analysis and recommendations.

In terms of the diversity of the participants, it is also worth noting that the level of involvement from the digital technology company was far more limited than anticipated. Whilst there was strong input in the interviews, there was limited input in the co-production workshop and none in the later elements of the study. Therefore, in terms of understanding the role of the technology sector in promoting inclusive citizenship, questions remain unanswered, and the focus was on the perspectives of the peer-led mental health organisation.

Sayer (2000) argues that critical realism does not seek to make generalisations but rather understand that the makeup of the group and the context within which it operates leads to the findings and their interpretation. I approached this research by trying to create as much transparency as possible so that value judgements can be made about the contribution and merits of this research (Hughes and Duffy 2018; Colder Carras et al. 2023), hence the importance of having a whole chapter reflecting on the process of co-production.

The co-production, whilst overall a strength, could potentially be seen as a limitation, as the research has not followed a linear process. It is therefore difficult to explain and there are multiple layers to the data collection, analysis and write up. The attempts to provide transparency may make it more obscure, due to the level of detail and overlap. Every attempt has been made to make this process easy to follow but this may not be every reader's experience. Bearing in mind the limitations outlined above, the research objectives will now be explored in turn.

#### 13.4 Key Factors Shaping Future Citizenship

This section addresses the research objective: *What do participants think are the key factors that will shape citizenship in the future?* Issues specific to citizenship and mental health are touched upon but will be explored in more depth in the following section. Four key factors have been identified as shaping future citizenship these are: inequality and divisions in society; how technology is changing what it means to be human; how people define citizenship; and the role of democracy and having a voice.

#### 13.4.1 The Impact of Inequality and Division on Citizenship

Unintentionally, this study became a real time narrative around the participants' and peer researchers' experience of Covid and the impact this had on their lives, noticing, and experiencing the increase in inequality in real time. Technology played a part in this and there were specific descriptions within the second findings section (chapter 11) of how people were being forced to use technology to access mental health supports (initially out of necessity and then custom) and/or to access Covid vaccinations. Whilst this may be convenient for some, it may exclude others, particularly those with less cultural, economic and/or social capital (Beresford et al. 2021). Jaegar (2021) described in their literature review that increasingly people are forced to utilise technology to access social supports. This study demonstrated the experience of people being pushed into accessing technology in real time. These findings chimed with those of Eiroa-Orosa and Tormo Clemente (2022). Participants championed the notion that the right to opt out of using technology was a citizenship right, but this increasingly was not an option, and potentially would only get worse in the future. Participants acknowledged that despite how digital inclusion is portrayed as positive or neutral, it is not always unquestioningly a good thing. This is a position supported by critical theorists (Isin and Ruppert 2020; Jæger 2021). Participants felt that people should be able to opt out without being disadvantaged. These findings bring empirical evidence from the lived experience of people with mental health challenges to support these

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claims. This highlights the importance of a critical perspective on digital mental health and the involvement of people with lived experience in these conversations. A key consideration is: whose interests are served by digital health and wider technological developments? It also raises the question of how people's rights are protected or even raises further questions, such as whether access to the internet should be a human right?

Throughout the study, participants and peer researchers raised concerns about the divide in society and people being left behind. There were multiple divisions, largely inequalities linked to wealth and education, but other factors such as internet connectivity, geography, age, and protected characteristics were also thought to be significant. There were several discussions about the level of division and potential further development of an 'underclass' or subsections of society being 'scary' or 'frightening'. This draws attention to the importance of intersectionality and multiple and potentially different impacts of exclusion when discussing present and future citizenship. People thought that those with money and education would be the ones to benefit. In the film, there was a discussion about whether this would lead to rapid physical enhancement through becoming cyborgs or through people being able to access enhanced thinking skills if they pay for more effective AI.

Authors in the literature review and the participants both describe how divisions may impact on people with mental health challenges. This is because mental health challenges can be a barrier to engaging in citizenship through having difficulties trusting, due to trauma; participating when struggling; or dealing with the prejudice of others (Hamer et al. 2014; Brekke et al. 2021). This echoes the concerns about being left behind, that "once you're behind you are out" (Vervliet et al. 2019). Vervliet et al. (2019) described this experience of citizenship without factoring in the rapid impact of digital technology, which may only exacerbate these concerns. This is the first study to specifically focus on the impact of technology on citizenship within mental health and strengthens the existing literature in this area by highlighting the importance of connection and equality in mental health citizenship. This adds to the call by Preibe et al. (2017)

for the need to address social inequalities and cultural competency in future mental health literature; however, here it is led from a lived experience perspective.

There were questions raised within the discussion concerning whether, in the future, different sections of the population would develop different mental disorders, creating a further divide. Participants raised whether those with power and privilege might develop more control disorders (e.g. eating disorders, substance misuse), whereas those on the lower socio-economic spectrum experience – with poverty and misery potentially becoming normalised – may experience more psychosis. Some of the negative impacts of technology on mental health are already being seen (Przybylski et al. 2021) and this raises the question of whether a public health approach to social media should be considered or whether digital citizenship education can support people to better identify the harms of technology (Choi and Cristol 2021). The question of continual connectivity and the impact it will have on attention was also discussed and the implications of this will be discussed further in the section on Challenges and Opportunities. These issues reflect the potentially changing nature of what it means to be human in an increasingly technologically driven society.

#### 13.4.2 What Does It mean to be Human in a Digital World?

A major theme coming through the second findings section and the round table discussion was the importance of understanding what it means to be a human in a digital world, and what this means for people with mental health challenges. People talked about fundamental changes in thinking about the role of the '5 senses', to what it means to be a peer or have lived experience. In the film, Juniper had a virtual key worker and currently people are already interacting with chatbots and smart speakers (Luxton et al. 2016). This poses the question of whether this fundamentally changes who we are as people?

This questioning of 'what it means to be human' is a new finding in relation to mental health citizenship and future technology. It has not been highlighted

within the literature in respect to the use of 'future' in mental health technology, where concerns are more specifically related to digital mental health treatments, privacy, accountability of psychiatrists, and the role of algorithms (Hariman et al. 2019). Equally, it is not represented in the mental health Future Studies literature, which focus on the wider implications of living in a digital world (Bhungra et al.2017; Giacco et al. 2017 Hariman et al. 2019; Preibe et al. 2019). Whilst social psychiatry is being promoted, there is very little focus on people's lives outside of psychiatry; how people inhabit digital spaces and the consequences of this. This may be due to professional concerns dominating the research agenda whilst the concerns of people with lived experience are ignored (Faulkner 2017; Russo and Beresford 2017). I would suggest that exploring what it means to be human is fundamental, but our ability to access this will come down to how we are able to define and exercise our rights as citizens.

There will be an increased need to move away from mental health treatment to public health approaches, prevention, and alleviation. Central to this is how we understand suffering, the role of mental health challenges and what constitutes a life worth living. Both peer researchers and participants, at different points, call for a reinterpretation of how we understand health and mental health. Participants in chapter 10 describe how they view neoliberalism and technologically informed capitalism as causes of mental health challenges and that this therefore needs to be understood as a concern for society. This builds on the current discussion within mental health, which is focused on increasing understanding of social disadvantage and psychological impacts of trauma in framing how we understand mental health challenges (Torrents 2022). This is defined by who informs knowledge and how knowledge is constructed. Unless citizenship is explored in the broader context of what it means to be human in a digital world, and how we constitute a life worth living, citizenship remains stuck in the here and now rather than being understood as an evolving and politically dynamic concept.

#### 13.4.3 The Definition and Evolution of Citizenship

The way citizenship is constructed and understood is a factor in how future citizenship will be shaped. The themes of division and inequality, alongside what it means to be human, should be seen in the context of neoliberalism. This includes how citizenship is currently constructed with a focus on economic activity as a product of neoliberalism, and the conflict with notions of collective and inclusive citizenship. Alongside this, participants identified technological developments as being primarily driven by power and profit. Citizenship is constructed accordingly and evolving in parallel (Isin and Ruppert 2020); it should be understood in relation to an individual's economic activity, transnational migration, the shrinking welfare state, and the rise of nationalism and populism. Neoliberal approaches also seek to distract and engage people through consumerism, drawing their focus from rights and justice (Cruikshank 1999; Zuboff 2019).

Despite this, participants from the peer-led organisation saw citizenship as something that you could self-define or shape through activism. It was not something that is prescribed or set, and people do not necessarily need to conform to be a citizen; non-conforming is potentially an act of resistance to neoliberal constructs of citizenship. There was not a wholesale rejection of the current construction of citizenship. Participants recognised the value of the legal and political rights and comparative material safety of living in a Western democracy (ground floor rights as described by Hamer and Finlayson (2015)) but identified an opportunity to extend the rights and value of all citizens through activism, protest and democracy. Within this study people also understood citizenship in terms of the traditional legal and political rights and responsibilities as described by Marshall (1987). They identified the participatory rights in the Durkhiemian (2014) and De Tocquevillian (2002) approaches that are the foundation of Rowe's 5Rs (Atterbury and Rowe 2017). Participants described the importance of 'belonging'. This need not be belonging to a nation state but

was described as having a 'tribe', or a community of identity which, through the internet, could be on a global scale.

The multi-faceted understanding of citizenship expressed by participants was more akin to critical citizenship (Isin and Neilsen 2008; Isin and Ruppert 2020), incorporating global and digital citizenship, compared to those of Rowe (Atterbury and Rowe 2017) described in the mental health citizenship literature. Participants in this study describe the role of technology in citizenship for people with mental health challenges, which has not been discussed in the literature to date, and therefore contributes new knowledge. Interestingly, participants did not see digital citizenship as something separate but rather a holistic part of their citizenship. Critical theorists argue digital citizenship should always be seen in the context of people's wider citizenship and off-line lives (Emejulu and McGregor 2019; Isin and Ruppert 2020). It is important this thinking is incorporated in the mental health citizenship literature as this is currently a gap.

Those from the peer-led organisation valued having a voice and participation in activism as a core element of citizenship. Whilst this was highlighted in other studies (Quinn et al. 2020; MacIntyre et al. 2021; Reiss et al. 2022), it did not come through as strongly as in this study, and this may be due to the participants not solely having lived experience but also being part of a peer-led organisation. This is aligned to 'acts of citizenship' (Isin and Neilsen 2008) or participatory citizenship (Quinn et al. 2020), making actions that drive change. Those from the digital technology company did not identify the activist element of citizenship, a similar finding to MacIntyre et al. (2021) who found that people who had life changes wanted to give something back as part of citizenship. Therefore, there is something important in raising awareness not just of mental health conditions (as in many of the mental health awareness campaigns) but the impact on citizenship and the need for conversations to be driven by people with lived experience. This suggests that peer-led organisations are crucial in driving change and having a core sense of activism. However, peer-led organisations have been subject to funding cuts over the past 10 years and have barriers accessing funding (Beresford 2019) and therefore this limits the

impact of the voice of those with mental health challenges. To challenge the dominant perspectives, it is important that those with lived experience have a voice in shaping citizenship and to fund and promote peer-led organisations. The following section explores the factors that can shape citizenship.

#### 13.4.4 Democracy and Having a Voice

Fundamental to future citizenship is the control of cyberspace and the internet and how much control will be in the hands of corporations, autocratic or democratic states. This includes consideration of how content is created and accessed, how data is protected, and the level of regulation (Isin and Ruppert 2020). The extent of democratic accountability within a state provides opportunities for citizens to influence these factors, although this is dependent on their own knowledge and understanding, underpinned by the role played by the education system.

Democracy was seen to be key as a check and balance to the dominance of the technology companies and enabling people to access their full rights as citizens; highlighted by participants calling for more direct democracy and identifying the role of GDPR legislation in protecting digital rights. However, there is need for democratic approaches not only to be advanced but also to be defended. Due to the impact of neoliberalism, the rise of populism and increasing voter suppression in western democracies (Mason et al. 2023) and the ability of digital technology companies to tie up governments in legal action to delay and deflect attempts to restrict their 'progress' (Zuboff 2019) democratic processes are being undermined.

Across the two findings chapters, the emphasis on having a voice was deemed to be key in determining citizenship, and participants valued a discursive and pluralistic approach. Having a voice, alongside access to education to make informed choices, underpins the power to act as citizens. However, having the power to influence decisions is key, particularly those decisions made by corporations and government. To understand dynamics of power it is important to recognise these discussions in their social and political context, alongside the foundations of democracy and social rights which ensure people have equal access to citizenship across all marginalised groups (Davidson and Rowe 2016; Brannelly 2018a; Carr and Ponce 2022).

The other opportunity identified is to lobby corporations and engage them through their social responsibilities in driving change. Depending on government commitment to promoting inclusive citizenship, it will become an increasing necessity for activist groups and social campaigners to engage in corporate lobbying. These 'acts of citizenship' are fundamental to drive change and digital media provides opportunities to communicate and raise awareness of issues. The next section explores the opportunities and challenges for future citizenship.

## 13.5 Challenges and Opportunities for Future Citizenship

This section addresses the second research objective: What are the perceived challenges and opportunities for People with Mental Health Challenges in relation to future citizenship? When talking about the future, we are not dealing with accurate prediction but rather likelihood and possibility. A key element in future challenges and opportunities is linked to the direction societies and countries move in. Bearing this in mind, this section focuses on two key elements, identified through the data, that reflect the challenges and opportunities for future citizenship for people with mental health challenges. The first is the opportunities that technology provide to create greater connection (but also further fragmentation); the second is the extent of the shift from a clinical biomedically-informed model of mental health treatment to a social model of madness (Beresford et al. 2010; Hamer et a 2017;).

#### 13.5.1 Connection and Fragmentation

Increasing connection came through as one of the most significant opportunities that technology can offer in providing increased participatory citizenship. This may have been prominent due to people's direct experience through the Covid19 pandemic. Several participants reflected how, over the past few years, they had benefitted from technology through having greater connection with people, whether this was access to treatment or social support or friendship. They acknowledged that without technology they would have been significantly more isolated. Interestingly, one participant identified that they had felt more fearful seeing people in real life, an important consideration in reference to the discussion concerning 'what it means to be human'.

As well as receiving support, participants, also felt that technology gave greater opportunity to have a voice and for engagement in activism and awareness around mental health challenges. At present, the ability to communicate digitally is an essential part of any activism (Isin and Ruppert 2020), and this is likely to continue. It is worth noting that it is not clear if online activism is increasing people's politicisation or whether it is facilitating communication between people who are already politically active (Jaegar 2021). Either way, the capacity to connect with others across the world with similar interests or struggles was appealing. This may provide an effective mechanism for people from various marginalised groups to work collectively.

The literature identified that a greater sense of connection (and belonging) comes with the ability to participate and opportunities to engage. This becomes a virtuous circle as the more people participate, the more they feel they belong (Hamer et al. 2017). Online spaces create more and broader opportunities to participate; for example, online groups or working remotely. However, as with in-person world communities, they are not always welcoming places for people with mental health challenges (Harper et al. 2017; Cogan et al. 2021). For people to be able to connect more in-person and online, there needs to be a focus on creating inclusive communities and spaces for people alongside their own skills development. This will be discussed further in the section on actions to promote future citizenship.

Whilst digital media and technology may create greater opportunities to connect, they present potential opportunities for increased division and

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fragmentation, especially when coupled with real world disadvantage and marginalisation. Connection, including access to technology, is potentially becoming a human right. A number of participants acknowledged they were more vulnerable online when they were struggling with their mental health, and could be more exposed to risks such as cyberbullying, recruitment by extremist groups (e.g. Islamic State, incels, Far-Right), or cyber criminals (Choi, 2016; Isin and Rupper 2020).

Any discussion relating to vulnerability needs to be nuanced and focused on empowering people and communities, rather than assuming people are incapable of safeguarding themselves. In the citizenship literature there is discussion of paternalism within mental health services and how vulnerability is conceptualised by services, which can undermine people's sense of self and their abilities (Hamer and Finlayson 2015; Vervliet et al. 2019). How clinical models of mental health can collapse people's sense of agency will be explored in the next section.

#### 13.5.2 Dominant Paradigms: Clinical Models vs 'Social Model of Madness'

Currently, the dominant paradigm in mental health is rooted in the clinical biomedical understanding of a mental illness model that locates the problem within the individual and focuses on treating symptoms. Whilst this model nods towards psychological and social explanations – the biopsychosocial approach - it is still individualistic, and deficit focused. Participants highlighted the impact of this on citizenship through the overtly clinical approach, which leads to feeling a lack of control and collapse in agency, which is further exacerbated by coercive practices and the Mental Health Act (Hamer et al. 2014; Hamer and Finlayson 2015; Brannelly 2018a). This is internalised and combined with societal discrimination, leading to self-stigma, which becomes a further barrier to engaging as a citizen (Hamer 2012; Hamer et al. 2014; Hamer and Finlayson 2015; Hamer et al. 2017; Harper et al. 2017; Hamer et al. 2019).

The Recovery approach, as described in chapter 2, attempted to address this by putting the person at the forefront of decision-making and shifting the emphasis to valuing lived experience as a form of expertise. However, due to a combination of the dominance of the clinical approach and the neoliberal context that mental health services operate within, the anticipated social change has not been delivered. Ten years on from Hamer's (2012) thesis, which was the first study to explore the lived experience of citizenship of people with mental health challenges, the same issues and themes are present in this study. These themes are exclusion and discrimination; lack of opportunities for participation; the relationship between mental health and dangerousness and the role of the Mental Health Act in depriving people of their rights. These are the same concerns that remain despite over 30 years of focus on Recovery, this demonstrates the potential value of having a specific focus on citizenship. The starting point needs to be citizenship and the struggle for rights rather than Recovery outcomes.

The 'social model of madness' (Beresford et al. 2010; Hamer et al. 2017) locates societal challenges and acknowledges structural inequalities whilst seeking to address them so that communities and people are better able to thrive. The challenges and opportunities for citizenship for people with mental health challenges in part depends on how we conceptualise mental health; the extent that the clinical model prevails over recognising the significance of societal impacts. This should include understanding the impact of trauma (Torrents 2022). A social model also looks at the world outside of mental health services, exploring adaptions that could make the world more accessible. Al may have a role to play in this, but there needs to be assurance and oversight of the data being used and lived experience input into any design. Within this study, participants and peer researchers call for a more socially focused, trauma informed mental health service. This includes repealing the Mental Health Act 1983; participants did not call for amendments but wholesale change, this suggests their view goes beyond the proposed changes within the current UK Government consultation (DHSC 2021b). These findings match those within the

literature and highlight the importance of a more humane mental health system. How this can be addressed is discussed further in the next section.

Technology potentially affords greater choice for people in terms of how they access services, the information available, and the sorts of treatment on offer. However, unless people with lived experience are involved (through 'acts of citizenship') in the development of both technology and care pathways, it is likely existing forms of coercive practice will be reinforced. This includes those that emphasise the link between dangerousness and mental illness. In the future the likelihood of this may increase if pathways are designed by algorithms, which reflect biased data sets, and lead to a reduction in choice and increased coercion, particularly for people of colour. There were fears that privatisation of mental health services would exacerbate this further due to the focus on profit and less accountability. Lack of choice was picked up by IW in the round table discussion, concerning how his online appointments had started as a necessity in the pandemic but now have become the only offer. This raises the question about whose interests are served by a move to online contact. This is intrinsically linked to funding, organisational structures and the extent of rationing, due to the current crisis in mental health services (Torrents 2022). Furthermore, this emphasises the importance of people with lived experience taking leadership roles in shaping the delivery of mental health services now and in the future. It also raises questions about the effective funding of public services to be able to deliver adequate and ethical care.

# 13.6 Promoting Future Citizenship for People with Mental Health Challenges

This section addresses the research objective: To examine the key areas for development to contribute to inclusive future opportunities for citizenship for people with mental health challenges. It considers what can be done to address more equal citizenship, through the analysis of the literature and findings of the study. The following areas have been identified: continuing to talk about citizenship; remodelling society; education; role of mental health services and allyship; and peer-led organisations, activism, and co-production.

# 13.6.1 Continuing to Talk: the Role of Future Studies and Participatory Methods

People valued talking about the future and found the film a useful stimulus for discussion. This felt particularly significant when reflecting on the impact of the Covid-19 pandemic and thinking about experiences of lock-down, the use of digital technology to connect with others and the impact this had on the sense of a divide as people were 'left behind.' This brought a sense of urgency to the discussions, not just about what needs to happen in the future, but what needs to happen now.

One of the most important elements participants and peer researchers described was being able to talk about citizenship and potential future impacts and opportunities. Both groups described wanting to forge further opportunities to participate in future thinking and valued the opportunity to contribute and share views. This suggests that using participatory methods within Future Studies has a valuable role in enabling people to reflect on the present and think about how they may be able to shape the future. This aligns with the findings of Ojala (2015) who found that talking to students about climate change increased their hopes for the future. Some participants in this study felt talking about the future gave them a greater sense of agency and helped them reflect on their actions in the present; for example, the peer researchers thought about the value of supporting the people they work with to have a voice, including paying greater attention to the barriers and social exclusion experienced. However, feeling more optimistic or feeling like you have more agency does not necessarily translate into having more control; therefore, it would be useful to follow up on any lasting impacts of this research. One of the participants cautioned that feeling like you have no control over the future can be a scary place. Part of the reason why people felt able to engage in future thinking was due to the collective power of a peer-led organisation. If there is wider usage of

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Future Studies approaches, it will be important to consider the ethics of involving people and ensuring effective support is in place. It would be valuable to co-produce this ethical approach with people with lived experience.

Initially, I had planned to talk to younger people with mental health challenges, mental health students and people from a national mental health organisation to obtain their views on future citizenship. However, the scale of the project and the co-productive methodology shifted this focused. The experience of the initial cohort suggests this would be a valuable activity. It would be useful to understand which elements of the process people found useful; for example, was it participating in all aspects of the research or was it watching the film in particular? There is the potential for further research exploring the impact and value of the film.

Through CBPR there are also opportunities to think about working with other groups who are marginalised, focusing on intersectionality and using other creative approaches to engage in future thinking; for example, art, fiction, and music has been used in afro-futurism and cyber-feminism (Morgan et al. 2020). It is beneficial not only to consider future citizenship but also what it means to be human in an increasingly digital world. Alongside co-production with people with lived experience it is important to draw on expertise from a variety of disciplines, such as philosophy, digital technology, social policy, and crosscultural perspectives. The purpose would not be to generate a definitive approach to citizenship and being human but rather as 'acts of citizenship' to disrupt norms, share understanding, explore what people can do within their contexts and have ongoing conversations. This aligns with 'acts of citizenship' (Isin and Neilsen 2008) which describes the importance of imagination in developing 'acts of citizenship' by seeing what is possible. Creative approach have an integral role in supporting this imaginary component.

#### 13.6.2 Re-modelling Society

The roundtable discussion suggested that promoting fully inclusive citizenship for people with mental health challenges not only requires a change to mental health services and legislation but change to other public bodies, such as the criminal justice system, education, and local authorities. It requires a paradigm shift away from neoliberalism to economic models more focused on social needs and sustainability. These findings add weight to those of MacIntyre et al. (2021) calling for a top-down-bottom-up approach involving people with lived experience in all elements of research, social policy, and implementation of any changes. People enacting their citizenship through participation chimes with the findings in this study, drawing attention to the role of democracy, the call for direct democracy and people having a voice.

To truly have inclusive citizenship, the struggle for inclusivity and equality should be a global one, which includes universal rights for people with mental health challenges (Priebe et al. 2017). It challenges oppressive business and working practices and low wages, in particular, by making visible how these technologies are still linked to colonialism; which correlate with the racist, patriarchal, enslaving and capitalist approaches to labour and mineral extraction that disproportionately affect the Global South (Emejulu and McGregor 2019).

The case for the reform of mental health services was described above. A core component of this, and a way of radically shifting the dynamic around mental health and citizenship, would be reform of the Mental Health Act 1983. One of the key findings suggests people want to repeal and redesign mental health legislation, through greater involvement of people with lived experience and replacing consultation with co-production. People want it to be more compassionate, with reduced coercion and control over such a broad swathe of people's lives. These findings strengthened existing calls within the Future Studies literature for less coercive legislation and universal rights for people with mental health challenges (Bhungra et al. 2017; Giacco et al. 2019; Priebe et al. 2019). O'Hagan (2013), in her YouTube video, outlines an alternative model for the Mental Health Act and the route to get there. A key element of this is the use of advocacy when people lack capacity, so that their rights and opinions are represented and organisations held to account. O'Hagan (2013) does not discuss technology in her video, but if technology was used ethically

and people have choice over its usage, it could potentially support enhanced choice; providing it has the correct oversight from those with lived experience and their advocates.

As part of the reform of the Mental Health Act 1983, there would need to be a fundamental review of the involvement of the police within mental health services and of the mental health support available for people throughout the criminal justice system. These themes did not come through as strongly within the findings, but were an important part of the round table discussion, alongside the call to reform social care. These elements were not explored in detail and would benefit from co-produced participatory Future Studies looking at what inclusive and humane systems could and should look like. This echoes the findings in the Future Studies mental health research (Bhungra et al. 2017; Giacco et al. 2019; Priebe et al. 2019), which calls for future mental health services to have a greater focus on the social determinants of health and to challenge poverty. Whereas those studies were predominately driven by mental health professionals, this study is the first Future Studies literature co-produced with people with lived experience to make this recommendation.

#### 13.6.3 Education

Within the literature there is a focus on the role of education in digital citizenship. A recommendation from the findings and the round table discussion was for co-produced citizenship education. Reis et al. (2022) call for people with lived experience of mental health challenges who participate in community connections to lead teaching on the subject. If there is a desire to transform society, education needs to be from an early age and throughout adulthood, especially if technology is to bridge the divide in relation to digital citizenship. It is necessary to think about the style of education and how it could be delivered so that people are not left out and left behind. The content needs to engage in critical perspectives and intersectionality to truly meet the needs of people with mental health challenges and make changes to society (Emejulu and McGregor 2019; Choi and Cristol 2021).

The peer researchers felt that recovery colleges could have a role in delivering co-produced co-delivered courses on citizenship, creating spaces for people to have exploratory conversations about citizenship. For citizenship to become more prominent in mental health care, it needs to be reflected in pre-registration programmes for mental health professionals and in the training for peer support workers and support workers. Eiroa-Orosa (2023) is currently developing and then evaluating the impact of a citizenship-based training programme. During this PhD the peer researchers and I have delivered training on the Occupational Therapy and Social Work courses on citizenship and justice.

#### 13.6.4 Role of Mental Health Services and Allyship

Implementing trauma informed approaches is important in reducing the dominance of the biopsychosocial model, which in turn should increase people's agency, improve their experience of services and reduce iatrogenic harm. Cogan et al. (2022) identify the significance of a relational dimension in implementing citizenship approaches. These approaches, alongside a greater focus on human rights, are being directed within the UK through legislation such as the Use of Force Act 2018. This is a milestone, as it paves the way for rightsbased approaches to mental health that enable citizenship to become a greater priority (Rowe and Davidson 2016; Carr and Ponce, 2022). Despite this, within this study there was not a significant discussion of the role of mental health services in promoting citizenship interventions. This highlights the ambiguity of the role of mental health services in citizenship (Davidson and Rowe 2016). Russo and Beresford (2017) argue the future of mental health and social psychiatry are not largely the province of psychiatry but of people and civic society. A significant portion of this work needs to be located in the field of social policy, although mental health services have a role to play (MacIntyre et al. 2021, 2019).

If mental health services, see citizenship as their core business this could prove problematic. This is due to the role services have in maintaining existing power structures and the mistreatment people continue to experience at the hands of mental health services. Mental health professionals hold the power to detain people and deprive them of their liberty and, without reform to the mental health legislation, compatibility with a citizenship framework is questionable.

The literature acknowledges the conflicted role of current mental health services in promoting citizenship (Davidson and Rowe 2016; Carr and Ponce 2022) and the challenges of trying to implement a systemic approach to this issue (Flanagan et al. 2023). Although services are not designed to promote citizenship and are often a significant part of the problem (due to clinical models and coercive practices), without their involvement, nothing is likely to change imminently. This raises the possibility of a similar situation to that of Recovery, which started with noble ideas, but became diluted and co-opted, undermining some of its founding principles. Therefore, I would argue a more radical approach is required to implement citizenship interventions. Whilst RCTs on citizenship have a role in demonstrating the value of citizenship, this should not be the only priority as they potentially primarily locate the need in the individual, whereas the value of citizenship approaches is the focus on the dynamic interaction between the person, the community and society they participate in. It is important that citizenship is addressed on micro, meso and macro layers with interventions at each of these layers that work with all parties involved; for example, community development is as much a priority as working at an individual level. This needs to be built into community mental health service redesigns. Mental health services will need to be involved, but they are unlikely to be the most effective organisations in supporting community development.

To 'up-end' existing structures mental health service involvement needs to be balanced with more fundamental approaches to citizenship, co-constructed with people with lived experience. Where possible, this should be led by people with lived experience and mental health professionals invited to participate. In places where the infrastructure for peer-led organisations is limited it may be that mental health services could support the development of new or existing grassroots peer-led organisations and, in alignment with other marginalised groups (such as anti-racist, and disability and LGBT+ organisations), implement citizenship approaches (Davidson and Rowe, 2016; Brannelly 2018a; Carr and Ponce 2022). If mental health services do take a lead role, and citizenship is to

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succeed in driving change where Recovery has stalled, they will need to avoid the same pitfalls. They will need to directly engage politically with the neoliberalisation of healthcare, whether through 'acts of citizenship' (Isin and Neilsen 2008) or 'collective citizenship' (Quinn et al. 2020). This political engagement involves considering the very future of mental health services as they exist and whether they become fully peer-led, have a role to challenge poverty and discrimination and what role mental health professionals will have (Priebe et al. 2019). It requires the creation of, and funding for, new roles focused on community transformation and campaigning for and upholding people's rights. It also requires a radical commitment from senior leaders, a focus on organisational preparedness and a structured approach to change (Flanagan et al. 2023).

In addition, existing roles will need to be repositioned so that mental health professional roles become that of an ally. It could be considered an 'act of citizenship' for mental health professionals to disrupt power, to give up power, or at least make explicit the dynamics of power: this should form a core part of the ethical dimension of mental health professionals' training. A good example of a discussion that could be considered an 'act of the citizenship' is the dialogue between King and Gillard (2019) around the dynamics of 'whiteness.' In this dialogue King and Gillard discuss the impact of whiteness and power on their involvement in a research project and explore how they were able to disrupt norms but also how existing inequalities were maintained.

Allyship is a skill and to transform services it should be taught to professionals, alongside an understanding of citizenship and the social model of madness.

Hamer (2012) and Hamer et al. (2019) describe people breaking or bending rules as 'acts of citizenship' to promote inclusion. Institutions need to support staff to take risks and blur boundaries to promote citizenship, and senior leadership should make this a priority in their service delivery. Approaches are needed to adjust organisational priorities to support staff to shift their priorities and manage staff that do not engage in this process (Nouf et al. 2023). This will

be challenging in an environment which is under-resourced, high paced and focused on managing risk (Clayton et al. 2020). Partnerships with other organisations will be crucial and should form part of the current nationally driven mental health community transformation.

Now I am in a senior leadership position, I can influence this locally and have been introducing the concept of citizenship and promoting the involvement of people with lived experience in the mental health community transformation. Although it is interesting working at a more senior level, there are significant pressures to act within very clinical frames to manage risk. Therefore, it is important that any meaningful change to promote citizenship needs to take place at leadership level, not solely at the level of frontline workers. Within this project and my previous role, I have been fortunate to work with a peer-led organisation, and the activist element of that organisation, in driving change. This is fundamental to how we move forward with any work on citizenship.

# 13.6.5 Promoting Citizenship: Peer-led organisations, Activism, and Coproduction

#### **Role of Peer-led Organisations**

As peer-led organisations themselves have said for many years, they are pivotal in the development of person-focused social justice mental health support. Despite this, and health trusts' commitments to Recovery, they have been subject to funding cuts (Beresford 2019). To meaningfully enact change to promote citizenship, people with lived experience of mental health challenges can work collectively with other groups who are marginalised to play a central role (Quinn et al. 2020), particularly if there is to be large scale lived experience engagement in future thinking and service design.

If citizenship is to become a mainstream focus of mental health social policy (as I would argue is fundamental, with the impact of technology) to address their marginalisation, negative stereotyping, stigma, and discrimination and to promote the dignity and rights it should be led by people with lived experience of mental health challenges; thereby enacting their citizenship. This is fundamental to the disruption of power and action. It highlights the importance of activism and having a voice, which has been a theme throughout. Working collectively is key to being supported through this process.

Existing groups need funding and support to grow, and new groups need to be established as mental health services or social services look to develop their approach to citizenship. There must be more investment in organisations that are able to lead and influence. Mental health services and those in power need to move over, to give up power and share resources to support wider conversations on future citizenship; but also address more pressing concerns and priorities of peer-led organisations, which include a focus on justice. Currently, funding structures focus on delivery and leave little opportunity for peer-led organisations to engage in activism and promoting justice.

#### Activism

Part of the function of peer-led organisations is being able to be activists to drive change, and as one of the participants, Marmite, described there are decisions to be made about the extent of activism. This may be influenced by resources and how public money can be spent, but it is fundamental that peer-led organisations are funded to promote the voices of people with lived experience to challenge and promote alternative viewpoints.

Isin and Ruppert (2020) see hackers and whistle blowers as people engaging in 'acts of citizenship'. With the governments' protest bill it may be seen as more difficult to engage in protest (Mason 2023), whilst making it even more important for all citizens to challenge a liberty curtailed.

Within the study there was a view that mental health rights were neither as accepted as the rights of lesbian and gay people nor had the profile of the Black Lives Matter campaign. Mental health campaigns have focused on increasing awareness of people's struggles with mental health rather than the rights violations of people with mental health challenges. It is also important not to neglect the focus on intersectionality and solidarity across multiple and interrelated forms of disadvantage.

The internet will play a key role in any awareness raising (Isin and Ruppert 2020). Activism shouldn't solely be left to those with lived experience, as part of their allyship clinicians and others need to act in solidarity in supporting campaigns for increased citizenship. A key part of this is lobbying local and national government to change their policies and promote inclusive citizenship, alongside lobbying corporations to act on their commitments to social responsibility. It would be valuable if people from marginalised groups and those with lived experience of mental health challenges were engaged in influencing the existing policy reform in relation to AI (Future of Life 2023). Understanding who has power and how to address inequality, whether this is through democracy, through protest or through lobbying, is all part of a broader political struggle to promote inclusive citizenship.

Overall, the most important elements identified to promote future inclusive citizenship were having agency and self-determination. Being able to do this is inextricably linked to having a voice and, through activism, driving change. This conceptualisation of citizenship was strongly linked to 'acts of citizenship', in the importance of disrupting dominant power structures (Isin and Neilsen 2008; Isin and Ruppert 2020). The approach to some of the solutions, such as creating a space for conversations and discussions, particularly with those with seldom heard voices relates to 'participatory citizenship' and people taking collective action (Quinn et al. 2020; Reis et al. 2022). One way, identified within this study, of developing and delivering collective action is through co-production.

### **Co-production**

As described previously, continuing to have conversations about citizenship was seen as essential and co-production was viewed as a central approach in moving these conversations forward. It is imperative to bring seldom heard or marginalised voices to the table but also to engage with other partners, such as industry or the commercial sector. As with *Recovery,* this brings another set of risks around co-option and another set of power dynamics to negotiate, but is crucial in thinking about future citizenship, especially with the ever-growing role of technology.

The use of co-production as a research method has been valuable in being able to undertake an in-depth analysis of the process of co-production, which can contribute to the knowledge base on co-production as a research method and its use in practice. The key elements of learning are as follows: the importance of describing the socio-political power structures and context within which coproduction is taking place (Farr 2018; Beresford 2019); thorough preparation for co-production (people knowing their skills, strengths and the perspectives they bring); being a developing process rather than always being possible to engage in fully from the start (Farr et al. 2021); and the importance of transparency, continual reflection and analysis of the dynamics of power (Hughes and Duffy 2018; Farr et al. 2021; Colder Carras et al. 2022;). One of the most important findings for me is the notion of co-production as an 'act of citizenship', whether you are claiming power through joint action or giving up power to enable transformation. This study is titled 'Towards Co-Production' in recognition of the fact that true co-production is a struggle and something to work towards. Looking ahead to the implications of this research, I would be aiming for coproduction to be the driving force in delivering more inclusive citizenship, whether this was in practice, research, education or policy.

Due to the use of CBPR and co-production, there have already been two sets of actions identified: one by the peer-led organisation in the research itself (in chapter 11) and the other in the round-table discussion (Appendix 16). As part of the Ethics of Care approach (Brannelly 2018b) there is a long-term commitment to working with the participants, so one of the first implications to acknowledge is that I will be following up with them to explore these actions. This is in addition to following up the identified actions in chapter 11.

## **13.7 Implications**

## **13.7.1 Implications for Practice:**

- To continue to promote citizenship approaches within the community mental health transformation in Dorset; this includes promoting the role of peer-led organisations to explicitly have advocacy and critical roles in promoting the rights of people with lived experience, and participatory community interventions. This has already seen an ongoing commitment to co-production and the use of the language of citizenship being incorporated into the review. Alongside this it will be important to incorporate additional training for people with mental health challenges, their supporters, professionals, commissioners and local communities and potentially develop a learning collaborative to promote organisational change (Flanagan et al. 2023). This will be picked up in the implications for education.
- To build in reflective supervision for myself, people with lived experience and mental health staff in how to promote citizenship and co-production. In particular, for myself, how to lead within the NHS and promote citizenship.
- To continue to promote, learn, and share learning about citizenship and co-production within practice: in particular, focus on inclusion and intersectionality to ensure seldom-heard voices/groups are able to participate on their own terms. A key element of this will be around how to engage others in promoting citizenship within the leadership of Dorset HealthCare (DHC).
- To encourage Dorset Recovery Education Centre to deliver on the educational recommendations within this PhD (see below).

- To work to establish local lived experience expert advisory panels to support the uptake of digital technology in health care and to promote this as best practice nationally.
- To continue to promote and develop trauma informed approaches to mental healthcare in Dorset, which are based on shared humanity.
- To share the learning from practice within national forums, using opportunities through my current role such as the NHS England Complex Emotional Needs Group, Regional and National 'Use of Force' working groups, links with ImROC (National and Internationally consultancy for Wellbeing and Recovery).

## **13.7.2 Implications for Education:**

- To co-produce, co-deliver and co-evaluate citizenship education programmes, with a focus on mental health and inclusive citizenship. These programmes should include modules on the impact of digital technology and digital rights. They should also include relational working and trauma informed approaches to understanding and supporting people with mental health challenges. These programmes should be informed by critical approaches and delivered across the education spectrum: schools, universities, adult education, recovery colleges and community groups. Initially these will be piloted within the Dorset Recovery Education Centre and offered to Bournemouth University. (Over the past two years I have already co-delivered (with the peer researchers) annual lectures on citizenship on the social work and occupational therapy courses).
- To raise awareness that citizenship education should be included on all pre-registration and peer support worker training for health and social care workers; to monitor and share the findings of the research into staff training as they become available (Eiroa-Orosa 2023); to follow up opportunities locally to extend citizenship lectures (described above) to 260

the pre-registration mental health nurse training at Bournemouth University.

- To advocate for training on intersectionality and allyship to be included on all pre-registration and peer support worker training for health and social care workers and managers; initially engaging with the Bournemouth University Centre for Seldom Heard Voices and leadership team within DHC.
- To explore the opportunity to develop a learning collaborative (Flanagan et al. 2023) focused on promoting organisational change and citizenship as part of the Dorset community transformation.

## 13.7.3 Implications for Research:

The implications for co-production as a research method have been made at the end of the previous chapter. They will not be repeated here but are available at the end of chapter 12.

To raise awareness of these recommendations and to disseminate the findings of this research through conference presentations and papers. I have done a presentation and shared the film at the Refocus on Recovery Conference September 2023. I am also writing a chapter titled *The Future of Occupational Therapy: Recovery, Participatory Citizenship and the Impact of Technology* in the book *Occupational Therapy in Practice in Mental Health: Models, Conditions, Interventions and Recovery* which is due for publication in 2024. As raised in chapter 2, through this book chapter I will bridge the gap between the occupational therapy citizenship literature and the mental health citizenship literature. At the beginning of the PhD I co-authored a paper Morgan et al. (2020) titled *Future Studies, Mental Health and the Question of Citizenship*. This paper has been cited twice (Cogan et al. 2020, Cogan et al. 2022).

- To explore post-doctoral funding to examine the value and impact of watching the film. This could include a facilitated or self-directed workshop to support discussions and potential actions. This approach could also simulate pluralistic approaches to understanding future citizenship using the film as a catalyst for discussion. The film could stimulate different thoughts with different groups of people: for example, different ages, protected characteristics, roles in the mental health field or technology industry. The post-doctoral funding could also examine opportunities for participants to develop their own creative media outputs to reflect their own versions of future citizenship.
- To, where possible, explore future research collaborations with existing research on citizenship within the UK and internationally. This is important because future citizenship for people with mental health challenges is such a new area of research, in fact this is the first study to look at citizenship within England so even that brings novelty. Therefore, there is the potential to develop a whole programme of research based on citizenship and future citizenship within this country and internationally. Since the Refocus on Recovery conference, I have been in touch with Professor Eiroa-Orosa to explore potential collaborations.
- To work with peer-led organisations and people with mental health challenges to prioritise and support with generating opportunities to lead their own research agenda in this field, including priorities for digital health care.
- To consider the effectiveness of co-produced approaches to engaging people in conversations about citizenship, future citizenship and what it means to be human and the implications for people with mental health challenges.

- To research the development and evaluation of co-produced participatory citizenship interventions or education programmes, that look to measure change within communities as well as individuals.
- To engage digital technology companies in working to co-produce research with people with lived experience of mental health challenges
- To develop co-produced Future Studies research on the purpose and role of future mental health services (and wider institutions) and how society can be remodelled to promote inclusive citizenship.
- To promote awareness of digital citizenship within citizenship research in mental health.

## **13.7.4 Implications for Policy:**

- To align with existing groups to advocate for transformation of the Mental Health Act 1983; for it to be replaced by a co-produced alternative that focuses on citizenship, human rights, people having a voice and considers the impact of technology.
- To campaign for social rights that provide a foundation of basic citizenship, for example: safe housing, welfare, and adequate funding for public services and the voluntary sector, with a focus on intersectionality and multiple impacts of discrimination. I am working locally with the Poverty Truth Commission on their Housing workstream.
- To link with other marginalised groups to develop shared approaches to citizenship and jointly lobby governments and corporations for change.
- To campaign for funding to be given to peer-led organisations with the explicit function of challenge, promoting the voices of people with lived

experience of mental health challenges and people from diverse background to promote inclusive citizenship.

- To campaign for digital rights and access to technology and the right to opt out.
- To highlight the importance of promoting and extending democratic processes locally and nationally so that people can influence change and participate as citizens.

### 13.8 Conclusion

The central aim of this thesis was to explore the impact of technology on future citizenship for people with mental health challenges. The purpose of this was not to create a definitive answer but, through the process of co-production, explore possible and probable futures, to generate new knowledge and stimulate discussion. It is worth noting that this is the first study to use Future Studies to explore citizenship for mental health challenges and the findings demonstrate that Future Studies has value as an approach to investigate both future and current citizenship. One of the key outputs of this PhD is the development of the film *Future Citizenship Forecast* which has been key to engaging people with the topic. It has been essential to develop this accessible tool to raise awareness of the topic, as it is complex in nature, and the role of technology and digital citizenship has not been addressed within the mental health citizenship literature.

The findings on how people define citizenship largely correlate to the findings in previous citizenship research, particularly the importance of belonging. A new discovery was the role of social activism as a core component of citizenship for those from the peer-led organisation. Interestingly, participants and the peerresearchers valued discussing what citizenship was and what it meant for them as an end in itself. The additional key findings were that participants were concerned about the impact of inequality and division, the fragmentation of communication and how technology is potentially changing what it means to be human. There was apprehensiveness about the negative impacts of technology increasingly infringing on rights and privacy and the impact of bias within AI and algorithms, particularly for those from marginalised groups, including people with mental health challenges. To truly create inclusive citizenship, there would need to be reform of the education system, criminal justice system, social services, and mental health system, towards systems which focus on promoting rights, inclusion and have an awareness of the impact of trauma. The role of lived experience within this will be paramount. It emphasises how fundamental having a voice and being an activist is as a key part of citizenship and

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demonstrates the value of the role of peer-led organisations and understanding intersectionality.

The starting point for me at the outset of this research was seeking to advance social justice and inclusion for people with mental health challenges and understanding how I could both contribute to the discussion but also enact learning in my practice. This research has illuminated the complexities of the role of mental health services in promoting citizenship, due to the inherent tensions of services both suppressing and promoting citizenship. To effectively promote citizenship, there is a need for a shift away from the primacy of clinical models to the incorporation of social models of madness (Beresford et al. 2010). It is also beneficial for mental health practitioners to understand critical or participatory citizenship and to join those peer-led organisations to campaign and support the reform of the Mental Health Act 1983 and develop more rights-based and trauma informed approaches. It is essential that mental health workers practice in a relational way, to maximise people's opportunities to have agency and citizenship.

Digital Technology, if the focus of its purpose was on inclusion, could have an important part to play in supporting participatory citizenship: building more connection, offering choice to people, and creating reasonable adjustments to support people's engagement in their communities. However, for this to happen, people with lived experience of mental health challenges and other protected characteristics will need a key seat at the table to shape the agenda. It demonstrates the crucial role of co-production in implementing and driving the agendas to change society.

In considering inclusive citizenship, the answer sits beyond the boundaries of mental health services. The research raised broader questions about how people will find meaning and purpose in an increasingly technological world. For there to be inclusive citizenship there needs to be a transparent appraisal of the impact of neoliberalism on the delivery of services, the impact of the market and how this effects people's mental health and inclusion. To create truly inclusive futures there will need to be a focus on belonging, participation and activism; for the solutions not to be located in individuals or services but within communities, and through engagement with governments and corporations.

For me, the key learning throughout this thesis has been having a deeper understanding of co-production. As someone who has worked alongside a peerled organisation for over 10 years I felt I had thorough knowledge; however, through this process I have been able to develop further, specifically in my depth of understanding of the interplay between the various power dynamics. The importance of a critical realist perspective using approaches such as Farr's (2018) social realist critique has been significant in achieving this. It has been particularly useful in relation to using co-production as a research method within this study and has contributed new knowledge to the use of co-production as a research method in the context of a PhD.

What I have learned is how to take into consideration the broader political and structural context impacting on co-production, to view co-production as struggle rather than an end point. Working towards citizenship through co-production and creating the conditions for citizenship is a shared endeavour but those with power, such as myself, need to create space and give up power to others. Core to this is working towards co-production and effectively engaging people from marginalised groups, such as people with mental health challenges, whether that is in research, education, practice, or public policy. Done well, this is a radical opportunity to create inclusive citizenship; done badly, it maintains the status quo under the illusion of inclusion. When working towards co-production, it is crucial that learning is shared; when it goes well and when it does not: this transparency is fundamental. It is also particularly imperative to engage with the technology sector and with government policy to ensure that people's voices are heard, and rights respected. As this is a broad ambition, it is important to celebrate and build on existing movements (particularly those peer-led and survivor-led organisations) that promote inclusive citizenship and to continue to engage in and promote acts of participatory citizenship, which in themselves will disrupt norms and have the potential to drive change.

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## Appendices

## Appendix 1: Core Literature Table

Note: the aims, sample, methods, and methodology are primarily recorded using the language within the original studies. The theoretical approach has been defined by this author in response to content of the paper.

	Study Reference	Aims	Sample	Methods	Methodology	Theoretical
						approach to
						citizenship
1	Bellamy, C. D., Kriegel,	To describe the	Clinical Providers	Survey of utility of	Community	5 Rs of
	L., Barrenger, S.,	development of	in the United	tool (scoring)	Based	Citizenship as
	Klimczak, M., Rakfeldt,	a citizenship	States in an urban	analysed using	Participatory	defined by
	J., Benson, V., Baker,	tool to support	community mental	univariate analysis	Research	Rowe (2015).
	M., Benedict, P.,	clinical case	health provision	using SPSS cross		
	Williamson, B. and	managers with	serving those with	referenced with	Researchers	
	MacIntyre, G., 2017.	the use of the	serious mental	demographic data.	partnered with	
	Development of the	Citizenship	health diagnosis.		clinicians and	
	citizens measure into a	Measure as	17 case	Survey also asked	people with	
	tool to guide clinical	developed by	managers test the	open ended	lived	
	practice and its utility for	O'Connell et al.	citizenship tool	questions about	experience at	
	case managers.	(2017) and	with 17 clients.	people's views on	each stage of	
	American Journal of	testing the		the tool. These	the	
	Psychiatric	practical utility of	The case	were analysed	development	
	Rehabilitation, 20 (3),	the tool and	managers were	with a quantitative	or the tool	
	268-281.	implications for	predominately	approach	and	
		practice	female and white.	capturing thematic	evaluation	
			The clients were	prevalence and		
			predominantly			

			female and non- white.	categorical patterns		
2	Brannelly, T., 2018a. An ethics of care transformation of mental health service provision: creating services that people want to use. In Wintrup, J., Biggs, H., Brannelly, T., Fenwick, A., Ingham, R., Woods, D (eds). <i>Ethics From the</i> <i>Ground Up: Emerging</i> <i>Debates, Changing</i> <i>Practices and New</i> <i>Voices in Healthcare</i> . London, Palgrave MacMillan	To explore the priorities for change in mental health services for service user activists	Interviews with Service User activists from New Zealand and the UK (n=9) (7 female and 2 male)	Data thematically analysed using Braun and Clarke (2006)	Semi- Structured Interviews	Acts of Citizenship (Isin and Neilsen 2008)
3	Brekke E, Clausen HK, Brodahl M, Lexén A, Keet R, Mulder CL and Landheim AS,. 2021. Service User Experiences of How Flexible Assertive	The aim of this study was to explore and describe service user experiences of how receiving	32 service users from five Norwegian FACT teams who experience serious mental health challenges	Participatory design, individual interview were analysed using thematic, cross- sectional analysis.	Semi structured interviews Co-production of this study involved a	5Rs of Citizenship (Rowe 2015)

Community Treatment	services from a	and/or substance	peer group	
May Support or Inhibit	Flexible	misuse	that was	
Citizenship: A	Assertive		consulted	
Qualitative Study. Front.	Community	Participants were	throughout	
Psychol. 12:727013.	Treatment	21 men and 11	the study and	
	(FACT) team	women between	gave advice	
	may support or	the ages of 20	on planning	
	inhibit	and 67 years	the study and	
	citizenship.	(mean age 37).	analysing the	
		One participant	findings, and	
		had a Community	involvement	
		Treatment Order	of the third	
		(CTO) at the time	author, who	
		of the interview,	has lived	
		while 25	experience of	
		participants had	receiving	
		experienced	mental health	
		compulsory	and	
		admissions and/or	substance	
		CTOs in the past.	use services,	
			who has	
			participated	
			as a co-	
			researcher in	
			all stages of	
			the study.	

4	Carr, E.R. and Ponce, A.N., 2022. Supporting mental health recovery, citizenship, and social justice. <i>Community</i> <i>Mental Health Journal</i> , pp.1-9.	To examine the interactions between Mental Health Recovery, Citizenship, and Social Justice and their	Two psychologist leaders, one a collaborator with a community homeless unit community agency and the other the director	Theoretical and explanations of practical application of shared learning and role of leadership across two mental health	Case Studies provided by psychologists as leaders in implementing Recovery and Citizenship approaches	5 Rs of Citizenship (Rowe 2015)
		application within mental	of the inpatient psychology	services, one community and		
		health settings	service, in US.	one inpatient service.		
5	Clayton, A., O'Connell, M., Bellamy, C., Benedict, P. and Rowe, M., 2013a. The Citizenship Project Part II: Impact of a Citizenship Intervention on Clinical and Community Outcomes for Persons with Mental Illness and Criminal Justice Involvement. <i>American Journal of</i>	To assess the effectiveness of an intervention based on a theoretical approach to citizenship on reducing alcohol and drug use, reducing psychiatric symptoms and increasing quality of life for people with	There were 114 participants with SMI and Criminal Justice Involvement Most participants were women (58%) the rest were men or did not identify as either gender, 65% were people from African American	Participants were randomised at a ratio of 2:3 into the citizenship project. Those in the experimental group received Peer mentoring, citizenship classes, and participated in valued role projects.	Randomised Control Trail	5R's of Citizenship (Rowe 2015)

Con	nmunity Psychology,	Severe Mental	background, 30%	The other group	
51 (	1/2), 114-122.	Illness and	were White, 9%	received treatment	
		criminal justice	Latino <1% native	as usual.	
		involvement.	American.		
				Participants	
				undertook a	
				baseline interview,	
				then others at 6	
				months and 12	
				months. These	
				interviews involved	
				completing a	
				battery of	
				standardised	
				measures that	
				covered	
				psychiatric	
				symptoms, alcohol	
				use, increasing	
				quality of life and	
				criminal justice	
				involvement.	
				Linear Mixed	
				model analysis	
				were used to	
				assess the	

				interventions impact This paper focuses on the analysis of the quality of life and psychiatric outcomes.		
6	Clayton, A., Miller, R., Gambino, M., Rowe, M. and Ponce, A.N., 2020. Structural barriers to citizenship: a mental health provider perspective. <i>Community</i> <i>Mental Health</i> <i>Journal</i> , 56, pp.32-41.	To understand how citizenship approaches can be used in mental health services by exploring mental health workers views of citizenship, using the Citizenship Measure.	Mental Health Professionals (n=77) in an urban community mental health provision serving those with serious mental health diagnosis, New England, United States. Centre staff were from a range of treatment teams and across a broad range mix of disciplines (mostly social workers and	Eight focus groups using semi- structured protocol. Analysed using Braun and Clarke (2006) Focus group participants were given a copy of the CM or CM-B with instructions to review and think about how its items related to, or did not relate to, their work with clients.	Focus groups	5 Rs of Citizenship (Rowe 2015)

			psychiatrists, no peer workers). Only demographic	The first focus group was the only group to review the full 45-item		
			breakdown by gender (72.7%	CM. As feedback from the group		
			Female)	was that the CM		
				was too detailed and time		
				consuming to		
				digest in the context of a focus		
				group.		
				Four themes were		
				identified, however		
				this paper on focuses on one		
				theme 'structural		
				barriers' and the		
				sub-themes within this.		
7	Cogan, N. A., MacIntyre,	To explore how	Participants who	6 focus groups	Community	Seeks to
	G., Stewart, A., Tofts,	adults with	had experience of	using semi-	Based	explore
	A., Quinn, N., Johnston,	experience of	mental health	structured	Participatory	people with
	G., Hamill, L., Robinson,	Mental Health	problems and	interview	Research.	mental health
	J., Igoe, M., Easton, D.,	Problems and	other life	questions.		problems

	McFadden, A. M. and Rowe, M., 2021. "The biggest barrier is to inclusion itself": the experience of citizenship for adults with mental health problems. <i>Journal</i> <i>of Mental Health</i> , 30 (3), 358-365.	other life disruptions identify potential barriers to citizenship.	disruption(s) within the last 5 years in Scotland (n=40). 75% where Male, 25% Female; all white British, Scottish or Irish; most participants	Analysed using thematic analysis using Braun and Clarke (2006).	6 Peer Researchers were involved in all steps of the research process	definitions of citizenship references Rowe (2015) 5Rs as a starting point but acknowledges that lived
			were between 35- 54)			experiences voices have been limited in defining citizenship.
8	Cogan, N., MacIntyre, G., Stewart, A., Harrison-Millan, H., Black, K., Quinn, N., Rowe, M. and O'Connell, M., 2022. Developing and establishing the psychometric properties of the Strathclyde Citizenship Measure: A new measure for health	To report on the development of the Strathclyde Citizenship Measure (SCM) which seeks to develop a psychometrically sound measure of citizenship that is relevant to the socio-	Participants were recruited using convivence sampling via online, e.g. social media, and off- line media e.g. newpapers. 407 participants completed the online survey. They were aged	The survey was subject to a principal components analysis which resulted in the 39 item SCM The short SCM was administered online along with additional	Community Based Participatory Research has underpinned this approach. 6 Peer Researchers were involved in all steps of the research	Lived experience voices have shaped this research. Rowe (2015) 5Rs has been used as an underpinning framework.
	and social care practice	cultural Scottish	between18-88,	measures	process.	

,	-			· · · · ·	
	and research. Health &	context. The	female (73%),	including the	
	Social Care in the	purpose of this	majority white	Warwick-	
	Community, 30(6),	is to be able to	Scottish (65.6%).	Edinburgh Mental	
	pp.e3949-e3965.	measure	Over three	Well-being Scale	
		citizenship	quarters identified	(WEMWBS), the	
		interventions	as having life	Depression,	
		and citizenship	disruptions	Anxiety and Stress	
		more broadly 'in	(diagnosed	Scale (DASS21),	
		action.'	mental health	the Sense of	
			problems n=139	Belonging	
		There were	being the largest	Instrument (SOBI-	
		three stages to	group). A majority	A); the Big Five	
		the process: in	of participants	Personality	
		the first, the	(n=312) were in	Inventory	
		items for the	part-time or full-	(Shortened	
		SCM were	time employment.	Version; BFI-10)	
		generated via		and the Personal	
		concept	The short version	Social Capital	
		mapping (see	of the SCM was	Scale (PSCS-16).	
		MacIntrye et al.	administered to a		
		2019; 2021)	sample of	The factor	
			Scottish residents	structure and	
		The second	(n=280) using	dimensionality of	
		piloting the 60-	same inclusion	the SCM was	
		item version as	criteria as the	examined using	
		an online survey	survey (the paper	exploratory factor	
		to reduce the	does not include a	analysis and it was	
			demographic		
		1	000	1 1	1

		number of	breakdown of this	found to be		
		items.	cohort)	reliable and valid.		
		The third was to				
		test the				
		psychometric				
		properties				
		through testing				
		its reliability,				
		convergent,				
		concurrent				
		discriminatory				
		validity. This				
		was through the				
		measure being				
		administered				
		online.				
9	Danielsen, K.K., Øydna,	The purpose of	Nine adults	The study was a	Semi-	5 Rs of
	M.H., Strömmer, S. and	this study was	experiencing poor	qualitative	structure	Citizenship
	Haugjord, K., 2021. "It's	to explore how	mental health who	explorative study	interviews	(Rowe 2015)
	More Than Just	individuals	engaged in	using individual,		
	Exercise": Tailored	facing mental	exercise at an	semi- structured,	There was	
	Exercise at a	health	open access	in-depth	limited lived	
	Community-Based	challenges	community	interviews. An	experience	
	Activity Center as a	experienced	activity centre in	inductive,	involvement.	
	Liminal Space along the	participating in	southern Norway	descriptive, and	In addition to	
	Road to Mental Health	tailored exercise		explorative type of	the research	

	Decey ond	programmes of	wore invited to		toom there	
	Recovery and	programmes at	were invited to	analysis was used	team there	
	Citizenship. International	a community-	take part.	systematic text	was a	
	Journal of	based activity	<b>-</b>	condensation	research	
	Environmental Research	centre, and how	The inclusion	developed by Kirsti	group	
	and Public	this supported	criteria were	Malterud (2017)	supporting	
	<i>Health</i> , <i>18</i> (19), p.10516.	an individual's	having mental		the project	
		process of	health challenges		who had	
		recovery.	and having		someone with	
			participated in the		lived	
		Their findings	tailored exercise		experience	
		were that there	sessions at the		contributing	
		is a need to	activity centre		their	
		treat mental	over the previous		perspective.	
		health	six months or			
		challenges as a	longer.			
		contextual				
		phenomenon	Participants were			
		and to create	aged 20-45, 5			
		arenas to	women and 4			
		promote	men. No further			
		community and	demographic			
		citizenship in	information was			
		society	collated.			
10	Davidson, L., Rowe, M.,	This paper	Perspectives of 5	Draws up on the	Perspective	5 Rs of
	DiLeo, P., Bellamy, C.	provides a	subject experts	policy context	piece	Citizenship
	and Delphin-Rittmon,	perspective on		within the US,		(Rowe 2015)

	M., 2021. Recovery- oriented systems of care: A perspective on the past, present, and future. <i>Alcohol</i> <i>Research: Current</i> <i>Reviews</i> , <i>41</i> (1).	the origins of Recovery, its implementation and potential future directions including the role of citizenship		existing Recovery and Citizenship literature (with a focus on the 5Rs) and the experience of the authors implementing 'Recovery Citizenship' within services within		
				Connecticut	-	
11	Eiroa-Orosa, F. J. and Rowe, M., 2017. Taking the Concept of Citizenship in Mental Health across Countries. Reflections on Transferring Principles and Practice to Different Sociocultural Contexts. <i>Frontiers In Psychology</i> , 8, 1020-1020.	To describe the process of transferring the concept of citizenship from the US and to Catalonia, Spain and discuss the implications of cross-cultural working within citizenship	Case study given as an example, involving 70 mental health professionals, 40 service users,10 family members. Information about participants not particularly detailed as focus is the discussion about cross cultural translation	15 Focus groups exploring citizenship how this could be translated into training interventions, analysed using Braun and Clarke (2006) Waiting list randomised control design based on non-	Case example of MH setting, drawing on multi-modal research approaches.	5Rs citizenship (Rowe 215) with a critical exploration of the challenges of cross-cultural translation.

				specified battery of assessments done pre, during and post training.		
12	Eiroa-Orosa, F.J. and Tormo-Clemente, R., 2022. Recovery, Citizenship, and Personhood of People with Lived Experience of Mental Health Problems during the Pandemic: Two Expert Focus Groups. In <i>medical</i> <i>sciences Forum</i> (Vol. 4, No. 1, p. 42). MDPI.	To consider possible violations of rights that have occurred in the Covid-19 pandemic for people with mental health challenges. To also explore the experiences of individual and collective resilience that have helped maintain well- being among this group of people.	Participants (n=17) with different mental health expertise from three Spanish-speaking countries (Chile, Colombia, and Spain). These included mental health professionals including peer support workers, policy makers, health managers, anti-stigma campaigns technicians, and mental health activists.	Two expert focus groups analysed using thematic analysis Braun and Clarke (2006)	Focus groups	5 Rs of Citizenship (Rowe 2015)

13	Eiroa-Orosa, F.J., 2023.	The purpose of	The research will	Plan for research	The focus	5 Rs of
	Citizenship as mental	this paper is to	commence with	is two-fold- the first	groups and	Citizenship
	health. A study protocol	share a	20 focus groups	is to explore the	usefulness of	(Rowe 2015)
	for a randomised trial of	research	each group	concept of	the	
	awareness interventions	protocol, within	consisting of 6-10	citizenship with	intervention	
	for mental health	which the	people.	professionals and	will be	
	professionals. Journal of	research seeks	(5 each with	people with lived	analysed	
	Public Mental Health.	to demonstrate	participants form	experience using	using Braun	
		how mental	the following	focus groups.	and Clarke	
		health is tied to	groups: adult		(2006)	
		citizenship, and	mental health	Mental health	(Interviews	
		to help	services users,	activist with lived	will be	
		professionals	youth mental	experience will	available for	
		understand	health service	lead on developing	people	
		mental health in	users, relatives,	the intervention	uncomfortable	
		the context of	and mental health	using targeted,	in focus	
		social rights and	professionals)	local, credible,	groups.)	
		responsibilities,		continuous contact		
		to move towards		methodology	The	
		a right-based	The awareness	outlined by	quantitative	
		practice.	intervention will	Corrigan et al.	data will be	
			aim to be	(2011). This will	analysed	
		This is through	delivered to 200	then have input in	using	
		focus groups to	mental health	the co-creation	statistical	
		inform the	professionals	from	analysis,	
		development of	across a range of	representatives	multi-level	
		an awareness	disciplines and a	from the groups	mixed effects	
		raising	number of mental		linear	

intervention for	health services in	represented in the	modules
mental health	Spain.	focus groups.	based on
professionals			demographics
and then testing		The awareness	and pre, post
the intervention.		raising intervention	and follow up
		will be delivered	measures.
		and evaluated	
		using a double-	
		blind, cluster-wait-	
		list randomised	
		control trial to	
		evaluate the	
		degree of belief	
		and attitude	
		change through	
		statistical	
		significance and	
		effect size	
		between the two	
		groups. Using	
		standard	
		measures.	
		The study will also	
		explore which	
		components of the	
		intervention are	
		more or less	

14	Flanagan, E., Tondora, J., Harper, A., Benedict, P., Giard, J., Bromage, B., Williamson, B., Acker, P., Bragg, C., Adams, V. and Rowe, M., 2023. The Recovering Citizenship Learning Collaborative: a system-wide intervention to increase citizenship practices and outcomes. <i>Journal of</i> <i>Public Mental Health</i> .	To describe the impact of Recovering Citizenship Learning Collaborative (RCLC), a training, consultation, and implementation effort for 13 local mental health authorities and two state hospitals.	Multi-site project setting up learning collaborative in Connecticut. This state-wide group had an average of 6 staff, plus there were local learning sets with un-specified numbers of staff (from a range of backgrounds) and people who access services which were described as being from racially, ethnically and linguistically diverse backgrounds	thematic analysis. Sites had undertaken a baseline assessment of Recovering Citizenship practices and Linguistically and Culturally Appropriate service standards. Participants evaluated monthly learning sessions against learning objectives Participants were asked about barriers and facilitators to implementing the RCLC in their area	Lessons learnt from feedback from learning collaborative.	5 Rs of Citizenship (Rowe 2015) Recovering Citizenship (Rowe and Davidson 2016)
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15	Georghiades, A. and	The Community	Self-selected	An intervention	Randomised	5 Rs of
	Eiroa-Orosa, F. J., 2020.	Engagement	sample recruited	research design	Waiting List	Citizenship
	A Randomised Enquiry	Project aimed to	using social	was implemented	Control Trial	(Rowe 2015)
	on the Interaction	identify the	networking sites;	with a randomised		
	Between Wellbeing and	strength of the	participants had	waiting list control		
	Citizenship Journal of	relationship	to be able to	trail		
	Happiness Studies	between	speak English			
	volume 21, pages 2115-	wellbeing and	and be over 16.	Participants		
	2139	citizenship. In		receiving the		
		addition, the	175 participants	intervention		
		study aimed to	were recruited to	watched videos		
		investigate the	randomisation.	and answered		
		capability of	74% were female	questionnaires		
		changing	( <i>n</i> =128), and	related to social		
		wellbeing and	participants	justice beliefs,		
		citizenship	represented 13	assertiveness and		
		levels over time	countries	values.		
		after exposure	(including			
		to a short	Australia,	Participants		
		experiment	Bahrain, Belgium,	undertook baseline		
		which also	Canada, China,	and post		
		involved the	France, Germany,	intervention		
		following	Spain,	measures of		
		variables: Social	Switzerland. The	citizenship,		
		Justice Beliefs,	Netherlands,	wellbeing, social		
		Assertiveness,	United Arab	justice beliefs,		
			Emirates, The			

Justice and	United Kingdom	assertiveness and				
Care Values.	and United States	values.				
	of America)					
		Repeated				
	The participants	measures of				
	were	factorial analysis of				
	predominantly	variance were				
	white 74.7%	used in order to				
	( <i>n</i> =130) with a	test within subject				
	small minority of	changes from the				
	participants	baseline to the				
	representing other	follow-up, taking				
	ethnicities. The	into account time				
	majority were in	and condition				
	employment					
	59.8% ( <i>n</i> = 104)	T tests and Chi				
	had an	squared tests with				
	undergraduate	odds ratios were				
	degree 50.6%	used to compare				
	( <i>n</i> =88) and were	socio-demographic				
	currently in a	characteristics				
	relationship	between the				
	67.8% ( <i>n</i> =118).	experimental and				
		control group and				
	28 participants	to compare				
	from the	baseline scores of				
	experimental	participants				
	group and 24	completing the first				
			participants from	follow-up with		
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			the control group	those who did not		
			completed the			
			final follow-up.			
16	Hamer, H. P., 2012.	To explore	17 Service User	Semi Structured	Mixed	Acts of
	Inside the city walls:	service users'	Advisors (those	interviews	Qualitative	Citizenship
	Mental health service	understandings	with their own	exploring the	methods	(Isin and
	users' journeys towards	of citizenship	lived experience	service user	interviews	Neilsen 2008)
	full citizenship	and whether the	who also advised	advisors	and focus	
	(Unpublished doctoral	recovery	others)	experience of	groups	
	thesis). The University	approach		citizenship.		
	of Auckland, Auckland,	hinders or helps	12 Key			
	New Zealand.	them to access	Stakeholders	The public		
		full citizenship	made up of public	servants were		
			servants (e.g. in	asked about their		
			Ministry of health,	views on current		
			human rights	and future service		
			commission,	development		
			leaders in the			
			development of	Data analysed		
			mental health	using Isin's		
			services) and	Citizenship		
			mental health	framework		
			nurses. All from			
			New Zealand	Findings were		
			apart from 1	discussed with		
			participant from	mental health		
			the UK.			

				nurses (n=7) in a focus group		
17	Hamer, H. P., Finlayson, M. and Warren, H., 2014. Insiders or outsiders? Mental health service users' journeys towards full citizenship. <i>International journal of</i> <i>mental health nursing</i> , 23 (3), 203-211.	Explores people with lived experience of mental health challenges on their journey to full citizenship	This paper used the data from the participants who were service user advisors in Hamer's (2012) dissertation as outlined above	This paper used the same methods from Hamer's (2012) dissertation as outlined above	Semi- Structured Interviews	Acts of Citizenship (Isin and Neilsen 2008)
18	Hamer, H. P. and Finlayson, M., 2015. The rights and responsibilities of citizenship for service users: Some terms and conditions apply. <i>Journal of Psychiatric</i> <i>and Mental Health</i> <i>Nursing</i> , 22 (9), 698- 705.	To explore the rights and responsibilities of citizenship for service users of mental health services and the conditions applied to them.	This paper used the data from the participants who were service user advisors in Hamer's (2012) dissertation as outlined above	This paper used the same methods from Hamer's (2012) dissertation as outlined above	Semi- Structured Interviews	Acts of Citizenship (Isin and Neilsen 2008)

19	Hamer, H. P., Kidd, J.,	The paper	This paper	Not clear other	Semi	Acts of
	Clarke, S., Butler, R.	presents	incorporates	than the data	Structured	Citizenship
	and Lampshire, D.,	services users	findings from	utilised from	Interviews	(Isin and
	2017. Citizens un-	of mental health	Hamer's (2012)	Hamer's (2012)		Neilsen 2008)
	interrupted: Practices of	services stories	dissertation and a	dissertation and a	Analysis was	
	inclusion by mental	of exclusion and	report completed	2014 report	undertaken	
	health service users.	inclusion	by the authors in		using Isin's	
	Journal of Occupational	regarding full	2014 which is no		citizenship	
	Science, 24 (1), 76-87.	citizenship	longer available.		framework	
			Therefore, other			
			than being			
			described as			
			service users and			
			their champions in			
			New Zealand			
			there is no further			
			demographic			
			information			
			included.			
		<del>-</del>				
20	Hamer, H. P., Rowe, M.	To describe the	12 Participants, 7	Semi-structured	Exploratory	Acts of
	and Seymour, C. A.,	'Acts of	Mental health	interviews.	Qualitative	Citizenship
	2019. 'The right thing to	Citizenship'	clinicians and 5	<b>-</b>	Approach	(Isin and
	do': Fostering social	embedded in	peer support	Thematically	(Rolfe, 2006)	Turner 2008)
	inclusion for mental	everyday	workers from a	analysed using		
	health service users	practices of	mental health	general inductive		
	through acts of	mental health	facility in the US.	approach		
	citizenship. International	workers that		(Thomas, 2006)		

	Journal of Mental Health Nursing, 28 (1), 297- 305.	promote social inclusion for people with mental health challenges	Demographic data: 3 men, 9 women, aged between 35-60, no data on ethnicity)	Vignettes were also presented to professional peer group and group of peer support workers to further validate the findings		
21	Harper, A., Kriegel, L., Morris, C., Hamer, H. P. and Gambino, M., 2017. Finding citizenship: What works? <i>American</i> <i>Journal of Psychiatric</i> <i>Rehabilitation</i> , 20 (3), 200-217.	To explore the community integration experiences of people with Serious Mental Illness (SMI), with a focus on the elements that are critical to integration	8 people with SMI who had been nominated by staff or their peers who had made progress in community participation and inclusion and received support from a community mental health facility in the US. (Demographic data: 5 men, 3 women; 6 white, 2 non-white; 6 in their fifties)	Interviews were carried out exploring the domains of the 5 Rs of citizenship. A thematic narrative analysis was undertaken	In-depth Semi- Structured Interviews	5 Rs Citizenship (Rowe et al. 2012)

22	MacIntyre, G., Cogan,	To provide a	Focus group	Concept mapping	Community	No specific
	N.A., Stewart, A.E.,	rationale for the	participants are	using Mixed	Based	frame other
	Quinn, N., Rowe, M. and	inclusion of	people who have	methods	Participatory	than for
	O'Connell, M., 2019.	citizenship in	experienced life	participatory	Research	citizenship to
	What's citizenship got to	Mental health	disruptions,	approaches.		be defined by
	do with mental health?	strategy and	including people			participants
	Rationale for inclusion of	describe the	with experience of	10 focus groups		
	citizenship as part of a	methodology	mental health	which developed		
	mental health	used to develop	problems,	110 statements		
	strategy. Journal of	a model of	substance	about citizenship.		
	Public Mental	citizenship	misuse, the			
	<i>Health</i> , <i>18</i> (3), pp.157-	within a Scottish	criminal justice	Stakeholders were		
	161.	context.	system and long-	then invited to		
			term physical	participate in		
			health problems,	concept mapping		
			and people who	exercise by rating		
			did not identity as	statements by		
			having	clarity and		
			experienced such	relevance.		
			life disruptions.			
			(n=77)	This was then		
				analysed using		
			Concept mapping	multivariate		
			participants (n=45	statistical methods		
			from focus group	multidimensional		
			participant plus an	scaling and		
			additional m=245)			

				hierarchical cluster analysis.		
23	MacIntyre, G., Cogan, N., Stewart, A., Quinn, N., O'Connell, M. and Rowe, M., 2021. Citizens defining citizenship: A model grounded in lived experience and its implications for research, policy and practice. <i>Health &amp; social</i> <i>care in the community</i> .	To chart the empirical generation of a model of citizenship within Scotland	Focus group participants people who have experienced life disruptions, including people with experience of mental health problems, substance misuse, the criminal justice system and long- term physical health problems, and people who did not identity as having experienced such life disruptions. (n=77). Plus additional participants who engaged in an	Concept mapping using Mixed methods participatory approaches. 10 focus groups which developed 110 statements about citizenship. Stakeholders were then invited to participate in concept mapping exercise by rating statements by clarity and relevance (N=45) Those participating on the online survey then rated the statement in	Community Based Participatory Design Using peer researchers to ensure lived experience is in each part of the research process/.	Acknowledge influence of 5Rs (Rowe 2015) without committing to specific framework and wish to focus on lived experience of citizenship

			online survery	relation to clarity		
			(n=245)	and relevance.		
			()			
				This was then		
				analysed using		
				multivariate		
				statistical methods		
				multidimensional		
				scaling and		
				hierarchical cluster		
				analysis.		
				There was also a		
				thematic analysis		
				of the focus group		
				data using Braun		
				and Clarke (2006)		
24	Nesse, L., Aamodt, G.,	To explore the	Participants were	Participants	The study	Not specified
	Gonzalez, M. T., Rowe,	relationship	people in	completed self-	used a cross-	<ul> <li>drew from</li> </ul>
	M. and Raanaas, R. K.,	between	supported	report	sectional	range of
	2021. The role of	objective	housing with	questionnaires,	design.	citizenship
	occupational	measures of	mental health	which included		literature
	meaningfulness and	occupational	challenges and	demographic		
	citizenship as mediators	status and	co-morbid	variables and		
	between occupational	quality of life	conditions	measures of		
	status and recovery: a	with subjective	(n=104), across 6	recovery, quality of		
	cross-sectional study	measures of	cities in Norway.	life, occupational		

among residents with	occupational		mooningfulnoss	
among residents with	occupational	The sample (n =	meaningfulness	
co-occurring problems.	meaningfulness	104, 76 men, 28	and citizenship.	
Advances in Dual	and citizenship		The demographic	
<i>Diagnosis</i> , 14 (3), 99-		women) primarily	variables included	
118.		consisted of	gender, age,	
		residents aged	occupational	
		above 40. The	status, educational	
		most common	level, main source	
		levels of	of income, length	
		completed	of residency and	
		education among	prior housing	
		the residents	situation.	
		were elementary	Occupational	
		school or courses	status, source of	
		attended after	income and	
		completing high	previous housing	
		school. The main	situation were	
		source of income	multiple choice	
		for the majority of	items, and the	
		the participants	remaining items	
		was social	were single	
		security benefits.	choice.	
			Linear regression	
			analyses were	
			used and indicated	
			that occupational	
			status was	

				significantly associated with the citizenship domains caring for others and community participation and with the quality of life measure positive affect		
25	Nesse, L., Gonzalez, M.T., Rowe, M. and Raanaas, R.K., 2022. Citizenship matters: Translating and adapting the Citizenship Measure to Norwegian. <i>Nordic</i> <i>Studies on Alcohol and</i> <i>Drugs</i> , <i>39</i> (3), pp.262- 278.	The aims of the study were to 1) translate and adapt the Citizenship Measure, developed by Rowe and col- leagues to a Norwegian context, and 2) to assess the internal consistency and convergent validity of the	A convenience sample of 104 residents with co- occurring problems living in supported housing completed the measure (see demographics in Nesse et al. (2021) study above)	The translation process was carried out using forward and back translation procedures. An exploratory factor analysis (principal component analysis) was conducted to investigate the factor structure and check how the	Translation of the Citizenship Measure and evaluation of internal consistency and convergent validity using statistical analysis.	5 Rs of Citizenship (Rowe 2015)

		Norwegian translated measure.		factors in the Norwegian version resembled the structure in the original version. To assess convergent validity, there was an examination of the correlation between the seven citizenship domains with the five domains of the Recovery Assessment Scale		
26	Nouf, F. and Ineland, J., 2023. Epistemic citizenship under structural siege: a meta- analysis drawing on 544 voices of service user experiences in Nordic mental health	The main objective is to identify barriers and facilitators of service user involvement in Nordic mental health services	This paper presents a meta- analysis, drawing exclusively on qualitative research ( <i>n</i> =38) published in the period 2017–	Assessment Scale – Revised. Direct content analysis was used to analyse the data. A Service User Committee was	Literature Review- Meta Analysis	No specific approach described, focus peoples lived experience and on 'active citizenship'

	services. Frontiers in Psychiatry, 14, p.1156835		2022, that examine the experiences of service users in mental health services in Denmark, Finland, Norway and Sweden.	consulted as part of the analysis		
27	O'Connell, M. J., Clayton, A. and Rowe, M., 2017. Reliability and validity of a newly developed measure of citizenship among persons with mental illnesses. <i>Community</i> <i>Mental Health Journal</i> , 53 (3), 367-374.	To test the Citizenship Measure for its reliability and validity. Their rationale for doing this is that it can improve the value of using the tool in: a) assessing citizenship status; (b) measurement of change in citizenship status following	110 participants were recruited from a mental health centre. 58% were male, 57% African American, 34% white. Over 50% had a history of substance use and over 50% had a history of homelessness	Participants completed a packet of questionnaire and a range of other measures looking at Quality of life, Community Participation and Personal Recovery to test internal reliability and consistency and analyses the findings using correlation matrices that the	Rating of internal consistency, convergent validity and discriminatory validity of citizenship tool	5 Rs Citizenship (Rowe 2015)

		clinical or psychosocial programmes; (c) identifying particular strengths or vulnerabilities (such as, safety in your neighbourhood.)		measure was psychometrically sound.		
28	Pelletier, JF., Corbière, M., Lecomte, T., Briand, C., Corrigan, P., Davidson, L. and Rowe, M., 2015. Citizenship and recovery: Two intertwined concepts for civic-recovery. <i>BMC</i> <i>Psychiatry</i> , 15.	To study the interplay between recovery and citizenship orientated supported employment. In order to do this the convergent validity between the Recovery Assessment Scale (RAS) and Citizenship Measure was tested	174 Individuals with serious mental illness involved in governmental work integration programmes in French speaking Quebec, Canada. 54% were male and the mean age was 45.5	<ol> <li>Exploratory factor analyses on the Cm and confirmatory factor analysis on the RAS,</li> <li>Calculate Cronbach's alphas for each dimension emerging from factor 1</li> </ol>	Testing reliability and validity of RAS and CM	Not explicit but use of the Citizenship measure would imply use of 5Rs framework

29	Ponce, A. N., Clayton, A., Gambino, M. and Rowe, M., 2016. Social and Clinical Dimensions of Citizenship From the Mental Health-Care Provider Perspective, 161.	The exploration of mental health providers view of the potential contribution of a citizenship framework using Citizenship Measure	8 Focus Groups (6-13 participants) Reviewed the citizenship measure (after the first focus group this was changed to only reviewing the brief measure) and explore its clinical application n=77 participants from staff working in outpatient mental health treatment teams in public mental health centre in US	<ul> <li>3) Calculate correlations between all dimensions from both tools</li> <li>Focus groups explored what people thought of the Brief Measure and how relevant they thought the items were for their clients.</li> <li>Thematic analysis</li> </ul>	Focus Groups	5 Rs of Citizenship (Rowe 2015)
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30	Quinn, N., Bromage, B.	To gain an	Case study of	Direct observation,	Ethnographic	5Rs
	and Rowe, M., 2020.	indepth	FACE project, a	recorded	participant	Citizenship
	Collective citizenship:	understanding	community group	discussions and	observation	(Rowe 2015)
	From citizenship and	of themes and	in US promoting	meeting notes of	case study of	
	mental health to	activities of	citizenship led by	which the second	collective	Explores the
	citizenship and	collective	people with lived	author was part as	citizenship	role of
	solidarity. Social Policy	citizenship in	experience. The	a founding	group	'collective
	& Administration, 54 (3),	practice through	group has roughly	member of FACE.		citizenship
	361-374.	the tension	20 members with			
		between	10-12 people	Inductive approach		
		individual and	attending any	to thematic		
		collective	given meeting.	analysis of		
		needs. Explores	Criteria for	meeting notes		
		the application	membership is a	using Braun and		
		of collective	desire to build	Clarke (2006)		
		citizenship	community and			
		theory	form			
			relationships. It is			
			open to all, the			
			majority of			
			members have			
			mental health			
			challenges or			
			significant life			
			disruptions			
31	Reis, G., Bromage, B.,	This paper	This paper	The article	Discussion of	5 Rs of
	Rowe, M., Restrepo-	describes a	represents the	described the	series of	citizenship
	Toro, M.E., Bellamy, C.,	four-session	presentation of	background of	Roundtables	with a

Costa M	and Davidson,	roundtable	four round-table	each project and	as part of the	particular
	citizenship,	series entitled	discussions from	then presented a	New England	focus on
social justi	•	Citizenship,	community	discussion of the	Mental Health	'collective
collective		Social Justice,	activist groups in	issues the	Technology	citizenship'
empowern	ent: livina	and Collective	New England,	presenters raised	Transfer	(Quinn et al.
outside me	0	Empowerment:	US.	using case studies	Center	2020) and
illness. Ps		Living Outside	00.	and direct quotes	Network	'recovering
-	<i>93</i> (2), pp.537-	•	The first was a	from each of the	(MHTTC).	citizenship'
546.	93(z), pp.337-		director from the	round tables.	(1011110).	(Rowe and
540.		They were built on the	Theatre of the	Touriu lables.		(Rowe and Davidson
		conviction that				
			Oppressed in			2016)
		people who	New York City			
		have lived	and two people in			
		experiences of	recovery			
		mental health				
		challenges and	The second,			
		engaged in	those involved in			
		making	community-			
		community	building in a			
		connections	neighbourhood in			
		should be at the	New Haven,			
		centre of	Connecticut: a			
		teaching about	peer support			
		those	professional, a			
		experiences.	man in recovery			
			who has been a			
			community			
			activist for many			

r	 1	 -	•
	years, a long-time		
	mental health and		
	community		
	advocate, and the		
	neighbourhood		
	association		
	president. (three		
	of whom where		
	members of		
	FACE project see		
	Quinn et al. 2020)		
	The third was		
	peer support		
	professionals		
	across		
	Connecticut who		
	play various roles,		
	and a woman in		
	recovery who		
	shared her		
	experiences		
	working with peer		
	support		
	professionals.		
	The fourth were		
	members of		

32	Rowe, M., Bellamy, C.,	See Clayton et	See Clayton et al.	As Clayton et al.	See Clayton	5Rs of
32	Baranoski, M., Wieland, M., O'Connell, M. J., Benedict, P., Davidson, L., Buchanan, J., Sells, D., Rowe, M., Bellamy, C., Baranoski, M., Wieland, M., O'Connell, M. J., Benedict, P., Davidson, L., Buchanan, J. and Sells, D., 2007. A peer-support, group intervention to reduce substance use and criminality among persons with severe mental illness. <i>Psychiatric Services</i> , 58	See Clayton et al. (2013) but with focus on outcomes of alcohol and drug use	See Clayton et al. (2013)	As Clayton et al. (2013) except measures reported were <i>Addiction</i> <i>Severity Index</i> and criminal justice data.	See Clayton et al. (2013)	5Rs of Citizenship (Rowe 2015)
33	(7), 955-961. Rowe, M., Benedict, P., Sells, D., Dinzeo, T., Garvin, C., Schwab, L., Baranoski, M., Girard, V. and Bellamy, C., 2009. Citizenship, community, and recovery: a group- and peer-based	Detailed description and discussion of the intervention detailed in Clayton et al. (2013)	As described in Clayton et al. (2013)	Detailed description of the different interventions and rationale. Impact examined through case	Case Vignettes	4 Rs Citizenship (this is study was conducted before Rowe add the 5 <sup>th</sup> R

	intervention for persons with co-occurring disorders and criminal justice histories. <i>Journal</i> of Groups in Addiction & <i>Recovery</i> , 4 (4), 224- 244.			studies no specific methodology discussed		of Relationships)
34	Rowe, M., Clayton, A., Benedict, P., Bellamy, C., Antunes, K., Miller, R., Pelletier, JF., Stern, E. and O'Connell, M. J., 2012. Going to the source: Creating a citizenship outcome measure by community- based participatory research methods. <i>Psychiatric Services</i> , 63 (5), 445-450.	To create a citizenship measure through concept mapping and participatory approaches	141 persons in seven focus groups (N=75) and three concept-mapping sessions (N=66). The total sample included 82 women (58%) and 53 men (38%); six participants (4%) did not report a gender. A total of 92 participants (65%) were African American, 42 (30%) were white; and one (>1%) was	Focus groups generated content about the meaning of citizenship. These were then reduced to 100 items and were rated during concept mapping exercises rated in important.	Community Based Participatory Research	5Rs of Citizenship (Rowe 2015)

	Amorican Indian	Multidimensional	
	American Indian;		
	six (5%) did not	scaling and	
	report a race.	hierarchical cluster	
	Twelve	analysis	
	participants (9%)		
	of the sample		
	identified as		
	Hispanic or		
	Latino. The mean		
	age of		
	participants was		
	42.35		
	75 persons who		
	participated in the		
	focus groups, 14		
	(19%) were		
	receiving mental		
	health services,		
	four (5%) were		
	currently on		
	probation or		
	parole, six (8%)		
	had a general		
	medical illness,		
	27 (36%) had		
	experienced two		
	or more types of		

			life disruptions, and 24 (32%) had not experienced any of the life disruptions.			
35	Soares, J.G., Moll, M.F. and Ventura, C.A.A., 2021. Promoting Citizenship and Access to the Right to Health: a Look of Caregivers. <i>Journal of</i> <i>Psychosocial</i> <i>Rehabilitation and</i> <i>Mental Health</i> , 8(3), pp.221-229.	To investigate the perceptions of caregivers about work in the Residential Therapeutic Service (SRT) and their relationship with the promotion of the right to health and citizenship for residents. The SRTs an important device for the psychosocial rehabilitation of those	Interviews with 7 Care givers within STR. All female who work in therapeutic residences in a medium-sized city in the state of Minas, Brazil. The care givers deliver direct care supervised by a nurse and a psychologist	Descriptive, cross- sectional study with a qualitative approach Interview questions were based around a Quality Rights (based on a tool developed by the World Health Organisation (WHO)) framework and were analysed using Collective Subject Discourse	Semi- structured interviews	A rights- based approach to citizenship linked to WHO as described in study.

		discharged from long hospital stays without family ties. However, the care and supervision of caregivers stands out in the challenge of reconciling the autonomy of residents.				
36	Vervliet, M., Reynaert, D., Verelst, A., Vindevogel, S. and De Maeyer, J., 2017. 'if you can't follow, you're out' the perspectives of people with mental health problems on citizenship. <i>Applied</i> <i>Research in Quality of</i> <i>Life</i> .	To promote the voices of people with mental health challenges and co-occurring substance misuse in the debates about citizenship	People with mental health challenges (n=16) and/or those with co-occurring substance misuse issues (n=14/16) who access 'low threshold' centres in Ghent, Belgium Participants were eleven men and	Photovoice, where participants were given a camera and to explore themes related to inclusive citizenship. These were supported by weekly group sessions for a 10- month period and individual semi-	Participatory Action Research	Citizenship as defined by Lister's (2007) feminist perspective

			five women, with	structured		
			a mean age of	interviews		
			42 years old.			
				The data was		
				analysed using		
				thematic analysis		
				(Braun and Clarke		
				2006).		
				Cross checking		
				themes with		
				participants		
37	Wong, F.Y.Y., Wong,	This study aims	Participants were	A questionnaire	Telephone	5 Rs of
57	K.K.L., Lam, P.C.W.,	to assess the	selected at	comprised the	Survey	Citizenship
	Chin, L.Y. and Fung,	knowledge and	random.	Mental Health	Survey	(Rowe 2015)
	C.T., 2023. Community	attitudes toward	Household and	Knowledge		and
	knowledge and attitudes		mobile phone	Schedule (MAKS),		
	-	recovering	numbers were	Short Form-		Recovering
	toward recovering	citizenship and the 5 Rs of	drawn from the			citizenship
	citizenship and mental			Community Attitudes Toward		(Rowe and Davidson
	illness: a telephone	Citizenship and	Numbering Plan			
	survey	mental illness,	provided by the	Mental Illness (SF-		2016)
	approach. <i>Journal of</i>	of people aged	Hong Kong	CAMI) and		
	Public Mental Health.	18 and above,	government.	questions on		
		in Hong Kong	Denticin ente work	attitudes toward		
		using a	Participants were	RC/5 Rs, was		
		telephone	aged 18 and	administered on		
		survey	above, able to	the phone.		
		approach.	communicate in			
			Cantonese and			

[	have the mental	Statistical analysis
	capability to	for the telephone
	complete the	survey was
	survey.	performed using
	Survey.	SPSS. All the
	There were a total	
	of 1,009	analyses were
	,	weighted by
	respondents who	gender and age
	completed the	from the mid-2019
	telephone survey	census data.
	with a response	Descriptive
	rate of 37%. The	analyses were
	gender and age	performed to
	distributions of the	examine the scale
	sample were	scores and
	comparable to the	sociodemographic
	Census data of	characteristics of
	Hong Kong in mid	participants.
	2020. More than	Correlations
	half of	between
	respondents were	knowledge,
	females (53.1%),	attitudes toward
	married or	mental illness and
	cohabiting	RC/5 Rs were
	(59.1%), receiving	assessed using
	a monthly	Spearman
	individual income	correlation.
	less than	Differences in

US\$2,573	scale scores	
(HKD20,000)	across different	
(53.1%) and	socio-	
claimed that they	demographics	
knew someone	were assessed	
with or had	using one-way	
recovered from	ANOVA.	
mental illness		
(56.7%)		

# **Appendix 2: Ethics**



# **Research Ethics Checklist**

About Your Checklist	
Ethics ID	29315
Date Created	22/11/2019 12:17:42
Status	Approved
Date Approved	03/04/2020 14:56:08
Risk	High

Researcher Details	
Name	Phil Morgan
Faculty	Faculty of Health & Social Sciences
Status	Postgraduate Research (MRes, MPhil, PhD, DProf, EngD, EdD)
Course	Postgraduate Research - HSS
Have you received funding to support this research project?	Yes
Is this external funding?	Yes
RED ID	
Please provide the External Funding Body	Dorset HealthCare University NHS Foundation Trust

Project Details	
Title	Co-producing Future Citizenship Alongside People with Mental Health Challenges
Start Date of Project	01/10/2018
End Date of Project	31/07/2025
Proposed Start Date of Data Collection	02/03/2020
Original Supervisor	Mel Hughes
Approver	Research Ethics Panel
Summary - no more than 600 words (including detail on background methodology, sample, outcomes, etc.)	

**Introduction:** Technology is leading to rapid change in society, including what it means to be a citizen (Isin and Nielsen 2008; Isin and Ruppert 2015). Whilst citizenship has been promoted within mental health for a long time, change has been slow. Citizenship in this context refers to how people with mental health challenges have access to the same rights and responsibilities as others in society (Hamer et al, 2018; Rowe and Davidson, 2016). In order to create inclusive opportunities for people with mental health challenges, any focus on citizenship in mental health needs not only to address the present time but to anticipate and influence future technological directions (Morgan et al, 2020).

Aim: To explore how future developments in technology will impact on citizenship for people with mental health challenges.

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Methods: The research will have two phases. The first will consist of interviews and a co-production workshop. The second will consist of two sets of focus groups and a photovoice interview.

Peer researchers (funded by Dorset HealthCare) will provide guidance on the design of interview schedules, co-production workshop and focus groups. They will also support the data analysis of the anonymised transcripts. They will support the development of the outputs in regards to dissemination, namely journal articles and film.

Participants: Participants will be purposefully sampled and will be over 18. Participants for phase 1 will be leaders from a digital technology company (who have a focus on promoting digital inclusion, and will provide expertise on the current and future developments in technology) and a peer-led mental health organisation.Participants for phase two will be drawn from two groups: current leaders in mental health from a national mental health organisation and potential future leaders. The potential future leaders will be current university students undertaking a mental health professional qualification and peer workers (from a 3rd sector mental health organisation). This second group will also be from generations Y and Z (born 1981-2002). These generations are considered digital natives and therefore may have a different perspective on technology.

#### Key Ethical Considerations:

#### Informed Consent:

Participants will be given an information sheet and have the opportunity to opt in to the study. To avoid coercion, the researcher will not directly approach individuals but rather support the organisations to promote the study and allow individuals to opt in and consent to participate.

Participants will have the right to withdraw from the study during data collection phase.

#### **Risks to Participants and Researcher:**

Some people may find discussing mental health challenges and the future distressing. The researcher is an experienced mental health professional. If participants become distressed or make disclosures they will be signposted to local supports and/or to their employer or university for further support. The researcher is able to seek support via the supervisory team and is able to access external support.

**Confidentiality and Data:** All data will be anonymised. Each organisation and each participant's identity will be anonymised and they will be given a pseudonym. Pictures submitted will not include personal identifiable content.

All digital data from the study will be securely stored on a password protected drive on the BU server and all paperwork will be locked in a filing system within a secure building at Bournemouth University.

**Demands on Time:** Participants will be required to participate for a maximum of 6 hours over a 3 month period. Focus groups and workshops will be held in accessible and convenient locations.

#### Withdrawing Consent:

Participants can withdraw from the study at any time prior to the completion of data collection stage. This includes withdrawing images from photovoice interviews.

It will not be possible to withdraw data from the focus group or co-production group due to the nature of it being a group discussion. Participants will be reminded of this at the beginning and the end of the focus group.

Dissemination: Journal articles, conference presentations, and public engagement film shared on YouTube.

#### Filter Question: Does your study involve Human Participants?

#### Participants

#### Describe the number of participants and specify any inclusion/exclusion criteria to be used

All participants will be over 18. There will be a total of 30 participants who will be purposively sampled. The reason for this purposive sampling is to provide a range of perspectives and include people who are able to influence change. For phase 1 the participants will be drawn from managers within a digital media company (n=2) and a peer-led mental health organisation (n=4). The rationale for this is that this will bring important perspectives from the technology industry and from mental health. The digital media company will be recruited from one promoting digital citizenship and inclusion. In the second phase participants will be recruited from staff who work for a national mental health organisation (n=6\*), and Bournemouth university students (n=6\*). \*These participants will be born between 1981-2002, who are considered digital natives as they have grown up with the internet.

Do your participants include minors (under 16)?	
Are your participants considered adults who are competent to give consent but considered vulnerable?	No
Is a Disclosure and Barring Service (DBS) check required for the research activity?	No

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#### Recruitment

Please provide details on intended recruitment methods, include copies of any advertisements.

A letter will be sent to the CEO, faculty lead or lead Director of each organisation to see if they would like to opt-in to the study.Within Bournemouth University the programme leaders will be asked to advertise the project to specific student groups and the project will be advertised to students on Landsdowne Campus.A number of organisations have approached the researcher following presentations of the research topic and have expressed an interest in participating in any research in this area.

Do you need a Gatekeeper to access your participants?

Yes

Please provide details, including their roles and any relationship between Gatekeepers and participant(s) (e.g. nursing home manager and residents)

Gate keepers will be organisational leaders. People they engage will be employees or, in the case of the University, students.For Bournemouth University it will be the Head of the Faculty for Health and Social Sciences and Programme Leads from the relevant the Schools. The relationship between participants and gatekeeper in this instance is academic and student.For the organisations with employees, the gatekeeper will be: Chief Executive Officer of Peer Led Mental Health Organisation, Chief Executive Officer of Digital Technology company, Director of National Mental Health Organisation. Participants will be staff who work for the organisation. The gatekeepers themselves may choose to opt in to be participants. It will be made clear to the Gatekeepers they are not to persuade or encourage people to participate.

Data Collection Activity			
Will the research involve questionnaire/online survey? If yes, don't forget to attach a copy of the questionnaire/survey or sample of questions.			
Will the research involve interviews? If Yes, don't forget to attach a copy of the interview questions or sample of questions			
Please provide details e.g. where will the interviews take place. Will you be conducting the interviews or someone	else?		
I will be conducting the interviews. They will be semi-structured. The interviews will take place at a convenient location for the participan either at their place of work or study. This will include the option of a phone or video call interview. The interviews in the second phase or the research will be photovoice interviews. Participants will be encouraged to bring with them and share a picture or GiF. The rationale for this is that it provides a more creative way for participants to be involved in discussions about the future.			
Will the research involve a focus group? If yes, don't forget to attach a copy of the focus group questions or sample of questions.			
Please provide details e.g. where will the focus group take place. Will you be leading the focus group or someone else?			
I am an experienced group facilitator and will be leading the focus groups. The focus groups will take place either at the participant's place of work or study or at a convenient local alternative. In the first phase of the interview there will be a co-production workshop that will outline the main themes in relation to technological advances over the next 25 years and potential impacts on citizenship for people with mental health challenges. In the second phase there will be two sets of two focus groups. One set will be with current leaders in mental health challenges and the potential future leaders. The first set of focus groups will explore the content generated in the co-production workshop and discuss the threats and opportunities technology will offer people with mental health challenges. The second will explore what desirable futures may look like and what would need to take place to get there and what would be potential or actual barriers.			
Will the research involve the collection of audio recordings?			
Will your research involve the collection of photographic materials?			
Will your research involve the collection of video materials/film?			
Will any photographs, video recordings or film identify an individual?	No		
Please provide details			
All interviews and focus groups will be audio recorded. As part of the photovoice interviews participants will be asked at the previous focus group to bring in two pictures or GIFs that represent their thoughts in relation to current and future citizenship for people with			

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mental health challenges. All participants will be asked as part of participant agreement to not include personally identifiable photos or video. This will be checked by the researcher and supervisors. In the workshop and focus groups photographs will be taken of any flip chart pictures or post-it notes that include no personal identifiable information.

Will any audio recordings (or non-anonymised transcript), photographs, video recordings or film be used in any outputs or otherwise made publicly available?

If Yes, please provide details.

For the purpose of dissemination for public engagement an online slide show of the research will be made available on the internet on YouTube. This will not include any personally identifiable audio or images. Participants may consent for the pictures they submitted in the photovoice interviews to be included.

#### Please provide details and measures taken to minimise risks

People will be discussing mental health and the impact of future technology on citizenship. Some people may find this distressing. The focus of the discussions will not be based on personal disclosures but rather thinking in general terms about the topics under discussion. The researcher is an experienced mental health professional and group facilitator. If participants become distressed or make disclosures they will be signposted to local supports and/or their employer or university for further support. Participants will be able to stop the interview or leave the focus group or workshop at any point.

Will any drugs, placebos or other substances (e.g. food substances, vitamins) be administered to the participants?	No
Will the study involve invasive, intrusive or potential harmful procedures of any kind?	No
Could your research induce psychological stress or anxiety, cause harm or have negative consequences for the participants or researchers (beyond the risks encountered in normal life)?	
Will your research involve prolonged or repetitive testing?	No
What are the potential adverse consequences for research participants and how will you minimise them?	

### Consent

Describe the process that you will be using to obtain valid consent for participation in the research activities. If consent is not to be obtained explain why.

Participants will be given a participant information sheet. This will outline the purpose of the research, the requirements of their participation, what will happen to their data, what would happen if they chose to withdraw. They will have the opportunity to discuss any issues or concerns with the researcher (face to face, via telephone or via email). All participants will sign a participant agreement form.

Do your participants include adults who lack/may lack capacity to give consent (at any point in the study)?	No
Will it be necessary for participants to take part in your study without their knowledge and consent?	No

#### Participant Withdrawal

At what point and how will it be possible for participants to exercise their rights to withdraw from the study?

Participants can withdraw from the study at time. They can request that the data for interviews is withdrawn from the study at any point before completion of data analysis stage. This will be clearly articulated in relation to dates on the participant information sheet. This includes withdrawing images from photovoice interviews. It will not be possible to withdraw data from the focus group or co-production group due to the nature of it being a group discussion. Participants will be reminded of this at the beginning and the end of the focus group.

#### If a participant withdraws from the study, what will be done with their data?

All data will be stored on a secure Bournemouth University Server for 5 years. It will not be used as part of the study unless the data has

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Printed On 17/09/2023 15:15:10

Yes

Yes

been analysed as part of the data analysis stage as described above.

Participant Compensation	
Will participants receive financial compensation (or course credits) for their participation?	No
Will financial or other inducements (other than reasonable expenses) be offered to participants?	No

### Research Data

Will identifiable personal information be collected, i.e. at an individualised level in a form that identifies or could enable identification of the participant?

Please give details of the types of information to be collected, e.g. personal characteristics, education, work role, opinions or experiences

The interviews, co-production workshop and focus groups will be audio recorded. Therefore, it would be possible to identify people by their voice. This will only be heard by the researcher who will transcribe the audio recordings. The audio recordings will not be made available to anyone outside of the researcher and supervisors. In addition, participants can optionally provide an email address to receive a copy of the summary report and URL for the research website and access to film. this will be stored securely on paper in a locked filing cabinet in the university. The reason for this is so that add an additional layer of security so that there is not a direct connection with the research data electronically stored securely on the electronic university server.Participants will be asked to complete basic demographic data, which generation they are from (e.g. X, Y, Z), ethnicity, gender, role (e.g. student or work role), sexuality and each question will include a "prefer not to say

	Will the personal data collected include any special category data, or any information about actual or alleged criminal activity or criminal convictions which are not already in the public domain?	No	
1	Will the information be anonymised/de-identified at any stage during the study?	Yes	
	Will research outputs include any identifiable personal information i.e. data at an individualised level in a form which identifies or could enable identification of the individual?	No	

Storage, Access and Disposal of Research Data	
During the study, what data relating to the participants will be stored and where?	The research data will be stored for a period of 5 years on a secure university server by the research supervisor. The participant's name, contact details, and consent forms will only be stored on paper in a locked university filing cabinet. The demographic data and audio recordings will be stored on a secure university server in a password protected file, under the pseudonym of the participant. The anonymised research data will be stored In a separate password protected file on the secure university server.
How long will the data relating to participants be stored?	The research data will be stored for a maximum period of 5 years. The personal contact details, audio recordings, and minimum data sets will only be stored for the life of the project and will be deleted as soon as the PhD is awarded and findings have been disseminated to the participants.
During the study, who will have access to the data relating to participants?	The researcher and supervisors will have access to data relating to the participants. The peer researchers will have access to anonymised transcripts
After the study has finished, what data relating to participants will be stored and where? Please indicate whether data will be retained in identifiable form.	The anonymised research data will be retained for a maximum of 5 years digitally stored on secure university server. No identifiable data will be kept following the award of the PhD. It will be deleted.
After the study has finished, how long will data relating to participants be stored?	The anonymised data will be stored for five years after the award of the PhD
After the study has finished, who will have access to the data relating to participants?	Researcher supervisors will be the only people who will have access to the data.

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Will any identifiable participant data be transferred outside of the European Economic Area (EEA)?	No	
How and when will the data relating to participants be deleted/destroyed?	All emails will be permanently deleted once sent from the email account.All electronic data will be deleted from the secure serverAll paper data will be shredded and securely disposed of.	
Once your project completes, will your dataset be added to an appropriate research data repository such as BORDaR, BU's Data Repository?	No	
Please explain why you do not intend to deposit your research data on BORDaR? E.g. do you intend to deposit your research		

Please explain why you do not intend to deposit your research data on BORDaR? E.g. do you intend to deposit your research data in another data repository (discipline or funder specific)? If so, please provide details.

I do not intend to deposit the research data in any data repository.

#### **Dissemination Plans**

How do you intend to report and disseminate the results of the study?

Peer reviewed journals, Conference presentation, Publication on website, Other

If Other, please provide details.

Youtube Film in form of slide show with commentary, promotion on social media (e.g. Twitter)

Will you inform participants of the results?

If Yes or No, please give details of how you will inform participants or justify if not doing so

A short report will be available for all participants providing an overview of the research and findings. This will be made available on a website which will be developed to promote the study. The website will include no participant identifiable information. It will include the following:-Film of slide show of research outputs with no personally identifiable content-Overview of the research and aims-Summary of the method used-Summary of articles published and where they can be accessed-Summary of presentations or conferences where research has been presented -Links to social media discussions on dissemination -Correspondence and contact details of researcher

#### **Final Review**

Are there any other ethical considerations relating to your project which have not been covered above?

Yes

Yes

Yes

#### If Yes, please explain.

Peer Researchers will be recruited to support the development of the co-production workshop, focus groups and interview schedules, and also data analysis. Funding has been agreed from Dorset HealthCare for 16 days peer researcher time and the aim to is to recruit two peer researchers. The peer researchers will be employed by Dorset Mental Health Forum in line with the existing partnership with Dorset HealthCare. Dorset Mental Health Forum will provide line management and supervision. The Researcher supervisors will provide the peer researchers with training and supervision for the duration of their involvement of the study.

#### Risk Assessment

Have you undertaken an appropriate Risk Assessment?

### Attached documents

Email to Gate Keepers org 29315.docx - attached on 06/01/2020 17:36:40

Email to Gate Keepers Uni 29315.docx - attached on 06/01/2020 17:36:52

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Interview and focus group schedule 29315.docx - attached on 06/01/2020 17:37:48		
ENQUIRY TO HRA QUERIES LINE.docx - attached on 06/01/2020 17:39:33		
HRA Checklist outcome.docx - attached on 06/01/2020 17:41:57		
29315 Participant Agreement Form Revised phase 2.docx - attached on 04/03/2020 10:50:39		
29315 Participant Agreement Form Revised.docx - attached on 04/03/2020 10:50:55		
29315 Participant Information Sheet phase 1 revised.docx - attached on 23/03/2020 09:19:07		
29315 Participant Information Sheet Template phase 2 revised.docx - attached on 23/03/2020 09:19:39		
29315 Participant Agreement Form Revised.docx - attached on 04/10/2020 11:10:28		
29315 Participant Information Sheet phase 1 revised.docx - attached on 04/10/2020 11:10:28		
29315 Participant Information Sheet Template phase 2 revised.docx - attached on 04/10/2020 11:10:28		
29315 Participant Agreement Form Revised phase 2.docx - attached on 04/10/2020 11:10:28		
29315 Participant Agreement Form Revised phase 2.docx - attached on 07/10/2020 16:39:20		
29315 Participant Information Sheet phase 2 revised.docx - attached on 07/10/2020 16:39:20		
29315 Participant Information Sheet Template phase 2 revised v.4.docx - attached on 08/09/2021 11:27:00		
29315 Participant Agreement Form Revised phase 2 v.4.docx - attached on 08/09/2021 11:27:00		

Approved Amendments	
Message	Amendments to EthicsThe Research Aim and Objective remain the same which are: To explore how future developments in technology will impact on citizenship for people with mental health challenges Research objectives: •What do participants think are the key factors that will shape citizenship in the future?•What are the perceived challenges and opportunities for People with Mental Health Challenges in relation to future citizenship?•To examine the key areas for development to contribute to inclusive future opportunities citizenship for people with mental health challenges.•To undertake a critical exploration of use of co-production and participatory research methods Due to impact of Corona Virus and the difficulties in being able to meet face to face I would like to undertake the data collection digitally, via Zoom. This would mean all of the interviews, focus groups, and co-production workshop and would now be done digitally via Zoom. As can be seen from the research aims and objectives, the move towards on-line data collection fits with the focus on technology and the exploration of participatory research methods. This will not only be a change to how the interviews and groups are undertaken but also how they will be recorded. Now, as well as an audio recording, a video recording will also take place. This will not be included in any external data presentation and is solely to aid transcription and to support the data analysis. In particular the analysis of the focus groups and co-production workshop. Only the researcher and his supervisors will have access to the video recording. The video recordings will be stored on the same server as the audio recordings with the same agreements in regards to length of time stored as with the audio recordings. For further detail see the participant information sheet and participant agreement form which have been amended accordingly.
Date Submitted	04/10/2020 11:10
Comment	Reviewed and Approved by Chairs Action
Date Approved	07/10/2020 16:39
Approved By	Sarah Bell

### Approved Amendments

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Message	The research aims and objectives remain the same. Following discussions with the peer researchers and supervisory team, using the principles of co-production (the research methodology in this study), an amendment to the second phase of data collection is being requested. It is proposed that instead of having a new set of participants for the second phase of the study that this phase is conducted with participants from the existing organisations that were involved in phase 1. It is also proposed that instead of asking them to participate in two focus groups and a photovoice interview, participants will be asked to watch the 15 minute film (which has been co-created by the researcher and peer researchers sharing the data analysis of the first phase) and then participants who took part in the phase 1 (anticipated n=6, actual n= 11)2) the data that was generated was far richer than anticipated. Therefore, it meant that phase 1 addressed the majority of the research objectives that were looking to be explored within phase 2. By working with the existing organisations to creates a more congruent piece of research as it provides participants from the two organisations an opportunity to reflect on their experience of participating in the first phase and reflect on any actions they would like to take in regards to promoting inclusive future citizenship for people with mental health challenges. This builds on the participants own reflections, who volunteered that they had found it valuable having these discussions and would welcome further discussions on this topic. An additional amendment is that Dr Tula Brannelly has left Bournemouth University and the supervisory team for this PhD. She has been replaced by Dr Mel Hughes as primary supervisor, and Prof. Lee-Ann Fenge has also joined the supervisory team.
Date Submitted	08/09/2021 11:27
Comment	Reviewed and approved by Chairs Action (Prof J Parker, SSH REP). The chair added the following comments "The Amendments are well thought through and sensitive to participant needs."
Date Approved	15/09/2021 15:33
Approved By	Sarah Bell

# Appendix 3: Letter to CEO Invitation to participate.





The Conifers Poundbury West Industrial Estate Dorchester Dorset DT1 2PG

Dear Sir/Madam,

I am writing to you to enquire whether your organisation is able to support a research project titled *Co-producing Future Citizenship alongside People with Mental Health Challenges*. The purpose of the research is to explore how future technologies will impact on citizenship for people with mental health challenges. The research seeks to bring together the technology industry, mental health organisations and university students to explore:

- what the likely technological impacts may be over the next 25 years?
- what the threats and opportunities are for people with mental health challenges?
- what would inclusive future citizenship for people with mental health challenges look like and how could we get there?

I hope this would appeal to your organisation with your focus on inclusive citizenship for people with mental health challenges and your awareness of the impact of technologies on society. I understand this topic and approach will be aligned with your organisational aims and values. If you were interested we would be looking for you to advertise the study within your organisation for staff to participate. The maximum time commitment for staff within your organisation would be 6 hours over a 6 month period. This will either be through participating in phase one which would be 1 hour interview and 2 ½ hour co-production workshop or in the second phase which would be participating in two 2 hour focus groups and one 1 hour photovoice interview. Please see the attached participant information sheet for more information. There is no obligation for your or your organisation to participate. If you did choose to participate it is essential there was no expectation or pressure for any staff to participate.

This research is being undertaken as part of a PhD with Bournemouth University and is funded by Dorset HealthCare University NHS Foundation Trust. The research will be carried out with the Ethical Approval of Bournemouth University Ethics Committee.

If you would like to find out any further information. Please do not hesitate to contact me on 07767003702 or morganp@bournemouth.ac.uk. If you are happy for your organisation to participate please contact me by return of email and we can discuss the next steps.

If you have any concerns about this email or any governance issues relating to this research please contact my supervisor Dr Tula Brannelly <a href="mailto:pbrannely@bournemouth.ac.uk">pbrannely@bournemouth.ac.uk</a> 01202 961055.

Yours sincerely

Phil Morgan PhD Student, Bournemouth University Lead for Recovery and Social Inclusion

# **Appendix 4: Participant Information Sheet Phase 1**

Ref & Version: 060120 V<sub>3</sub> Ethics ID: 29315 Date: 27.07.20



# Participant Information Sheet Co-producing Future Citizenship with People who Experience Mental Health Challenges Phase 1: Interview and Co-Production Workshop

This project is funded by Dorset HealthCare NHS University Foundation Trust.

**Invitation to take part** You are invited to participate in this postgraduate research project as you have valuable experience that can inform this research. You will either have experience of working for a digital technology company that has a focus on inclusivity and promoting digital citizenship or working for a peer-led mental health organisation, and have an interest in promoting citizenship for people with mental health challenges. To decide whether to participate, please read this information sheet carefully, and you can contact the researcher for more information if you like - contact details are below. It is your choice whether to participate and if you choose not to take part this will not disadvantage you in any way. The research is being undertaken by Phil Morgan, a PhD Student at Bournemouth University who is an experienced mental health professional who works for Dorset Healthcare University NHS Foundation Trust. You can contact Phil on 07767003702.
What is the purpose of the project? This research seeks to explore views about technology, mental health and citizenship. Technology is advancing quickly with the use of smart phones, internet connected devices, increased use of artificial intelligence and algorithms. This is changing how we relate to one another and society. In mental health there is an increasing discussion about the importance of citizenship and how people with mental health challenges have access to the same rights and responsibilities as other people in society. As technology is moving fast it is important not just to explore what citizenship means now but to examine how technology will impact on citizenship for people with mental health challenges in the future. This research has two distinct phases. You are being invited to participate in Phase One. Specifically, this phase will explore what you think are the key factors that will shape citizenship in the future.

**What is involved?** Involvement, in this phase, consists of an interview and a coproduction workshop. This will take place digitally, using Zoom. This will require you having access to a laptop, tablet, or smart phone and WiFi. You will also need to download the Zoom App or access the meeting via the web application. You will be given a meeting room number and password. You will attend an interview (lasting 1 hour) and a co-production workshop (lasting 2 1/2 hours.) This will take place over a period of 3 months, planned to take place between TBC. You can choose whether you participate in just the interview or co-production workshop or both. We are happy to run them during the day or early evening, depending on people's preference. You will not need to do any preparation for the interview or workshop – you will be asked about your experience connected to the issues under discussion. This will help the researcher answer questions related to how future developments in technology will impact on citizenship for people with mental health challenges.

What will happen during the interviews? In the interviews Phil Morgan will ask you a series questions relating to future technological impacts on citizenship and in particular how they may impact on people with mental health challenges. There are no correct answers we are just interested in your perspective. The interview data will then be analysed for themes by the researcher and two peer researchers. What will happen during the co-production workshop? In the co-production workshop Phil Morgan will lead the discussion, bringing together different perspectives, and guide you through the various issues we want to explore. This will include feeding back the anonymised themes from the interviews. There are no right or wrong answers in a discussion of this kind – we are simply interested in your opinions. The discussions in this workshop will form the basis for discussions in the second phase of this study. You can expect the group to be approximately 6-8 people and it will take up to a maximum of 2 1/2 hours (to include registration and group discussion). The interview and workshop will be online via Zoom, using the most recent version, and arranged at convenient times for the people involved. You will also have the option to use Google Jam Board which is an online whiteboard that you can access anonymously. It has a post-it notes feature which can support discussions in workshops. A link will be posted during the workshop, which will take those who chose to use the Jam Board to that page whilst on the Zoom call. You do not need to put any personal details in Jam Board. Those who do not wish to use Jam Board can share suggestions via the chat in Zoom.

**Do I have to take part?** It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a participant agreement form. We want you to understand what participation involves, before you make a decision on whether to participate. If you or any family member have an on-going relationship with BU or the research team, e.g. as a member of staff, as student or other service user, your decision on whether to take part (or continue to take part) will not affect this relationship in any way.

**Can I change my mind about taking part?** Yes, you can stop participating in study activities at any time without giving a reason.

#### What happens to my data if I do withdraw?

**Interview:** If you withdraw from the study after the interview has taken place, you will have up to one month after the interview to withdraw your data. After that date, one month after the interview, it will not be possible to remove your data from your interview. This is because it will have been analysed alongside all the other data into

themes and it will not be possible to extract it from the other data.

**Co-production workshop:** Once you have participated in the co-production workshop it will not be possible to remove your data. After you decide to withdraw from the study, we will not collect any further information from or about you. As regards information we have already collected before this point, your rights to access, change or move that information are limited. This is because we need to manage your information in specific ways in order for the research to be reliable and accurate. Further explanation about this is in the personal information section below.

#### What are the advantages and possible disadvantages or risks of taking part?

Whilst there are no immediate benefits to you from participating in the project, this work will inform the future development of ideas in relation the impact of technologies on citizenship for people with mental health challenges. It is hoped that you can utilise this understanding in your work. Whilst we do not anticipate any risks to you in taking part in this study, you may find it challenging discussing the future and mental health. If so, we are able to offer support in and immediately after the interview or co-production workshop and can then signpost you to further support within your organisation.

**Will I be recorded, and how will the recorded media be used?** The interviews and workshop will be video and audio recorded. The video and audio recordings of your activities made during this research will only be used only for analysis and the transcription of the recording(s). No other use will be made of them without your written permission, and only the researcher and supervisors will be allowed access to the original recordings. Only images without personally identifiable information will be shared in any dissemination online or in presentations.

**How will my information be managed?** We will only collect and store the minimum of personal information from you. You can optionally give us your email contact details. This will be used for us to make arrangements with you in regards to the research and to send you, if you would like, a summary of the research and a link to the research website which will host the film that will be produced as part of the PhD. The video and audio recordings are also considered personal information. The video

and audio recordings will be transcribed and once transcribed will be made anonymous.

Bournemouth University (BU) is the organisation with overall responsibility for this study and the data controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university. Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals,

but do not apply to anonymous research data: "anonymous" means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU's Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information. Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To safeguard your rights in relation to your personal information, we will use the minimum personally-identifiable information possible and control access to that data as described below.

### Publication

You will not be able to be identified in any external reports or publications about the research. Otherwise your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable. Research results will be published in the PhD thesis and peer reviewed journals. A short report will be shared with you and will be available on the research project website. When this is up and running you will be informed of the URL. A film of a brief slideshow and commentary will be posted on Youtube. This will not include any personally identifiable information. Security and access controls

BU will hold the information we collect about you in hard copy in a secure location and on a BU password protected secure network, where held electronically. Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations. Once the research activities are completed your personal information in identifiable form will be deleted. Anonymised data will be kept for five years after which it will be deleted.

In the interviews you will be given a number to identify you. At the beginning of the workshop we will ask you to identify a pseudonym and we will refer to you by it throughout. We will not tell anyone that you have taken part in the workshop, although there is of course a possibility that another member of the group might recognise you. We will also not name you in any of our reports or publications. In addition, you will be asked to respect the confidentiality of your fellow participants in the workshop. You will all refer to one another by your pseudonyms. Your personal information and anonymised information will only be used for the purpose of the study.

**Keeping your information if you withdraw from the study** If you withdraw from active participation in the study we will keep information which we have already collected from or about you, if this has on-going relevance or value to the study. This may include your personal identifiable information. As explained above, your legal rights to access, change, delete or move this information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate. However, if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study. You can find out more about your rights in relation to your data and how to raise queries or complaints in our Privacy Notice.

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**Project governance documentation**, including copies of signed **participant agreements**: We keep this documentation for a long period after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results.

### **Contact for further information**

If you have any questions or would like further information, please contact Phil Morgan morganp@bournemouth.ac.uk tel. 07767003702 If you have any concerns about the study please contact Dr Tula Brannelly pbrannelly@bournemouth.ac.uk Tel. 01202 961055. If your concerns have not been answered by Dr Brannelly you should contact contact Professor Vanora Hundley Deputy Dean of Research, Faculty of Health and Social Sciences, Bournemouth University by email to researchgovernance@bournemouth.ac.uk.

**Finally,** if you decide to take part, you will be given a copy of the information sheet and a signed participant agreement form to keep. Thank you for considering taking part in this research project.

### **Appendix 5: Participant Agreement Form: Phase 1**

Ref & Version: 060120 V3.

Ethics ID number:29315

Date:27.7.20



### Participant Agreement Form: Phase 1

# Full title of project: Co-producing Future Citizenship with People who Experience Mental Health Challenges

**Researcher:** Phil Morgan, PhD Student <u>morganp@bournemouth.ac.uk</u> 07767003702

**Supervisor:** Dr Tula Brannelly <u>pbrannelly@bournemouth.ac.uk</u> 01202 961055 To be completed prior to data collection activity

Section A: Agreement to participate in the study You should only agree to participate in the study if you agree with all of the statements in this table and accept that participating will involve the listed activities.

I have read and understood the Participant Information Sheet (060120 V3) and have been given access to the BU Research Participant <u>Privacy Notice</u> which sets out how we collect and use personal information (<u>https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy</u>).

I have had an opportunity to ask questions.

I understand that my participation is voluntary. I can stop participating in research activities at any time without giving a reason and I am free to decline to answer any

particular question(s). (You can participate in both the co-production workshop and interview or either element. It is your choice which elements you participate in.)

I understand that taking part in the research will include the following activity/activities as part of the research:

- Being video and audio recorded during the project
- my words will be quoted in publications, reports, web pages and other research outputs without using my real name.

I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study **except** where my data has been anonymised (as I cannot be identified) or it will be harmful to the project to have my data removed.

I understand that my data may be used in an anonymised form by the research team to support other research projects in the future, including future publications, reports or presentations.

Initial box to agree

I consent to take part in the project on the basis set out above (Section A)

I confirm my agreement to take part in the project on the basis set out above.

Name of participant	Date	
(BLOCK CAPITALS)	(dd/mm/yyyy)	
		Signature
Name of researcher	Date	
(BLOCK CAPITALS)	(dd/mm/yyyy)	
		Signature

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### **Appendix 6: Participant Information Sheet Phase 2**



### **Participant Information Sheet**

## Co-producing Future Citizenship with People who Experience Mental Health Challenges

#### **Phase 2: Action Phase**

This project is funded by Dorset HealthCare NHS University Foundation Trust.

**Invitation to take part:** You are invited to participate in this postgraduate research project as you have valuable experience that can inform this research. To decide whether to participate, please read this information sheet carefully, and you can contact the researcher for more information if you like - contact details are below. It is your choice whether to participate and if you choose not to take part this will not disadvantage you in any way. The research is being undertaken by Phil Morgan, a PhD Student at Bournemouth University, who is an experienced mental health professional who works for Dorset Healthcare University NHS Foundation Trust. You can contact Phil on 07767003702.

What is the purpose of the project? This research seeks to explore what people's views are about technology, mental health and citizenship in the future. Technology is advancing quickly with the use of smart phones, internet connected devices, increased use of artificial intelligence and algorithms. This is changing how we relate to one another and society. In mental health there is an increasing discussion about the importance of citizenship and how people with mental health challenges have access to the same rights and responsibilities as other people in society. As technology is moving fast it is important not just to explore what citizenship means

now, but to examine how technology will impact on citizenship for people with mental health challenges in the future. This research has two distinct phases. **You are being invited to participate in Phase Two.** Specifically, this phase will explore:

- What the perceived challenges and opportunities are for people with mental health Challenges in relation to future citizenship
- Examining the key areas for development to contribute to inclusive future opportunities for citizenship for people with mental health challenges.

### Why have I been chosen?

You will either have experience of working for a digital technology company that has a focus on inclusivity and promoting digital citizenship or working for a peer-led mental health organisation, and have an interest in promoting citizenship for people with mental health challenges. You or other members of your organisation may have participated in the first phase of this research.

What is involved? Phase two explores the content generated in Phase one. You will be asked to watch a 15 minute video in your own time and participate online in a focus group, this will take place digitally, using Zoom. This will require you having access to a laptop, tablet, or smart phone and WiFi. You will also need to download the Zoom App or access the meeting via the web application. You will be given a meeting room number and password. The video is a representation of the findings in phase 1 of this research outlining the key themes relating to future citizenship for people with mental health challenges. Through participating in the focus group you will discuss the content generated in the co-production workshop and explore how this can inform future developments in relation to citizenship and mental health. The focus groups will last two and half hours.

What will happen during the focus groups? You will be asked to watch the film ahead of the focus group. In the focus group you will be asked to discuss various issues relating to future technological impacts on citizenship and in particular how they may impact on people with mental health challenges. Phil Morgan will lead the discussion in each focus group and will guide you through the various issues we want to explore. There are no right or wrong answers in a discussion of this kind – we are simply interested in your opinions. You can expect the group to be

approximately 12 people and it will take up to a maximum of two and half hours (this will include registration and group discussion). The focus group will be online and arranged at convenient times for the people involved. We are happy to run them during the day or early evening, depending on people's preferences.

#### Do I have to take part?

No, you do not have to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a participant agreement form. We want you to understand what participation involves before you make a decision on whether to participate. If you or any family member have an on-going relationship with BU or the research team, e.g. as a member of staff, as student or other service user, your decision on whether to take part (or continue to take part) will not affect this relationship in any way.

### Can I change my mind about taking part?

Yes, you can stop participating in study activities at any time and without giving a reason.

#### What happens to my data if I do withdraw?

Once you have participated in the focus group it will not be possible to remove your data. The discussions in a focus group are based on conversations and it is not possible to remove one part of a conversation, as the discussion then loses its clarity. After you decide to withdraw from the study, we will not collect any further information from or about you. As regards information we have already collected before this point, your rights to access, change or move that information are limited. This is because we need to manage your information in specific ways in order for the research to be reliable and accurate. Further explanation about this is in the personal information section below.

### What are the advantages and possible disadvantages or risks of taking part?

Whilst there are no immediate benefits to you from participating in the project, this work will inform the future development of ideas on the impact of technologies on citizenship for people with mental health challenges. It is hoped that you can utilise

this understanding in your work. Whilst we do not anticipate any risks to you in taking part in this study, you may find it challenging discussing the future and mental health. If so, we are able to offer support in and immediately after the interview or co-production workshop and can then signpost you to further support within your organisation.

### Will I be recorded, and how will the recorded media be used?

The focus groups will be video and audio recorded. The video and audio recordings of your activities made during this research will be used only for analysis and the transcription of the recording(s). No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

### How will my information be managed?

We will only collect and store the minimum of personal information from you. *You can optionally give us your email contact details,* this will be used by us to make arrangements in regards to the research and to send you, if you would like, a summary of the research and a link to the research website which will host the film that will be produced as part of the PhD. The video and audio recording are also considered personal information. The video and audio recordings will be transcribed and once transcribed will be made anonymous.

Bournemouth University (BU) is the organisation with overall responsibility for this study and the data controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university. Undertaking this research study involves collecting and/or generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals, but do not apply to anonymous research data: "anonymous" means that we have either removed or not collected any pieces

of data or links to other data which identify a specific person as the subject or source of a research result.

BU's <u>Research Participant Privacy Notice</u> sets out more information about how we fulfil our responsibilities as a data controller and about your rights as an individual under the data protection legislation. We ask you to read this Notice so that you can fully understand the basis on which we will process your personal information. Research data will be used only for the purposes of the study or related uses identified in the Privacy Notice or this Information Sheet. To safeguard your rights in relation to your personal information, we will use the minimum personally identifiable information possible and control access to that data as described below.

### Publication

You will not be able to be identified in any external reports or publications about the research. Otherwise your information will only be included in these materials in an anonymous form, i.e. you will not be identifiable. Research results will be published in the PhD thesis and peer reviewed journals. A short report will be shared with you and will be available on the research project website. When this is up and running you will be informed of the URL. The film generated in phase 1 and a commentary will be posted on YouTube. This will not include any personally identifiable information.

#### Security and access controls

BU will hold the information we collect about you in hard copy in a secure location and on a BU password protected secure network where it will be held electronically. Personal information which has not been anonymised will be accessed and used only by appropriate, authorised individuals and when this is necessary for the purposes of the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff or others responsible for monitoring and/or audit of the study, who need to ensure that the research is complying with applicable regulations. Once the research activities are completed your personal information in identifiable form will be deleted. Anonymised data will be kept for five years, after which it will be deleted. At the beginning of the focus group you will be asked to identify a pseudonym. We will refer to you throughout the focus groups and interview by your pseudonym. We will not tell anyone that you have taken part in the focus groups, although there is of course a possibility that another member of the group might recognise you. We will also not name you in any of our reports or publications. In addition, you will all be asked to respect the confidentiality of your fellow participants in the workshop. You will all refer to one another by your pseudonyms. Your personal information and anonymised information will only be used for the purpose of this study.

#### Keeping your information if you withdraw from the study

If you withdraw from active participation in the study we will keep information which we have already collected from or about you, if this has on-going relevance or value to the study. This may include your personal identifiable information. As explained above, your legal rights to access, change, delete or move this information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate. However if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study. You can find out more about your rights in relation to your data and how to raise queries or complaints in our Privacy Notice.

**Project governance documentation**, including copies of signed **participant agreements**: We keep this documentation for a long period after completion of the research, so that we have records of how we conducted the research and who took part. The only personal information in this documentation will be your name and signature, and we will not be able to link this to any anonymised research results.

#### **Contact for further information**

If you have any questions or would like further information, please contact Phil Morgan morganp@bournemouth.ac.uk tel. 07767003702

If you have any concerns about the study please contact Dr Mel Hughes <u>mhughes@bournemouth.ac.uk</u> Tel. 01202 962806.

If your concerns have not been answered by Dr Hughes you should contact Professor Vanora Hundley, Deputy Dean of Research, Faculty of Health and Social Sciences, Bournemouth University by email to researchgovernance@bournemouth.ac.uk.

**Finally**, if you decide to take part, you will be given a copy of the information sheet and a signed participant agreement form to keep. Thank you for considering taking part in this research project.

### Appendix 7: Participant Agreement Form: Phase 2

Ref & Version: 060120 V4 Ethics ID number:29315 Date: 9.8.21



# Participant Agreement Form: Phase 2 Full title of project: Co-producing Future Citizenship with People who Experience Mental Health Challenges

Researcher: Phil Morgan, PhD Student <u>morganp@bournemouth.ac.uk</u>
07767003702
Supervisor: Dr Mel Hughes Mhughes@bournemouth.ac.uk 01202 962802

To be completed prior to data collection activity

Agreement to participate in the study

You should only agree to participate in the study if you agree with all of the statements in this table and accept that participating will involve the listed activities.

I have read and understood the Participant Information Sheet (060120 v4) and have been given access to the BU Research Participant <u>Privacy Notice</u> which sets out how we collect and use personal information

(https://www1.bournemouth.ac.uk/about/governance/access-information/dataprotection-privacy).

I have had an opportunity to ask questions.

I understand that my participation is voluntary. I can stop participating in research activities at any time without giving a reason and I am free to decline to answer any particular question(s).

I understand that taking part in the research will include the following activity/activities as part of the research:

- Being video and audio recorded during the project
- my words will be quoted in publications, reports, web pages and other research outputs without using my real name.

I understand that, if I withdraw from the study, I will also be able to withdraw my data from further use in the study **except** where my data has been anonymised (as I cannot be identified) or it will be harmful to the project to have my data removed.

I understand that my data may be used in an anonymised form by the research team to support other research projects in the future, including future publications, reports or presentations.

Initial box to

agree

I consent to take part in the project on the basis set out above

Name of participant (BLOCK CAPITALS)

Date

(dd/mm/yyyy)

Signature

Name of researcher (BLOCK CAPITALS) Date

(dd/mm/yyyy)

Signature

### **Appendix 8: Interview Questions**

Question

Notes

- 1 How would you describe your understanding of technology (e.g. internet of things, articifical intelligence, wearable technologies) in regards to the future developments in society?
- 2 What do you think are likely to be the key developments in technology over the next 25 years, and what do you think will drive them?
- 3 What is your understanding of the concept of citizenship?
- 4 What do you think are the current key issues relating to citizenship in regards to people with mental health challenges?
- 5 (to what extent to do you think these issues are specific to or magnified for those with mental health challenges?)
- 6 What do you think are likely to be the key future issues relating to technological developments and citizenship for people with mental health challenges?
- 7 (to what extent to do you think these issues are specific to or magnified for those with mental health challenges?)
- 8. Anything else you'd like to add?

Would you like a copy of the recording of the interview? Would you like to participate in Co-production Group?

#### Appendix 9: Sample of slides from Co-Production workshop

### **Aims of the Workshop**

- To explore peoples' experience of participating in the interview stage of the research
- To sense check the initially coding of the interviews
- To discuss the key issues and themes relating to future citizenship for people with mental health challenges

### **Experience:**

- · What was your experience of participating the interviews?
- Did you have any further thoughts on the topic area?

### **EXAMPLES OF NODES AND SUB** NODES

- SELF DEFINED- MULTIPLE CITIZENSHIPS
   PRESSURE
- PART OF A COMMUNITY

- PART OF A COMMONT
   BELONGING TO A GROUP
   SOCIAL MOVEMENT
   COMPASSION/ASPIRATION
- PART OF THE WHOLE
   NATIONAL/ LEGAL/POLITICAL
   SAUDOLS
- TAUGHT IN SCHOOLS
- CORPORTATE
- GLOBAL
- DIGITAL

#### DEFINING CITIZENSHIP BARRIERS CITIZENSHIP

- ECONOMIC
- OWN MENTAL HEALTH
- FEAR/TRAUMA/PARANOIA
- STIGMA
   TECH KNOWLEDGE
- BEING OUTSIDE
- PACE OF CHANGE
- BEING LEFT BEHIND
- LACK OF OPPORTUNITY TO PARTICIPATE
- HOW MH IS DEFINED/RISK

#### **Breakout discussions:** Your Reflections:

1a) on Trends in Tech over next 25 years and their drivers?

1b) On the meaning of Citizenship (and specifically for people with mental health challenges)?

• Discuss themes from interviews

· Anything missing – anything that needs more weight

#### THEMES:

- HOPE FOR THE FUTURE

- -REBALANCING OF POWER

#### CONCERNS FOR THE FUTURE:

 RECONNECT (RE-INVENTION) TO BEING HUMAN
 LIGERATION COMPASSION
 LIBERATION COMPASSION
 LIGERATION COMPASSION
 LIGERATION COMPASSION
 LIGERATION
 LACK OF LIMITATION LOSING SKILLS - MH- GREATER OPENESS -REDEFINING MH AND MH ACT SURVAILENCE/TRACKING SOCIAL MEDIA- MEDIA ECHOCHAMBERS/FAKE NEWS -ADAPTATIONS FOR PEOPLE STRUGGLING LACK OF CONTROL PRIVATISATION IN HEALTHCARE LACK OF ACCESS TO SERVICES AND SUPPORT MH DECISIONS MADE FOR YOU GREATER PRESSURES

#### BALANCE:

OFFERING CHOICE AND CONTROL TRANSPARENCY, REGULATION AND SURVEILLANCE (ALEXA, TRACKING) DATA SECURITY ENGAGING WITH HUMANS OR NOT

#### MORAL QUESTIONS?

SURVEILLANCE (ALEXA, TRACKING) TRANSPARENCY, REGULATION AND CHECKING LIVING IN A VIRTUAL VS REAL WORLD CO-DESIGN IMPLANTS SOCIAL MOVEMENTS PROVIDING PEOPLE WITH MEANINGFUL ACTIVITY/EMPLOYMENT INDIVIDUAL CHANGE NOT LEAVING PEOPLE BEHIND SUPPORT AND NAVIGATION RISKBEING FORCED TO ACCEPT MH TREATMENT PATHWAYS

#### **Breakout discussions**

1) What are your thoughts on the overarching themes? Anything missing?

2) What are the Key considerations/most important issues?

### Appendix 10: Questions used for Focus group

- Having watched the film, what are your reflections on future citizenship for people with mental health challenges?
- Are there any additional considerations regarding threats and opportunities for citizenship for people with mental health challenges?
- What are the priorities for action in order to create inclusive futures?
- What if any actions will you take (either personally or as an organisation), if any, having participated in the research?
- How has the process of participating in the research been for you?
- What are your reflections on co-production in this context?

# Appendix11: Braun and Clark (2019) analysis applied to Phase 1

	Interviews	Co-Production Workshop	
1) Data	Data familiarisation process, revisiting the interview and		
familiarisation and	workshop transcripts.		
writing		The participants were involved in	
familiarisation notes		data familiarisation as the findings	
		from their interviews were discussed	
		with them as part of the knowledge	
		exchange.	
2) Systematic data	This initially took place	The data from the co-production	
coding	in NVivo in analysing	workshop, was layered with the data	
	the interview data.	from the interview and these were	
		created into mind maps.	
	In keeping with critical		
	realism, the focus of		
	the coding was on how		
	citizenship is formed,		
	this was represented		
	as a mindmap ( See		
	Appendix 12 for intial		
	coding and mindmap).		
3) Generating initial	The interview data	These were then sense checked and	
themes from coded	was divided into	developed with the participants.	
and collated data	personal experiences,		
	descriptive themes		
	and moral and ethical		
	questions.		
4) Developing and	These were then	The discussions in the co-production	
reviewing themes	developed into a	workshop were then analysed and	
	PowerPoint, with the	discussed further with the peer	
		researchers	
		16360101613	

	peer researchers (see	
	Appendix 9)	
5) Refining,	The whole data set was the	hen discussed and summarised in
defining and	the two-page document (a	appendix 13)
naming themes		
6) Writing the report	The report in this instance	e was the film

Name	No. of Files (this can either relate to individual participant interview files or the co- production workshop file)	References
Activism	2	5
participation	1	1
adaptability	1	4
Attention as a commodity	1	1
Attitude to Tech	6	10
Barriers to Citizenship	8	13
Barrier to citizenship - being outside	-	_
Barrier to citizenship - being under pressure	2	2
Barrier to citizenship -cost of technology	3	7
Barrier to citizenship- Fear	1	3
Barriers to citizenship - lack of trust	1	2
Barriers to citizenship - own mental health	4	5
Barriers to citizenship - Stigma (Including community understanding)	6	9
Barriers to citizenship- lack of compassion (Including "manufactured compassion")	1	3
Barriers to Citizenship- tech knowledge	3	7
Becoming a number	1	1
Being Left behind	5	10
Benefits of tech	1	1
Brexit	1	1
Challenging preconceptions Choice	1 4	1 7
Defining Citizenship	4	1
Citizenship - self defined	2	3
Citizenship as Utopia	1	2
Citizenship as a social movement	4	8
Citizenship as being part of community	5	7
Citizenship as Participation in society	1	1
.36	0	

# Appendix 12: Phase 1 initial coding in Nvivo and examples of mindmaps

Name	No. of Files (this can either relate to individual participant interview files or the co- production workshop file)	References
community responsibility	1	1
Citizenship as compassion	1	3
citizenship being part of society	2	3
Citizenship Belonging to a group (Including Identity)	5	10
citizenship in schools	1	1
Citizenship Nationhood	7	11
Corporate citizenship	1	3
Digital Citizenship	1	1
Global Citizenship (Global Citizen or ideas of different cultural experiences)	4	6
Understanding of citizenship (Participants confidence in what they understand citizenship to be)	1	1
Co-design	1	1
Control	5	15
Current trends	2	2
Covid-19	6	7
Current trends -education	1	1
Dark Web	1	3
Data Management	2	2



Image 1: Mind map- Drivers (personal collection)



Image 2: Mind Map- Citizenship (personal collection)



Image 3: Mind Map-Barriers to Citizenship (personal collection)



Image 4: Mind Map Inter-relationship of themes (personal collection)

### Appendix 13: Two-page summary

#### Co-Producing Future Citizenship alongside People with Mental Health Challenges: Summary of Phase 1 Data

Throughout the data collection people were sharing their personal experiences and anxieties as well as hope for the future. Looking forward participants shared, technology could positively *"redefine what it means to be human"* or it could *"break down the fabric of society."* These are two views expressed through the phase 1 of data collection. These weren't expressed as opposing views but rather as a spectrum of the potential impacts of technology. This phase of data collect seeks to expand the key issues and potential developments in regards to future citizenship for people with mental health challenges in order to stimulate discussion and action in regards to more equal futures.

Technology currently impacts on every sphere of life. The impact of Covid-19 has seen an acceleration in the use of digital platforms in communication. Whilst there are some thoughts there may be a backlash post-covid, all participants thought the use of technology would only grow. This would involve improved hardware and increased processing speeds, and the expansion to the use of: virtual/augmented reality; automation and semi-automation; user interfaces (implants, wearables, voice recognition); big data; and social media. These would shape all parts of life: domestic; leisure; employment; education; transport; healthcare; communication; manufacture; military; politically; and accessibility (MH/Disability.)

Primarily people thought this would be driven by profit and consumerism, but also how government and large companies maintain power and privilege. Some participants thought there were also social and moral drivers as well, in particular in relation to healthcare and sustainability. It was also acknowledged that there were also hidden developments which were perhaps more nefarious forces on the dark web. There was no doubt expressed that these changes would shape society and what it means to be a citizen.

The definition of Citizenship is shaped by a combination of power relations, cultural norms, and individuals themselves. People acknowledge the legal and political definition of citizenship but generally see it as something broader which has a focus on *belonging*. This can be to a geographical community, to the world as a whole, or to having a shared interest or experience. Those from the peer-led organisation in particular described this sense of belonging to social activism and in particular the importance of "having a voice." None of the participants saw digital citizenship as an entity in itself but rather the means to broader forms of citizenship. There was a suggestion that how identity was constructed was different for young people and older people, with older people have a stronger focus on employment as a key part of identity whereas for younger people it was more about place in the world.

People can be excluded from citizenship through poverty, struggling with the pressures of day-to-day life, lack of opportunity, the impact of socio-cultural expectations and oppression and having a lack of power. As more and more of life moves online, lack of access to and understanding of technology can exacerbate these inequalities. This brings a sense of people being left behind and alongside the material hardship a loss of identity, purpose and control. There was particular concern about the pressures on the mental health of young people and of older people being left behind.

Mental health challenges were seen to be a barrier in two ways: one, when our mental health is impacted that it is difficult to engage more broadly in society; two, the stigma and discrimination people experience in relation to their mental health. This stigma also included

how we conceptualise mental health and questions were raised in regards to the framing of mental health through the biomedical paradigm.

Those from the peer-led organisation felt that people with mental health challenges experienced additional barriers to accessing citizenship that were distinct to those from other marginalised groups. A number of people described the LGBTQ+ movement and Black Lives Matters activism as being more prominent than rights movements for people with mental health challenges. These additional barriers were seen as being due to culture of low expectations, perceived lack of capacity in regards to decision making, and perceived concerned about risk and having a "lack of a voice," in particular for those who have more moderate to severe mental health challenges.

The key themes for further exploration were:

The need to ensure people with mental health challenges (and other marginalised groups) will have a **voice** and have **choices**, both in regards to treatment but also engaging as a citizen.

This includes increased equality of opportunity and the material conditions to support people. Without this there is a concern that people will be "**left behind**"

Concerns that future treatment pathways would be rigid algorithm and **risk driven** (especially if privatised) and that people could be forced into receiving treatment they did not want/need. Linked to this the role of digital mental health monitoring for support vs **surveillance** and vulnerability to exploitation.

Greater understanding our how our MH impacts on how we interact with tech and equally **how tech impacts on our mental health.** This includes potential impact of echo-chambers, narrowing of world view, the draw on our attention, addictive nature of internet, the impact of **bad actors** (dark web, trolls)

There needed to be a discussion of how modern life impacts negatively on mental health and how our current conceptualisations may not be fit for purpose. Understanding **how we all find meaning, purpose and identity in a changed world** (particularly one with less work)

Opportunities to promote a great sense of shared humanity: **compassion** and acceptance around mental health

Increase our understanding around the balance of people living more of their lives online in **virtual worlds** with virtual people vs real life with connecting with real people through "**5** senses"

**Who will have power** and access to decision making? Who will define citizenship, Who will make decisions about society? What will the checks and balances be and how will there be transparency? What will be the role of protest and **activism**?

### Appendix 14: Coding table and photographs of co-analysis of focus group

### Co-generated codes – taken into final coding session with Peer Researchers

Initially there were 5 core themes – however, in the final coding session it was agreed that the nodes and sub-nodes within the pace of change theme could be captured within the other themes.

Theme	Code	Sub- Codes	Frequency
Pace of	Context Mental Health		1
Change:	Discrimination now		
Future and	Future of Work and		1
Present	Leisure		
	Impact of Film and Future		5
	Thinking		
	Covid Accelerated Pace of	Rapid Uptake of technology	2
	Change	Impact on different	1
		generations	
		Impact on Service Delivery	1
		Increased inequality	1
		Positives	3
		Importance of Skills	1

Theme	Code	Sub- Codes	Frequency
Divide	Divide		5
		Drive division	1
		Lots of reasons	2
	Left behind (inequalities)		8
	Falling between the gaps		1
	Scary Fear		6
		Dystopia/Sci Fi	3

		Digital Harms -Bullying	1
	Dissenting views- fears		3
	about not being		
	progressive		
	Being able to opt out		3
	Geographical divide	Urban/rural	1
		Global	1
	Digital Poverty		3
	Split between those who		2
	have data and those who		
	exploit it (links to power)		
Theme	Code	Sub-codes	Frequency
Agency and	Power	Knowledge is Power	3
Power			
		Data is Power	3
		Holding to Account	2
	Inclusivity		1
	Responsibility to influence		2
	Asset focused –		2
	opportunities		

Theme	Code	Sub- codes	Frequency
Activism and	Coming together	Redefining democracy	4
having a voice		Global mental health	2
(rights and		movement	
responsibilities)	Having a voice		1
		Enabling voices of others	1
		Asking questions not having	1
		answers	

	Seldom heard voices and	1
	inequalities	
	Space to dissent	1
	Lobbying corporations	1
Coproduction		6
Ethics		3
Activism	Promoting collective action	2
	Taking action	5

Theme	Code	Sub-codes	Line Nos
'What it means	Connection		1
to be Human'		Choices and options in being	2
		human	
		Fear of Human Contact	1
	Fear of Consequences of		1
	just being digital		
	Impact of Robots		1
	Changing how we relate		3
	Ambivalence and lack of		1
	certainty		
	Exploring what it means to		3
	be human in a digital world		
	Benefits of technology in		1
	mental health supports		

As well as the themes related to the research objectives linked to citizenship. There was also analysis of the value of future focused conversations and participants experience of co-production.

Codes	Sub code	Line no
Stimulates discussion and supports		2
reflection on present		
Trying to make sense of it		1
Address in equalities		1
Agency	Can give a sense of agency if	2
	role to play	
	Scary if you see it as a	1
	runaway train	
	Balancing local and global	1
	control	
Creating space for conversations		1
Focusing on developing digital rights		1
Importance of building on momentum		1

### Value of Future Conversations:

### **Experience of Coproduction:**

Codes	Sub code	Frequency
Focus on process	Life of its own	
		3
	Ladder	1
Equal Platform		1
	Participating on own terms	1
	Traditional approach wouldn't	1
	have worked	
	Respecting different	2
	perspectives	
Value of peer researchers		1

Attention to power	GW role to make it difficult	1
	Supress inner wants	1
	Anxiety in copro process in	1
	PhD	
	Coproducing future	1
	citizenship	

Photos of coding activity that further refined the themes and codes.



Image 5: Coding Workshop1 (personal collection)



Image 6: Coding Workshop 2 (personal collection)

# Appendix 15: How themes and sub-themes are represented in the film

Scene	Description	Themes and Sub- Themes
Scene 1: Introduction:	The presenter introduces what had informed the forecast. This scene highlights the involvement of participants with lived experience and those from a digital technology company. The visuals chosen shown on the display behind the presenter highlight some of the views expressed in the film and demonstrate and describe some of the technological advancements (e.g. backlash against technology, riots to demonstrate breakdown of society, biotechnology to show technological advances). The introduction sets the scene in terms of some of the questions about who is included in citizenship and the impact of technology on mental health	-Personal experiences -Impact of Covid -Backlash -Future technological Developments -Drivers of technological change Impact of technology on mental health
Scene 2: Citizen Scientist:	The provides the opportunity to highlight some of the descriptions of citizenship within the literature (informed by Marshall (1987) and the 5Rs by Rowe (Atterbury and Rowe 2017; Rowe and Pelletier 2012) and the views of participants related to belonging and having a voice.	-Citizenship as belonging -Citizenship as activism
Scene 3: Interview with XA754 in 2042:	The interview with XA754 provides the opportunity	-Impact of technology on mental health
	to present a possible scenario of future mental health support. This includes her accessing a range of different technological advancements and artificial intelligence. It also draws out some of the ethical issues related to consent as medication, for example remotely adjusted medication or having an AI key worker.	-Finding meaning, purpose and identity -Voice and choice
--	--	--
Scene 4: Interview with Juniper in 2042	The interview with Juniper provides the opportunity to explore a contrasting perspective to XA754, further posing some of the moral and ethical questions. These questions relate to rights, consent, choice, accountability, risk, social connection, and those being left behind. It includes reference to the Mental Health Act with the mention of home lock down orders.	-Impact of technology on mental health -Finding meaning, purpose and Identity -Voice and choice -Power and activism -Intersectionality
Scene 5: Concluding Questions	The final scene concludes the film by revisiting the ethical and moral questions highlighted in the interviews and co- production workshop. The film concludes with audience being left with the questions of who defines citizenship, how can more inclusive futures be created and what will the future have in store.	<ul> <li>Impact of technology on mental health</li> <li>Finding meaning, purpose and Identity</li> <li>Voice and choice</li> <li>Power and activism</li> <li>Intersectionality</li> <li>Inequalities as barriers to citizenship</li> <li>Generation gap</li> <li>Mental health challenges as a barrier to citizenship</li> </ul>

#### Appendix 16: 'Citizenship is the doing' Summary of round table discussion

#### Introduction:

This appendix provides an overview of the round table discussion between the peer researchers and myself. The session was facilitated my Mel Hughes (MH) lead supervisor for the PhD, so that I could fully participate on similar terms to the peer researchers, rather than being in a lead role. The purpose of the session was for the research team to discuss the findings of the research and consider implications in relation to future citizenship for people with mental health challenges. This is not about consensus but rather as part of the co-productive process as each member of the research team was able to give their perspective on the research findings and to reflect a co-produced approach to the discussion.

This appendix is divided into two parts: the first outlines the structure of the session and the second part is the transcript of the later stages of the discussion. This transcript has only been edited in limited way, largely to make it more concise and to enhance comprehension. The full transcript is over 35 pages. It has not been thematically analysed. The reason for this is to create transparency over the actual words of the peer researchers and myself without an overlay of additional analysis. This is important to enable the reader to make inferences on the dynamics of power and approach used in relation to co-production.

The rationale for the inclusion of appendix 16 in this format is to emphasise the value of lived experience perspectives, so when we come to the more traditional discussion, it is possible to hold this not just in the context of the literature review and the research findings but also through the views of the peer researchers. Therefore, the transcript presented here is not subject to further analysis within this chapter, but has been synthesised into chapter 13.

# Round Table Format:

Prior to the session everyone was provided with a handout providing a reminder of the research objectives and an overview of the themes with selected quotes. This was developed by the academic researcher as an aide memoir to support the discussion.

The session began with an explanation of the purpose of the workshop and the opportunity to clarify themes or sub-themes. This led to a discussion of the themes in turn. MH asked:

- Why does this theme matter?
- What are the implications/significance of this theme?

The purpose of doing this was not to unpick the themes but rather to have a reflective conversation to inform the overarching approach to next steps and key actions. Therefore, in the interests of brevity, this section of the transcript has not been included.

Once each theme had been discussed we then looked at the findings as a whole and identified:

• What are the next steps/recommendations from a local, regional, national and global perspective?

The session concluded with each participant being asked:

- What do you think is the most important thing to take away from the study?
- What key action do you think should be taken forward?

The transcript below outlines the next steps and recommendations on a personal/local, regional/services and national and global/societal level. It concludes

with final remarks from each of the participants. The headings (in bold) have been added to guide the reader through the chapter.

### Next Steps and Recommendations:

Mel Hughes (MH): Okay, so we're gonna move on to the 'now what' bit of 'what', 'so what', 'now what,' which are 'what are the next steps and recommendations?' We can look at these at three different levels so local, regional, national and global, or personal, services, society. We can think about it in different ways, but it's the real, think of this as the bigger picture. You've done all of this work, you've done all of this thinking, all of this finding, analysing, so what do you now want to happen? What are the recommendations that are, are coming out of this? [...]

### **Personal and Local Actions:**

George Reynolds (GR): Yeah, I can come in on that, just because I feel like it's something that I've got out of today is probably the realisation on the personal level, I am already doing things to enable people to have a voice. And, just reaffirmed how, how important that is. Because, whatever the changes in society, the technological advances and changes that happen within mental health services, probably the most powerful thing you can do is, not think about anticipating a negative future and how you're gonna change that but, how you can enable the right voices to be heard in the context of the change. So, to carry on doing that and be open to the threats that have come out in the themes about power and divide... So, yeah, to, on a personal level, reaffirm that facilitating that voice and enabling it to come out is probably the most important thing. [...]

Ian Warrington (IW): I feel very much the same, that it is what I can do. As an individual or how far I can push my agenda, or my kind of thinking to represent others. And it has to be, talking today is just, put it in mind that, that collective force is much stronger than an individual and to perhaps use it to unify more people to actually promote the challenges of the course you have. And not just try and just aimlessly go around waving a flag single-handedly, you know, just get other people

like minds together and actually use it as a force to be reckoned with and keep doing that.

#### MH: Phil? Personally, locally?

Phil Morgan (PM): ...So if I was looking at, when I started this I was in my old job [Lead for Recovery and Social Inclusion], so if I was in my old job, I would be thinking about how do we make the mechanics of this happen, whereas in this new job [Head of Nursing, Therapies, and Quality], I'm thinking how do you create the space to be able to create the mechanics that make it happen. If that makes sense. So, and I think the other thing is the depth of appreciation that I have for the work that you do [peer researchers] and that you've done with me is really, I always know it's important but also I think the, the powers of, I guess the, the institutional power, and institutional anxiety is so great, and that's what's different about my new role and my old role. It's so helpful to be in these conversations in my new role more so because I'm subject to so much more institutional power and anxiety that it's easier to be pushed into trying to fix things in a very biopsychosocial clinical type way rather than engage with citizenship and what that means... I think I've probably got more questions than answers and more reflections to do but I suppose fundamentally for me, it's keeping that reflection alive and that that being core to my development.

Bex Symons (BS): So, I think I shared earlier that through this process I think I've critiqued my own skills that, you know, building communities, or starting to build communities, groups etc. And it struck me straight away I could improve that and that's something that I'm very much taking on board and trying to be active with, but also encouraging where now I supervise, mentor other people to inform, or share with them some of my learning from, from this too, to try and get the knowledge out there so as many of us as possible are trynna think really inclusively...

MH: So, if as almost a sort of bullet point, the recommendations, the next steps at that level. How would you kind of try and capture that, what needs to happen? What would you like to see happen to keep the conversation going or keep this alive, those things that you all touched on.

BS: Well, I suppose I would say we need to keep active in our own ways and, and coming back together as well but then also trying to educate out as much as we can. That would be mine.

IW: Yeah, I was just gonna say, just to be more self-aware of what citizenship is. And actually put that into practice when you're dealing with other people, you know, just seeing where they feel they are on that spectrum of citizenship as well. Whether they feel included, whether they're completely marginalised or not, you know, it's made me look at myself and say what is citizenship to Ian. And it's kind of like this multi-layered thing, you know, we talk about, you know, working with an organisation, you're part of a community, then you're part of a political viewpoint, then you're part of this, that and the other, but it's literally stripping it all back and saying what is important to Ian? For me, the most, the most crucial thing from the bullet point will be what am I doing in citizenship myself.

GR: [...] if one of the themes that's come through is technology, is this thing that progresses and develops out of people's control and is that the, on a local level, on a societal level, what are the other forces that move in the same way and can they be, counteract that? Can they, can they mitigate some of the, some of the, the threats where it comes to participation and engagement in society and just picking up on what Phil said, about he's thinking on another level now that he's in a new role, where I'm only able to do my work because of the existence of an organisation [Dorset Mental Health Forum] which creates that space for people's voices to be heard and I think it's about making sure that there are organisations like that that, that, that gather people to, collectively exercise influence on the areas of society where technology is, is being rolled out in the way that it impacts people...There has to, there has to be that institutional space, a genuine, for that voice to genuinely be heard at that organisational level. Because, you know there, you can't do it without money, you're beholding to where the money's come from and it's the, is where the money's coming from, does that allow an independent, a genuinely independent voice to emerge, or does it, does it create a voice that's trying just to keep the organisation afloat and generate more money? There's other, there's other

technological and economic conditions around having a voice and having a voice at a societal level.

MH: So, there's some vehicle needed (GR: Yeah, yeah, yeah) or that, so what does that look like? In terms of recommendations and what you want to see happen or what needs to happen out of all of this, what does that look like? [...]

GR: Maybe this isn't relevant I don't know, but I see this, the foundation of a healthy society is good education, independent education that allows for people to reflect on what a human life is like in some form. Now, whether that has to be a school or, or it can happen in other organisations that are able to gather people together, to reflect on that whether explicitly or implicitly that they, they're understanding of that comes out without outside influence or being dictated to in order that, the, that voice can be heard in other organisations where that question's marginalised and people's needs don't get met, they need to be able to exercise that knowledge in, in those organisations. Does that make sense? [...]

So, I don't think that what that education or cultivating voice looks like is having a, a curriculum, its enabling people's voices to come from the ground up, around important topics [...] And that's that anarchic model, for me it's not about getting the anarchy being chaos, it's the things that kind of grow from the group up rather than the top down, more organisations work in that way. Uh, it, it is what I would like to see. Whether they can survive in a, in a broader culture and economy that doesn't work in that way is a really important question.

MH: Well, your recommendation is more organisations that work in that way.

GR: Yeah, mm, yeah, yeah, yeah. [...]

MH: Phil?

PM: So one from me, thinking about, continual reflective spaces for myself to keep this on the agenda, is to approach peer-led organisations probably the [Dorset

Mental Health] Forum would make sense as a starting point (BS: Haha.) to a, discuss whether they would like to engage in the programme of work around citizenship.

Then thinking about our expertise that we've developed but also broader expertise in terms of being able to shape that agenda a programme of research that looks at the questions that we are talking about more broadly in terms of, I guess, you know, those sort of notions of radical help and how do people do things for themselves and, cos I think there's a real problem with trynna talk about what our outputs are and trying to fit it in the world we're currently in.

And I think it's, I guess it's this thing about the value of Future Studies, being able to be in these imaginary spaces and for me it feels really strongly that there's something about being an imaginary space about what does it mean to be human. And then, the opportunity to, so again, one of the pieces of research from around citizenship was a participatory research around what does it mean to be a citizen, well I wondered, if we had the question about what does it mean to be human, and then citizenship is a by-product of being human rather than, you know, we've taken the lens from what does it mean to be a citizen, but I think what's that led us to is a potentially what does it mean to be human more fundamentally, so it, for me there's something about a programme of research which is the space where actually potentially you can be funded for doing things that don't fall within a, such rigid things, but that might just be me being idealistic.

Focus on local mental health services:

MH: And I want to move on in a minute to thinking about the more national, societal, implications but there's something about you, you as in, as Ian, George, Becks, you've got the ear of somebody that's really senior in mental health services, what needs to happen? I was just wondering if we could just capture that more, because we've just moved it from kind of personal to the local, but actually think more broadly in terms of service provision, before we think more broadly in terms of society and

people as a whole. Actually what needs to happen in terms of mental health service provision or health service provision? If it's come out of this for you?

IW: A re-education I think for people, you know, like you say, there's people expecting the services to pick up the pieces, let's start before they get to services, let's start earlier on with education through schools, through places of work...church communities, you know, these different communities out there that will promote good mental health but currently are doing nothing, and we're expecting people to pick up the pieces and be there like the NHS is 24/7, um, whether that's a reality anymore in this life we're living and the financial challenges is another debate.

MH: So, emphasis on communities promoting good mental health rather than only responding to poor mental health.

IW: On the, on responding to the stuff yeah. Putting the cart and the horse back in the right place.

MH: George, so you've got that ear of a senior person, what do you want to...What do you want, what needs to happen?

GR: I, I don't know in very specific concrete detail, so, my, I think the thing that I come back to is I want mental health care to be humane. I think people, people are always gonna be a force in society. Phil mentioned about almost, about all mental health services getting out of the way, you're gonna need some sort of support there, you're gonna need some care there but I want, I want it to be humane and I think that what I mean by that is putting that care into the context of a person's whole life and the factors that have brought them to where they are. Instead of, so, I, we're doing a bit of training through the Forum with an organisation, around what peer support means and one of the, the way that I just explained what the difference between clinical support and peer support is like, as I said well, in a, in a clinical relationship, in clinical support, you're the problem. When a peer supports you, life is the problem. And that's where I want, where I think that, the focus of attention needs to shift to is, we try and be alongside people, both examining life and what that means and how,

how a person with whatever their experience, whatever their journey is like can lead a meaningful life. And I think that rather than, I think if there was a change to people, that would be a shift in perspective, from seeing people as a problem to be examined so often and rehabilitated to being alongside people in order to explore life and the potential for life. More that, that shifts. Quite general but, but that's, that what I think is what a humane approach should, would consist of, and general outcome. IW: I'd like to see parity actually. I'd just put that back in there, you know, mental health, physical health, both on the same levels, both on the same platform, same amount of funding, same amount of dignity that's provided through some of the other services.

MH: Bex.

BS: I think, I think dignity and respect is what I would like to see and, even a really simple shift from service user to client.

GR: Or person! This is what I'm trynna say, person!

BS: But do you know what I mean, even that, there is a level...

IW: I don't mind being a patient, you know, you go to a hospital, you're a patient so, you know, its, it's a view isn't it.

BS: It is but I, I like, I like what client gives to us. There's a level of respect there. I am not, a service user, I might have used services but it, it's a, its just that like you said, its actually quite subtle shifts, but they are important shifts. And how every time we should be looking at someone in front of us and thinking if this was happening to my family member, if this was happening to me, how would I feel. And do I morally and ethically feel okay about this and you know it's exhausting, I feel, I feel so sorry because we have some, there are wonderful staff out there, but its holding that, we all need to hold it in mind day in, day out, because what is it to be human? To be human, you look at someone, you're there with that person, alongside that person, what is there, there was something um, there's a quote about someone jumped into

a hole with someone and, and the person said why did you do that, and he said well I've been in here before, I know how to get out. Haha. But its that get alongside people, not I'm better than you, oh you're choosing to smoke, oh I'm gonna note down all your eating for the day for no apparent reason, oh I'm gonna lock you out, do you wanna go to the toilet? Oh, let me unlock the door for you its, you know, its, its being human isn't it. It is being human and looking at another human and going how can I support you best and get the best out of you. Wow, not passionate at all haha [...]

### **National Recommendations:**

MH: So, move us into that national perspective, what do you want to see happen and by national it might be the society things you're thinking about, in terms of people, or it might be legislation, policy, government responsibility, you know, what, what's the, what needs to change about the national picture? What do you want to see happen?

IW: The way the government treats mental health, the Mental Health Act is, you know, part of it. You know, just again, that parity, mental health, that just needs scrapping overruling and rewriting with people actually involved in it, you know, out in some lived experience in there, put in some clinical experience in there, and making that balance of things, not just a political ping pong. And actually, use it for people who care about the service.

MH: What would fundamentally be different about a new Mental Health Act? What would its focus be?

IW: Less political and person centred. You know that's, if you're locking people up against their rights, and stuff like that and denying them this, that and the other, just isn't right in this day and age, just needs to be brought up to date, people's rights need to be looked at a lot more importantly, that human side of things again. That would be the national picture for me.

MH: Yeah, yeah.

PM: I agree. I agree, I also think a decoupling of, or if we're going big, a review of the criminal justice involvement in mental health and the mental health involvement in criminal justice, particularly the role of the police, but also, I guess prisons and mental health forensic and mental health services and, I suppose and that, and I, and I think it's almost again this is gonna sound, I think this is all interrelated, I guess it's that sort of proper informed understanding of education, um, psychological safety, how that then plays out into health, how that plays into criminal justice systems, how that plays out and into police and justice and then how that, where people, where people have rights and not and who, and again, coming back to this thing about the importance of the person having a voice through all of those elements because again... so I think it's, you know, as George has thought, I think its rethinking about our education system, our, our mental health system and our criminal justice system through a lens of citizenship and trauma informed approaches.

MH: And how do those four themes, because its about being really clear that these recommendations are coming out of this research.

PM: So, its readdressing power, its making visible the divide and, and tackling that within this, I guess the notion of trauma informed approach is a shift to understanding what it means to be human and what distress and I was struck by what you said George about experiencing suffering as well you know, talking about what does a good life mean but actually do we talk enough about what it means to suffer, and actually how, how does that fit. And then the, the, the, all of these above are driven by having a voice and that creating, so all of those processes and reviewing that bigger picture would be around how do you incorporate people's voices within that.

MH: So you're, what both of you have been talking about is just completely recreating the system based on these.

GR: Yeah. [...]

MH: You've mentioned the Mental Health Act, you've mentioned criminal, the systems, criminal justice and mental health systems. Anything else you would add around that national, what you want to see change nationally, again, covering legislation, policy...

IW: Social services. They come in massively. You know people are falling through the gaps and there's just so much need out there for people. You know whether it is mental health orientated or not. You know there's a shortage of beds in hospitals, there's a shortage of accommodation for people when they leave hospitals and it's just that never ending circle. And it's finding somewhere safe, you know, Maslow's Hierarchy, you know, somewhere safe is a roof over your head, something to eat, something to drink, just the very basics and we're failing on that for, you know, a number of people, (MH: So, a system that meets those basic needs.) a large number of people in the system. Yeah.

BS: And understanding those needs, the importance of those needs.

#### **Global Recommendations:**

GR: ...I mentioned about suffering and I think when, when, when you look at the World Health Organisation's definition of health, it's something like total physical, mental, emotional health integration, and I think like, that sounds good, I get where they're coming from, but back on planet earth, none of us are healthy then. So, we're setting up a uh, a conversation, an ideal which excludes nearly everybody, and it's about having a recognition of what it is to be human, the inevitability of certain sorts of suffering, of loss, of grief, of human emotion that is never gonna be one hundred percent positive. As part of our understanding of health, as part of our understanding of the good life is gonna have to be something that incorporates those, those, the inevitability of those experiences and then we've got like a, we marginalise distress and suffering when actually it's human. And, I think then at a more broader national level there, there's been a relative, relative progress with respect to certain types of, of distress or suffering, mental health and well-being, so talking about stress, anxiety and depression. I think society, and I don't know if this qualifies as a national level,

but society has progressed quite a way with understanding the, the, the fact of those things and people have needs around them. But much less so with hearing voices, or other unusual experiences (BS: Bipolar), yeah, yeah. Where actually it's still publicly quite taboo. (BS: And uncomfortable I think). Yeah, and so marginalised and I think that for me it's part of, the progress would be part of going back to thinking about what it is to be human, what it is to be, live a human life, a healthy life, a fulfilled life, one that incorporates the inevitability of degrees of suffering for everybody and so that there's less, less of a, of a separate groups of people so that we have uh, have educated better of our understanding of the human experience and contextualising mental health in that. So that would address perhaps stigma and other forms of marginalisation.

MH: So, there's something really interesting there, cos that global definition of health was a deliberate um, way of trying to see health as more than just the absence of ill health.

#### GR: Yeah.

MH: So in my, from what you're saying is that that risks denying ill-health and that experience as part of that whole...

GR: Yeah, completely, yeah, yeah, it builds into a definition of health something that is a fantasy. III-health is part of health. Like injury is part of sport. III-health is part of life. That's the beginning of a humane appreciation of it, the, admitting fragility and vulnerability and suffering and everything in some form and building our understanding of mental health on that basis, not on, people have fallen by the wayside, have just become ill and, the rest of us are healthy. There's something, something fundamentally wrong for me in that definition, yeah its, almost like, well no I won't go off onto that, but it's almost like a kind of, a legacy of heaven if you like and, and, and an idea of perfect existence that doesn't exist, but we pretend that it does and keep our suffering and things to ourselves, actually, back on earth, ha, illhealth and health are tied together, and we respond. MH: We've entered in really nicely to that more global perspective, so that, as, as big as you get just thinking about views and concept of health and mental health and living a good life. What are your thoughts on the recommendations and what needs to happen from this study about how we, just that global perspective. What are your thoughts?

PM: Can I chuck something into the mix, cos I suppose I'm just slightly uncomfortable about the framing of living a good life and whether we talk about a life well lived or something like that rather than, cos I suppose good, good has connotations, and I guess if we're thinking globally, it's just really important that we don't have a western view of what good, or even what mental health is considered, and part of having that global view is, is I guess that plurality of perspectives and critique and ability to negotiate where there may be cross-cultural clashes in understanding or perspective or, and, and so there's something about that that, that I think in terms of what...

MH: In terms of your recommendation what phrasing do you think would be more helpful?

PM: I think its life well lived or something like that. It has value with it, but I think the notion of a good life is, is particularly (MH: Yeah, good and bad) sort of a western philosophical way of looking at it.

GR: Yeah, that's where I'm coming from. Because I think the way I'm coming from that perspective is because one of the negative things that has dropped the what does it mean to be human question out, a public discussion is a kind of cultural relativism where you don't feel like you can state any answer to that question or, or important values, and I get where you're coming from but that might then seem to, um, put one particular form of life as more important or better than others, but I think its really important when we're talking, to even hold on to the question of what it means to be human, that there is something that it is to be human. That there is, perhaps you can even talk about human nature and human needs in order to critically leverage um, a kind of discussion where these aren't being met or being

denied, they're something that, they're foundational. How I would be explained, where I would go with that one, um, totally sensitive to the, what Phil's saying about you need to actually look for the possibility that there might be a plurality of conceptions of the good life.

One thing that I found interesting which came up when Ian was talking, he was making references to other countries and continents, where the, the, technology is, the state of technology is, is completely different and I'm thinking yeah, I wonder what the mental health is like. Is it better for that in some respects? Is it, is, and thinking about the nature of mental health and its cultural construction using them so yeah, I think, I'll always, I think, I do think this in question, an important phrase for me is thinking about the good life, and reasons why I'd want to hold on to it. But yeah, I'm sensitive to it, to that but...

MH: And there's something there about that acceptance of that meaning something different to each person.

IW: Living your best possible life regardless of mental health conditions or differences in abilities and physical abilities (GR: Yeah, sure, yeah), I think that's one of the things that's quoted in some of the REC [recovery college] courses we do isn't it.

PM: But I think the thing is, you know, we're not trynna get a consensus necessarily either (BS: No, no), you know it's, its, and I think it's, I think there's something about how do we have the mechanisms to have the conversations (GR: Yeah) about this rather than ,you know, and actually I think for me that, that a lot of this research and the value of the research is creating the spaces to have the conversations which are held respectfully, allowed difference dissent whatever, and that's part of the programme, and you know, again, if we were going off being a bit hit, I think there's almost like a global network of having conversations about what does it mean to be human and what does it mean to be a citizen in different ways and what does that, you know it, its, and where is that taking place and whose responsibility is that and what does that mean and I, is it important to do that. IW: Is that at governmental level, you know, do they get together, are these G7 meetings, whatever it is, G13s and talk about this stuff, what it is to be human, what it is mental health, you know, what importance is it to our citizens?

PM: But what happens when the good life comes down to earn as much money as you can, and get as much material stuff as you can and live a normative citizenship life, is that the good life? And that's the good, that's the, you know, and actually that will be a significant portion of the population's view as well.

GR: Yeah, I guess there's, I'm assuming there's interesting things out there that suggest that, that material satisfaction doesn't improve people's emotional well-being and mental health, that, but.[...]

MH: In terms of ahead of the absence of poverty, does that affect (BS: Yes, definitely) the, yeah, having more doesn't.

IW: Mhm, it doesn't fix it.

MH: Yeah.

### **Final Discussions:**

GR: I think but what I've learnt through this work and through this project is always come back to the humility to realise that even if you think you know the answer it won't be the right one because it's just come from you and that the most important thing going forward, cos this is, this is research right and I think it's, the tendency is for it all to be very funnelled back into one individual and, I think we're all, we seem to be in agreement here, or at least a theme that's emerged is that the, in terms of future action and any changes, it isn't about coming up with an answer and delivering it, its about creating the spaces in which those solutions can be manifest. And I think that yeah, that's the, the next steps would be, how can you Phil, or whoever's involved, create those?

MH: And, and that's come out really strongly that actually it's the having the conversations. I'm gonna move us onto this last bit if that okay which is around pulling this together so, what do you think is the most important thing to take away from the study? And its not intended to be reductionist, its not the only thing that, but actually what's the really key thing you each, um, want to take away from the study and what key action do you think should be taken forward? So there's two parts to that. So, what's the most important thing to take away from the study, what's the one thing you don't want to get lost or to be forgotten, and what's a key action that you think should be taken forward.

BS: I haven't, I don't think I've given enough thought to what it means to be human because I, I think I've very naturally fallen into the.. hand me the voice because I'm really passionate about that. So I think for, for me, I'm gonna take that away, to think even more about, because I feel with having a voice I've already, I'm already trying to actively implement some changes. So, I think, yeah, for me, it's what it means to be human, cos it's a big one.

MH: And what key action do you think should be taken forward and that could be personally, but it could be these bigger, more kind of national things that we've been talking about. What's the one thing (BS: Yep) you think absolutely, if anything else, needs to come out of this study?

BS: I really would like more people to have an opportunity to, to talk around all of this. Um, so I was even just thought of taking whether like, Phil started to filter it down, you know, but I don't know, but I think they are really important questions and as many people as possible need to have the opportunity to have a think about them.

GR: Yeah, I don't know if it boils down to one thing but it goes back to what I was saying earlier, like at the start of this we were, thought we were speculating about the future, cos the future is unknown. And guess what, the future's still unknown. The question was a kind of, a reason of opportunity to realise that and to think actually the most important thing is about our, whether we sleepwalk into the future or whether in the present we think critically about the kind of future we want. That critical voice can't come from one individual, or a small group of individuals, it has to be enabled by the creation of spaces for many voices to be heard from the bottom up. I think. That's what I'd take from it.

IW: I think for me it's finding a safe platform or space where we can listen firstly, find out what is actually going on, and then start the, you know, the action, and to kind of move forward again and progress stuff. Cos unless we've created these spaces and that opportunity to actually have discussions, it's kind of all wasted, it's, you know, it will be a valuable thing to have done but without talking it forward and kind of having further reflection on the whole thing. It's kind of just left out there as one, one person's work almost. So, to continue this legacy I think is probably the best word.

PM: I kind of agree with everyone really, so I, I think there's also part of looking at who else is doing these things in different forms and different ways of doing it and that conversation, so it's not just about this thing but it's about recognising who else is engaging in these conversations and what does that mean and then how you could potentially, I guess, create spaces to work together to then to maximise that. I think on a local level it's, that's putting in training and a programme of work which we can engage with the abstract and engage with the practical, and I suppose it's interesting listening to this conversation cos I was starting really going down the root of we really need to understand what it is to be human and actually citizenship is the vehicle to get to understanding that. But, actually through the process of going round the room, I'm back to why citizenship is important because citizenship is the doing (BS: Yeah) and being, well not, we are being human, we are human, but the act for me, citizenship and activism and an action are inextricably linked. And it's, and that's why the conversation about citizenship is important and if it spills, and we open it up in a way that it includes what it means to be human in a digital world or human in the world that we're in, that's really important because I think that tells us something about citizenship. But, I think if we extract it from citizenship, there's a danger that it becomes too abstract, too philosophical for the need to be the track share in terms of delivering change.

# **Conclusion:**

This round table is designed to stand alone and the text is not subject to an additional layer of analysis, so rather than adding a summary or analysis in this conclusion, I list the actions and recommendation that were made during this chapter. The issues raised and recommendations in this section form part of the overall discussion chapter, to be analysed alongside the literature review and the findings chapters that inform the implications that stem from this research. It is fitting that this is the closing section of this thesis.

## **Personal/ Local Actions**

- To continue to have conversations promoting citizenship and educate others around the importance of citizenship
- To continue to have self-awareness of own sense of citizenship
- To increase awareness of being inclusive in own practice as peer specialists
- To further support 'voice organisations' and work with peer-led organisations (starting with Dorset Mental Health Forum)
- To develop programme of further research on citizenship, what it means to be human, Future Studies and how people can be supported to engage in participatory citizenship to help themselves.

## **Regional/Service level**

- For mental health services be more humane, focusing on life being the problem rather than the person.
- Parity for mental health alongside physical health

- Communities to be able to support people with mental health challenges and have a role in promoting positive mental health.
- Address questions of language, move away from service user to 'person' or 'client.'

## National and Global/Societal level

- Promote education which facilitates conversations around 'citizenship' and 'what it means to be human' driven from the ground up: organisations to be developed to support these forms of education.
- To review the Mental Health Act involving people with lived experience and clinicians, to make it more personalised, less restrictive, and more protective of people's rights
- To address question of power and people having a voice to transform mental health services, criminal justice system, education system and social services to be focused on citizenship; for the local authorities to be able to meet people's basic needs such as safe housing.
- To address discrimination and stigma of mental health conditions, especially people's experience of bi-polar or hearing voices, which are less openly talked about
- To build an understanding of what living 'a good life' consists of and the global commonalities of being human and within that understanding the role of suffering
- For governments and international bodies such as the G7 to discuss and promote what it means to be human in a digital world, what it means to live a 'good life' and how this can be accessible for people with mental health challenges

## Final Recommendations:

- To create spaces to listen and have conversations about citizenship and being human
- To develop a programme of training that supports conversations and understanding about citizenship