

**Between responsibility and obligation:
The need for a solidarity-based
framework for psychiatric genetic
research participation**

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Abstract

Psychiatric genetic research has become ‘big biology’, relying heavily on willing donations from its many participants. However, psychiatric genetic research also has a contested history including resistance to biomedical accounts of psychiatric conditions. This makes engagement with its various publics a challenge for psychiatric genetics. At the centre of these debates, there is a gap in our understanding of the social processes surrounding participation and this is particularly true in the context of psychiatric genetic research.

This thesis is about what psychiatric genetic research participation means to researchers, mental health professionals, and people with experience of psychiatric conditions. It uses Q methodology to elicit four styles of thought that highlight tensions within efforts to recruit participants to psychiatric genetic research. Individuals are broadly categorised as (1) untroubled, (2) strategic, (3) concerned and (4) cautious in relation to participation; each group is analysed in detail using in-depth discussions of the Q methodology statements.

The findings tell a story of how psychiatric genetic researchers have worked to bypass powerful gatekeepers to their participants and, in doing so, have attempted to foster a sense of community to attract and retain participants. These apparently benevolent, but also strategic, attempts at “giving back” are entangled with the demands of everyday science and of recruiting participants. Appealing to a sense of responsibility that verges on moral obligation creates a tension that has been difficult for researchers to navigate. Ultimately, I argue that the idea of participation as an altruistic ‘gift’ is increasingly ineffective, and that, following Prainsack and Buyx (2017), psychiatric genetic research participation should be reframed in terms of solidarity, radically changing what it means to be a participant.

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Finally, I'd like to dedicate this PhD to my Dad whose cancer robbed him of the chance to finish his own and who I sincerely believe would still be here today if his voice had been heard and taken seriously enough when it counted. I miss him every day.

Chapter 1: Research Context and Background

1.1 Introduction

“Is it time to wage war on mental illness?”

(Owen 2013)

In 2013, Professor Mike Owen, the director of a leading centre for neuropsychiatric genetic and genomic¹ research posed this question at a UK public engagement event, a meeting so well attended that people were sitting in the aisles of the large multi-tiered lecture theatre. This was a public call to arms, a deliberate strategic call much like that which had served the ‘war on cancer’ so well through mass mobilisation of society to accrue funding and support for research (Sontag 1991; Marshall 2011; Ledford 2014). However, given the audience’s very mixed responses to the proposition of a war on mental illness, two key questions hung in the air: how would the soldiers be mobilised and how would we make up the army? Indeed, even if we *were* to think of tackling the problems of mental illness as a war, then one particular kind of soldier would be the people enlisted to take part in psychiatric genetic research.

Studying psychiatric genetic research participation is important because experiences of mental ill health are global and common (Collins et al. 2011; Steel et al. 2014; World-Health-Organisation 2019) but also *perceived* to be an increasing problem of living with morbidity (Wahlberg and Rose 2015). Researchers describe psychiatric conditions as a complex combination of biological, psychological and environmental factors, and genomic research aims to understand how these

¹ Genomics is the study of the whole of an organism’s genetic material rather than just focusing on individual genes and their heritability. When writing, I will use the phrase psychiatric genetic research to include both genetic and genomic research.

conditions arise, to develop new approaches to diagnosis and to identify novel treatment targets (Smoller et al. 2019; Rees and Owen 2020). Despite initial successes, scientific progress in this area has been slow and disappointing (Merikangas and Merikangas 2019), has realigned initial expectations and created the demand for a dramatic up-scaling in the recruitment of research participants (Arribas-Ayllon et al. 2019). Consequently, psychiatric genetic research has become 'big biology' (Weinberg 1999) that relies heavily on the willing donation of time and blood from its many research participants. However, psychiatric genetic research carries with it a long history of psychiatric abuse, anti-psychiatry and resistance to biomedical approaches to understanding and treating psychiatric conditions (Propping 2005; Lewis and Bartlett 2015). The broader UK mental health field persists in disciplinary disagreements over theory and practice (Pilgrim and Rogers 2009; Hannigan and Coffey 2011). This potentially makes the public engagement of psychiatric genetic research a challenging arena of diverse opinions over the fundamental concept of mental illness and approaches to treatment (Lewis and Thomas 2017). From the perspective of psychiatric genetic researchers, public engagement is challenging and can be very emotive; attempting to solicit public support simply through the provision of scientific information is likely to be insufficient.

Recent trends in public engagement for research participation reflect more socially orchestrated calls for people to play a part in research, changing what it means to be a participant compared to historical understandings of the participant as a passive research 'subject' and relatively more recent understandings as an individualistic autonomous biocitizen.² And yet, these calls for people to come together as part of a research enthusiastic society for the public good is not a neutral process and is shaped by political and commercial influences (Adams and McKeivitt 2015), as well as by research institutions themselves (Tutton 2007; Woolley et al. 2016). Set against this landscape are the more immediate needs of

² The biocitizen is a particular representation of the individual within a relationship between the individual and their governing nation, or state, in which they have rights and responsibilities that are enacted through their biological characteristics. Biocitizenship is discussed in Chapter 2.

psychiatric genetic researchers to recruit the help of sufficient and specific kinds of participants, and in which biomedical approaches to mental illness compete with psychological approaches within future imaginaries of hope.

From a sociological perspective, and specifically from the standpoint of science and technology studies (STS), we know very little about what is going on within the social processes of recruitment to psychiatric genetic research and what the repercussions might be, both for the research and for what it means to *be* a participant. Having a greater understanding of the social processes at play within attempts to recruit participants will highlight the challenges ahead for psychiatric genetic research participation but, from an STS perspective, also brings to the fore what sociological work these processes do. I argue that what it means to be a participant in psychiatric genetic research is moving towards the need to explore this position as something in which people cooperate in a shared, morally evaluated and negotiated, regulated *solidaristic* practice.

In this opening chapter, I outline some of the key trends and concepts relevant to psychiatric genetic research participation whereas additional literature and concepts, particularly relevant to the production and development of the research 'participant', are dealt with in Chapter 2. These chapters work together to identify the need for a critical empirical analysis of how psychiatric genetic research participation is socially organised and intervened, exploring the many perspectives on psychiatric genetic research participation as both a decision and process. After drawing this first chapter to a close, I will outline the structure of the thesis.

1.2 Sociological work within participation

Whatever the influences for why people participate in biomedical research, and psychiatric genetic research in particular, the increased need for large numbers of participants along with the prolific use of public engagement and social media means that the decision as to whether to participate is no longer restricted to a singular private interaction between clinician and patient; recruitment and participation is now potentially very public and socially interconnected.

There are a number of concepts that deal with forms of social organisation or group membership that are relevant to this thesis. Individualism, collectivism, communitarianism, citizenship and solidarity are all concepts that can help to think about the values, rights and responsibilities of people in relation to each other and to social entities that represent people, such as the government or state.³ In turn, these help when thinking about how psychiatric genetic research participation is framed and socially organised.

Collectivism and Individualism

Collectivism and individualism are concepts that have found particular favour within political science, resulting from the development of political and economic theories of people's behaviour. Harry Triandis (1995) theorised that people have both an individualistic and collectivist outlook and that societies need a balance of both to reduce the number of social problems that occur. An individualistic outlook will favour autonomy and the individual's rights as a rational free-thinking person with choices. This is favoured over the collective's wishes and demands, whereas a collectivist outlook will prioritise the needs of the group and stress human interdependence. According to Geert Hofstede (2010), people's identities in individualistic societies are multiple and individuals change identity according to context whereas, in collectivist

³ State: a legitimised system of power and authority composed of institutions (i.e. government, legal system, military, police) that regulate society within a territory (Bell 2013).

societies, individuals generally derive their identity from being a member of the collective group.⁴

Communitarianism and Community

Communitarianism is a particular form of collectivism, which has also been more recently conceptualised in its contemporary form as neo-communitarianism.⁵

Traditional communitarianism considers the individual as embedded within a community with local concerns and with a network of relations in which autonomy of the individual is devalued. Individual concerns and identity are subsumed to that of a group and the common good is prioritised over the pursuit of individual interests. As such, 'the good' and associated moral values are not determined by the individual but develop from a collective commitment to shared values and norms (Etzioni 1996; Etzioni 2000, 2010). From this perspective, communities are not simply an amalgamation of individuals and involve the concepts of reciprocity, trust, solidarity and tradition but, significantly, for communitarianism there is no direct relationship between individuals and the state (Tauber 2002).

'Community', however, is not a neutral word; in the UK it is sometimes romanticised, imitated, and also appropriated for politically rhetorical purposes (Bauman 2001; Sage 2012). Despite the romanticism of the word 'community', scholars have criticised traditional communitarianism (for details, see Hoedemaekers et al. 2006; Prainsack and Buyx 2017). From the individualistic perspective, communitarianism suffers from the risk of leaning too much towards an authoritarian way of thinking. Trying to find a balance between the security of community and the freedom of individuality is, to some, nostalgically appealing but also repeatedly elusive and disappointing (Bauman

⁴ Despite little evidence justifying typical categorisations, countries are often described as either individualist or collectivist societies; the UK and the US are currently regarded as individualistic whereas Asian countries such as China and Japan have been regarded as collectivistic (Voronov and Singer 2002).

⁵ Within the bounds of this PhD thesis, I do not have space for a detailed and historical consideration of communitarianism and the meaning of community. I have used Hoedemaekers et al. 2006; Chadwick 2011; Prainsack and Buyx 2017 as the basis for an overview of this in the specific context of genomic research and then drawn on other scholarship for more general understandings of communitarianism.

2001). Nevertheless, the contemporary form of neo-communitarianism tries to balance enhancing individuals' ability to contribute to the production of community outputs with opportunities for them to pursue their own individual interests (Hoedemaekers et al. 2007; Etzioni 2009, 2014).

Citizenship

An area that has received a lot of academic attention has been research participation as an act of citizenship. Theorising about citizenship has focused on the rights and responsibilities of individuals (Marshall 1983 [1950]; Lazar 2016). Liberal thinking argues that citizenship is a status whereby individuals have rights as a result of being a member of a larger nation state, with citizens seen as rational thinking individuals who utilise the provisions of the state and are seen as self-governing with minimal responsibilities other than to maintain the state. Citizenship has been theorised further in relation to both increased globalisation and rapid changes in the life sciences (See, for example, Leach et al. 2005). New genetic understandings and technologies were perceived as creating the person 'genetically at risk' and that individuals could then manage their lives accordingly, subject to available choices but also responsibilities (Novas and Rose 2000).

Scholars writing about *biological* citizenship⁶ argue that biocitizens, imbued with responsibilities as well as rights, are expected to be self-governing and enterprising in their pursuit of how best to manage their life, their risks and their future (Rose 2001; Petersen et al. 2010). Public health critiques highlight the sociological implications of market-led reforms that have promoted this self-governance.⁷ In their overview of healthy living in relation to citizenship, Alan Petersen and colleagues (2010) describe how discourses and directives aimed at individuals taking responsibility for their health

⁶ Note that the development of this biological, and more specifically genetic, citizenship will be discussed in more detail in Chapter 2.

⁷ Whilst seeming to promote choice and empowerment, the encouragement to take individual responsibility for our health and wellbeing, rather than relying on state provisions, has been criticised for its implications for those who fail to conform to or achieve such obligations (Petersen et al. 2010).

is a reflection of the changing relationship between citizens and their governing state.⁸ According to some ethical philosophies, personal responsibility is the cost we must bear for asserting ourselves as autonomous citizens (Roemer 1993, 1995, cited in Wikler 2002, p. 50).

The lack of capacity within forms of social organisation

Melissa Leach and colleagues (2005, p. 30) make a particularly important point that citizenship is a *practised* engagement:

Citizenship is then associated with those who are able to participate, and who do 'practise engagement', which suggests in turn a category of contextual non-citizens who do not.

Therefore, despite being promoted as a universal form of social organisation, such citizenship as it has evolved represents a particular privileging of the concerns of those who have the capacity and resources with which to practise that engagement.

This criticism is not unique to citizenship. From the perspective of Leach and colleagues, collectivism bridges communitarianism and liberal ideas of citizenship such that "a notion of the common good is seen to emerge out of a rational debate amongst free citizens in which different claims have their say and give way to collective agreement" (Leach et al. 2005, p. 24). From this perspective, the agency to actively engage in public debate about society and its values is a feature of collectivism. Furthermore, this criticism is also relevant for modern forms of communitarianism that attempt to accommodate individualistic features (Hoedemaekers et al. 2006). Consequently, failure to address the lack of capacity to socially participate is a problem that is not just limited to ideas of citizenship; each of

⁸ The question of how to attribute individual and social responsibility within health care is still highly controversial and there are attempts to take into account the intertwining nature of these responsibilities, aiming to move away from this individualistic responsabilisation (Daniels 2011).

these forms of social organisation depend on individuals being able to actively engage in decisions that contribute in some way beyond their own existence.

Amitai Etzioni (1996, pp. 7-9) has previously argued there is a mutuality between individual rights and social responsibilities and that societies need to recognise when this is out of balance and respond to those changes without fear of a 'slippery slope' towards either excessive individualism or excessive forms of collectivism.

Furthermore, with continuously rising concerns about the negative effects of individualism on medicine and public health provision, philosopher and historian of science Alfred Tauber (2002) argues that there needs to be a greater *moral* relationship between the individual and the state, a form of reciprocity of responsibility akin to that which sustains communities.

We can see from this work that critiques of individualism, citizenship, collectivism and communitarianism legitimate an alternative framework when thinking about a socially organised approach to biomedical research participation. Consequently, one further concept I will discuss, and one that has arisen in debates about the governance of genetic research, is solidarity.

Solidarity

In the last 20 years, after decades of research governance prioritising the rights of individuals, growing dissatisfaction has shifted attention towards how to balance the autonomous rights of individuals with the public good of society (Chadwick and Berg 2001; Knoppers and Chadwick 2005; Hoedemaekers et al. 2006, 2007; Sutrop 2011; Mulvihill et al. 2017). According to these debates, the dichotomy between individual autonomy and the welfare of individuals has focused too narrowly on the need to allow *each* individual to make informed choices about whether or not to participate in research and taken it out of the context from which we derive good health, i.e. within a socially interdependent world. Ruth Chadwick and Kåre Berg defined solidarity within the context of research participation quite simply as 'participation in research for the benefit of others', and by 2005 Chadwick had noted a shift in ethical debate

towards the less individualistic principles of reciprocity and solidarity (Chadwick and Berg 2001; Knoppers and Chadwick 2005).

Recent bioethical work about the governance of research biobanks attempts to recognise people's willingness to participate in research and focuses on the concept of solidarity as an alternative to approaches that prioritise individual autonomy. Barbara Prainsack and Alena Buyx (2011, 2012, 2013, 2017) argue that solidarity is widely considered important to how society functions but has been poorly conceptualised, thus affecting its usefulness as a concept. They also argue that there are few explorations of solidarity in practice that highlight the dynamics of the social, political and economic influences that make solidarity possible (Prainsack and Buyx 2017). They provide a detailed conceptualisation of solidarity in biomedicine, summarised as "enacted commitments to accept costs to assist others with whom a person or persons recognise similarity in a relevant respect." Of particular use to this thesis, is the authors' detailed conceptualisation of solidarity as a practice that works at different levels, defined as tiers, from that practiced between individual people (tier 1), to group-based practices (tier 2), through to the institutional level (tier 3) in which contractual, legal or administrative norms emerge as a solidification of group-based practices.

There have been some critiques of this conceptualisation (see (Prainsack and Buyx 2017, pp. 62-70) for details and authors' responses), the most relevant for this thesis being whether solidarity can exist at the inter-personal level or whether it needs pre-existing groups to exist (Dawson and Verweij 2012). Angus Dawson and Marcel Verweij also question whether solidarity is to be used normatively, i.e. as a morally endorsed ideal that invokes obligation. Philosopher Ashley Taylor's work is useful here in thinking about this critique. Taylor (2015) eloquently describes how popular usage of the term solidarity has meant that it holds different meanings depending on a person's group membership, arguing that solidarity does not necessarily have to be a moral relationship. One can be outside a group, *feel* and express solidarity with the group, but only take on moral obligations when one

becomes, and sustains being, a member of the group. In this situation, the relationship then becomes both moral and normative. As such, I do not think that this distinction precludes solidarity at the inter-personal level between two people but it does reflect a different kind of solidarity and this is something that Prainsack and Buyx have acknowledged in both the usage of a tiered system and the specificity of their conceptualisation as *enacted* commitments rather than only *feelings* of solidarity.

We see from this theorising that the last twenty years has seen a shift in thinking about what might be possible in terms of more collective approaches to research participation. In the context of the increasing interest in solidarity and its specific application to psychiatric genetic research participation, an important aspect to think about in this thesis is how these solidaristic groups might emerge. Invariably, this ties in with looking at what happens in practice and what we have already learnt about the social organisation of participation and recruitment to research.

1.3 Why take part in biomedical research?

Studies exploring why people take part in biomedical research of various kinds have primarily addressed participant's ideas of 'the common good', therapeutic misconception,⁹ informed consent¹⁰ and trust, the return of individual results, and validation of the illness experience (For example: Appelbaum et al. 1982; Dixon-Woods et al. 2007; McDonald et al. 2008; Dixon-Woods and Tarrant 2009; Wasan et al. 2009; Townsend and Cox 2013; Lidz et al. 2015; Thong et al. 2016). These studies have tended to focus on individual motivations and perspectives pertaining to the individual and their relationship with others, rather than looking at the macro-level of how participation as a process is socially organised.

⁹ The concept of therapeutic misconception describes the way in which individuals misunderstand the benefit of taking part and believe there will be some sort of personal therapeutic advantage (McDonald 2008).

¹⁰ Informed consent within research is a process whereby a competent individual voluntarily decides whether to take part in research as a result of receiving and understanding information about what the research is and what they are consenting to.

Views about participation have been found to depend on whether participants were members of the public or were also patients with specific conditions, the latter having a vested interest for themselves, family or their future generations (Ryan et al. 2020). In a review of 36 qualitative sociological studies about lay people's attitudes and experiences regarding tissue donation to biobanks¹¹, Wendy Lipworth and colleagues (2011) summarised the reasons for donating or for considering donation. These reasons included altruism, reciprocity¹², the expectation of personal benefit through new therapies, direct feedback of study results, the opportunity of the clinical encounter, or monetary compensation.¹³ In other studies, individuals saw it as an extension of the clinical setting in which they had already developed a trusting relationship (Ponder et al. 2008) or "simply did not mind donating, particularly when there was so little (perceived) cost or risk involved" (Lipworth et al. 2011, p. 798). An in-depth qualitative study of participants in the UK's 100,000 Genomes Project¹⁴ concluded that participants felt "pride" in taking part as a result of their trust in the NHS 'brand', bolstered by the publicly funded status of the project (Ryan et al. 2020, p. 35). Despite some concerns, most were optimistic about the benefits of genomic medicine for society.

Studies in the US, based on open-ended survey questions and data from in-depth focus groups of both potential and existing participants, has shown that one of the main positive reasons why people take part in genetic research is the desire to help,

¹¹ A biobank was defined as a stored collection of normal and diseased human tissue.

¹² Reciprocity is the act of giving and receiving whereby when something of benefit is given or a positive action is done, something of similar value is given or done in return.

Reciprocity therefore embeds an expectation of exchange. It is generally associated with positive acts and, when negative, it is specifically called negative reciprocity.

¹³ Whilst monetary compensation was amongst the reasons for participating, a number of other studies have found that participants did not expect financial gain (Hoeyer and Lynöe 2006; Haddow et al. 2007; Steinsbekk et al. 2013). In general, participants expected not to be out of pocket as a result of participating but did not expect to make money from the process.

¹⁴ The UK's 100,000 Genomes Project launched in 2012 and is sequencing 100,000 genomes of NHS patients, with a view to developing routine genomic testing in NHS clinical practice. Coupled with this clinical vision, the data will be made available to research, making it the first research-clinical hybrid on this scale within the NHS (Genomics_England 2020).

to benefit the public good and as an act of social solidarity (Lemke et al. 2010, p. 372; Michie et al. 2011). Despite barriers and potential risks, most were likely to take part in genetic research although people from marginalised and minority groups tended to have greater concerns about authorising storage of information and samples for future use in, as yet, undefined research projects (Wang et al. 2001; McQuillan et al. 2006). Participants also noted trust in the research organisation as a positive motivation for taking part whereas a lack of trust in government oversight of the sharing of genetic research data was a reason for not taking part (Lemke et al. 2010).¹⁵ The possibility of genetic discrimination due to data sharing was one of the concerns about participation along with a lack of understanding about what genetic research entails and what is involved in the process of participating in genetic research. In a study about participating in genetic research on blood pressure, Mary Dixon-Woods and colleagues (2007) reported a number of factors that influenced people's decision to take part including a reliance on research regulation, a perception of low risk, a positive attitude to medical research, and the possibility of a health check. However, the desire to do good, interpreted by the authors under the theme of citizenship, was a factor that motivated *everyone's* decision to take part.

Therefore, what we know from this literature on what motivates people to participate in research is that a key theme is an altruistic orientation towards the public good. Indeed, participation in genetic research has been of particular sociological interest because of the 'gifting' of bodily tissue such as blood (Titmuss 1997; Mauss 2002; Tutton 2002, 2004; Dixon-Woods et al. 2008a) in which the idea of donating is the same as the giving of a gift whereby nothing is expected in return. This literature is particularly useful when thinking about theories of research participation in terms of altruism, the role of reciprocity and the relevance of 'exchange' within relationships between researchers and participants. Note that some participants do not hold great value in the tissue itself, expecting nothing in return from their desire to do good in the future (Dixon-Woods et al. 2008a; Locock

¹⁵ This study was a US study and the authors noted a difference from other countries where protection of biobank participants was greater.

and Boylan 2016).¹⁶ However, when analysing parents' accounts of participation in autism genetics research, Ilina Singh (2015) found that parents balanced participation in terms of their short-term responsibilities to their own family with a longer-term sense of solidarity and obligation towards families with autism in the future. As I show in the next section, once people have agreed to take part in scientific or medical research there are still a number of problems and issues such as this to consider.

1.4 Complexities of participation in practice

In the early 2000s, Dixon-Woods and colleagues (2007) observed a dominant idea within the ethics literature that misunderstandings about participation in research were primarily of a technical nature. Such literature had focused on questions regarding the efficacy of participant information leaflets with respect to the decision-making process of participation. The perceived aim of researchers had been to improve the clarity and explanatory content of information leaflets and consent forms. However, empirical research was suggesting the leaflets persisted in either not being read, not being readable, or not understood (Cox 2002; Sharp 2004). This led Dixon-Woods to propose that leaflets and consent forms provide an alternative function to that idealized by researchers for the purposes of ethical accountability.

Based on semi-structured interviews of 29 volunteers within a genetic epidemiology study, Dixon-Woods and colleagues (2007) revealed a lack of understanding of the study aims by volunteers and their mistaken thinking that there would be a reciprocal exchange of information as a direct result of their participation; participants expected to be given personalised results. Most interestingly, the

¹⁶ Some studies found that participants demonstrated an ambiguity in what they think about the use of the 'gift' metaphor, seeing the term gift as denoting something more special (Locock and Boylan 2016) or rejected the idea of tissue donation as a gift, viewing their tissue as unwanted waste (Dixon-Woods et al. 2008a).

authors argue that informed consent and full understanding from information sheets concerning research aims and risks may not be necessary or even realistically achievable since they found volunteers relied very little on the content of the participant information leaflets for making a decision on whether to participate. What this research suggests is that information about the research is not the driving force behind how and why people take part. This parallels critiques about what is referred to as the 'deficit model' within the public understanding of science, a model that was mistakenly founded on the idea that filling a deficit in scientific understanding would alleviate the public's disengagement with science (see Miller (2001) for further details).

Whilst this lack of reliance on information is incongruous with the requirements for understanding as laid down by a biomedical ethics perspective, it does have the desired effect of expediting research recruitment. One suggested alternative function of information leaflets and consent forms is that they serve as signifiers of a legitimate process that enables trust in research and researchers to develop (See, for example Carter et al. 2015). A study of participants recruited from a clinical genetic service has also shown that the process of informed consent is often overlooked by participants because they see the research as an extension of the clinical setting in which they have already developed a trusting relationship (Ponder et al. 2008). Furthermore, for patients and carers, considerations of bioethical issues such as informed consent and patient privacy/confidentiality may need to be viewed within the context of more pressing considerations such as personal family situations and the constraints of diagnostic and treatment services.

In her study of participation in autism genetics research, Singh suggests parents' narratives focused less on bioethical considerations and more on practical and moral obligations to the affected child and the wider affected community (Singh 2015). The parents viewed the genetic research as a means to legitimise and understand their child's condition, to alleviate feelings of guilt for possible parental causation, and to gain access to services with, crucially, parents viewing appeals to participate in exchange for a diagnosis as a coercive act on behalf of the research

institution, resulting in complaints by participants when the bargain of exchange was unfulfilled. Appealing to people's individualistic desires to circumvent the problems of inequitable access to services, combined with an inadequate infrastructure with which to fulfil the bargain, raised questions about the morality of such recruitment practices. This research highlights that recruitment practices can become entangled with personal patient needs.

The US context of Singh's research is important here though, in that access to services is based more on private health care than in the UK and there may be more incentive in the US to take part in research in order to access some forms of care. As Tara McKay and Stefan Timmermans (2009, p. 1795) note, bioethicists in the US "have given high priority to participants' autonomy and their ability to distinguish care from research." The authors question whether individuals understand that taking part in research aims to benefit society as a whole rather than to provide immediate individual benefit. Even a knowing participant, who chooses to balance altruism with access to care through taking part in research, still opens themselves up to the risk of subtle coercion compared to the standard care situation (Townsend and Cox 2013).

What we can take from these complexities is that any understandings about the process of participation and its problems need to be interpreted within the specific context of the health condition, health care provision, participant's personal circumstances and the attitude of the research institution towards informed consent. These studies suggest that the illness experience and implicit trust in clinicians and medical science means 'informed choices' can be difficult to achieve in practice. Indeed, based on analysis of the accounts of UK clinical trials participants, Oonagh Corrigan (2003) has argued there is an *emptiness* in the bioethical principles of informed consent and a need to explicate the social processes taking place within the decision to take part. Corrigan found that, for some participants, informed consent provided them with the opportunity for choice about whether to participate whereas others found the decision burdensome and

interfering with their care; for others there was little understanding of the information they were provided in order to consent.

These problems demonstrate that research organisations need a greater understanding of the social organisation of participation, to take this seriously and question how participation is achieved in practice. So far, we can learn about the complexities of research participation from initiatives that have sought to circumvent some of the problems described above. Two particularly controversial initiatives are England's data-sharing project care.data and the proposed Icelandic Health Sector Database (IHD) by commercial company deCODE.

England's care.data initiative in 2013 sought to extract information from routinely collected NHS medical records and re-purpose it for research. Such routinely collected medical records have been regarded as an under-exploited resource that, through research, can help to deliver better care and treatments for UK healthcare.¹⁷

Drawing on Pam Carter and colleague's review (2015) of care.data and their attempts to conceptualise it in the context of a social licence,¹⁸ we find that those involved in care.data assumed the public would be more amenable to the use of medical records than the regulatory process allowed. This analysis argues that care.data suffered from three problems: (1) Defects in the warrants of trust – there were practical deficiencies in providing the public with sufficient information and opportunity to opt out; (2) Rupture in the traditional role of the GP – there was a significant threat to the traditional understandings of privacy within the GP-patient relationship; (3) Uncertainties about the status of care.data as a public good – there

¹⁷ It is also important to note that another motivation for care.data was to address accountability and improve UK economic growth through the provision of health research data.

¹⁸ Using the work of sociologist Everett Hughes (Hughes 1959), I refer to a social licence for scientific research as the activities afforded to science by society, over and above its legal requirements for carrying out research (Raman and Mohr 2014; Carter et al. 2015).

was a lack of clarity about its aims that raised concerns about commercial exploitation and data sharing.

Satisfying these concerns hinged on people's perception of the sufficient regulation of medical and scientific research and one of the problems with care.data was the perceived risk that private data could be shared with commercial organisations. However, a key issue was an emphasis on the idea that the implicit social contract between the NHS and its users, along with the public's support of research generally, would be sufficient to assume a broader consent to re-purpose patient data for research purposes.

Using the care.data controversy as a case study, Carter and colleagues (2015) highlight how the provision of the legal authority for research activities is not sufficient to legitimise the research from the public's point of view nor to secure what is termed the 'social licence' to operate. A social licence involves expectations that concern the conduct of organisations and, although their conduct may be within the regulations, it may be outside of what society approves of. Failure to attend to this appropriate conduct may cause problems of mistrust and contestation regarding the public good of the research.

The deCODE initiative in Iceland provides a clear example of how public health agendas and commercial opportunities can become entangled (for details see: McInnis 1999; Fortun 2001; Pálsson and Rabinow 2001; Potts 2002; Merz et al. 2004; Fortun 2005). In 1998, attempts to pass legislation permitting the private enterprise deCODE to exploit data from the health service without informed consent was done under the Icelandic government's remit of improving the nation's health care. Lured by company hype, proposing the economic benefits of job creation and the promise of free medicines that might result from pharmaceutical applications of the research, the Icelandic government attempted to rush through a law based on presumption of both consent and the general moral support of the Icelandic people. Heavily criticised for not complying with the Nuremberg code of

conduct, international debate about the opt-out format was fierce, with accusations of eugenic principles and commercial exploitation.

Anthropologist Mike Fortun describes the practices of both deCODE and the Icelandic government at the time as full of “intellectual and financial dishonesty, questionable science and ugly politics” (Fortun 2005, p. 158) during which public debate and discussion with scientific and medical communities was avoided wherever possible (Fortun 2001). Analysis of interviews with various stakeholders in the debate has shown that the venture was considered much more beneficial to deCODE than it was to the public good, undermining the claim that presumed consent was ethical (Merz et al. 2004). It’s legacy, however, has been one of heightened concern regarding commercialisation of biobanks and genetic research along with a suspicion of presumed consent (Hoeyer 2008) which, in the case of Iceland was later found to be unconstitutional (Knoppers and Chadwick 2005).¹⁹

These two case studies highlight the problems that can occur when governments and institutions do not pay sufficient attention to the social organisation of research participation. The care.data case is particularly useful in showing the repercussions of a failure to understand and attend to the broader concerns of individuals and how it affects the relationship between researchers and participants. It also demonstrates that legal compliance of a research project is not sufficient to convince potential participants of why they should take part and demonstrates the distinction between activities that enable the broader social licence for research to practice and those that are effectively public relation exercises to consolidate a mandate to practice that has already been assumed by those doing the research.

Similar issues arise within public dialogue and engagement activities for research. Like the symbols of trust performed by informed consent forms and public information leaflets, public engagement may provide an alternative form of this

¹⁹ Updates on the situation in Iceland reveal that deCODE’s subsequent bankruptcy meant it was bought out by an American multinational company and, more recently, sold onto China.

symbolism and an opportunity to promote the research as an endeavour for the public good. However, Carter and colleagues (2015, p 408) state that “a social licence for research will require, as a minimum, that certain conditions of social engagement have been respected” and that this dialogue is genuine and not for the purposes of capturing the public.

As I have shown in the previous sections, more recent scholarship demonstrates that, although the ethics surrounding participation in research has prioritised the rights of individuals, participants seem less concerned with these individualistic issues, suggesting that participation to them is more socially organised.

Furthermore, social research concerning the lack of understanding, or even reading, of participant information leaflets (PIL’s) and informed consent forms has highlighted the more nuanced and socially negotiated ways in which participants enter into research.

Mary Dixon-Woods and Carolyn Tarrant (2009) have argued that there should be greater focus on the institutional context and the joint action with others that makes *cooperation*²⁰ with research possible, instead of thinking in terms of individual participation. In contrast to the predominantly individualistic models and literature that focus on the reasoning and beliefs of individuals about personal costs and benefits, the authors argued that it might be more useful to think of a collaboratively oriented cooperation. Their empirical qualitative exploration analysed the accounts of 128 participants across three UK studies. The three studies differed in terms of both the expectation of personal gain to participants and the cross-section of motives for participation and this provided a rich basis for interpretation.²¹ Based on the empirical data available, the authors concluded that prospective participants look beyond the substantive purpose of the research when deciding to take part. They argue that potential participants look for signs of

²⁰ Here, the authors define cooperation as purposeful personal contribution to a common effort.

²¹ One drawback, however, is that the study only looked at those people who had agreed to participate in the medical research and potentially misses some important counterbalance to this debate from those who did not agree.

reasonable practice and reciprocity such as indications that researchers are conducting themselves in a way that limits the risk of harm or exploitation of participants.

These expectations of the reciprocity of medical research are based on borrowing from a broader view of the reassurances of 'disinterested' medicine and healthcare. In doing so, Dixon-Woods and Tarrant conclude "The social organisation of research is fundamental to the judgements people make about cooperation with research." (Dixon-Woods and Tarrant 2009, p. 2221). They argue that the cooperation of potential participants relies on individuals' beliefs about a reciprocal appreciation of common goals by the researchers as part of a bargain between a professional group and society. According to Dixon-Woods and colleagues (2008b), the future governance of research studies and biobanks relies "critically upon trust, solidarity, shared values and displays of etiquette" in order for publics and research organisations to come together.

However, in thinking about the way potential participants look at how research is socially *organised*, it is useful to think about this from an STS perspective because of its particular attention to the practice of science. In doing so, this highlights how governments, institutions and researchers attempt to socially *organise* potential participants in order to achieve recruitment.

1.5 Institutional responses to ambivalence and the creation of a research-enthusiastic obligated society

A consequence of changes in the relationship between citizens and their governing state was that it challenged the legitimacy of any new appeals by governments towards what had become regarded as "private moral choices about health" (Sulkunen et al. 2004, cited in Ursin 2010, p. 461). Given this change in the relationship between government and UK citizens, it is not surprising that, in their comparison across three different biomedical research projects, Dixon-Woods and

Tarrant (2009) found that not participating in research was seen as a culturally acceptable position to take on the public good in the UK.

Returning to the idea of donating blood as a 'gift' to genetic research, Helen Busby (2006, p. 853) argues that Richard Titmuss's writings about blood donation as a gift have been "wrenched" out of its context of a socially organised post-war national endeavour, to be heralded as indicative of the altruism by individuals in order to promote blood donation for genetic research as a national resource. Based on analysis of historical (policy) documents, Busby regards this 'gift' as a prevailing assumption and metaphor that has come to play an important mediating role in tensions concerning the relationship between commerce and biomedical research. According to Richard Tutton (2004) and Helen Busby (2006), both 'gift' as metaphor and nostalgic associations with the welfare state sustains the evasion of ethical and public debate in the UK about the commercial uses of donated blood, allowing an "elasticity" between commercial resource and public good. Furthermore, they argue that the powerful image of gifted blood donations as providing help to those in need performs rhetorical work in representing the social contract between biomedical researchers and publics and, in particular, potential participants.²²

Using language to frame participation and tissue donation as a public act of altruism is not the only way to create a research-enthusiastic society. In the last 20 years, a great deal of investment and work has gone into promoting research participation in the UK and, in particular, patient and public involvement within health and social care research. UK initiatives within the National Health Service (NHS) such as INVOLVE²³ have emerged in response to increasing demand for research participants and their involvement. Since April 2017, the National Institute for

²² Although not convincing, Dixon-Woods and colleagues (2008a) claim people's rejection of the idea of tissue samples as a 'gift' contradicts Busby's cynical view of its use as some kind of social mechanism to promote altruism and effect public support. Such rejection, however, was when the tissue was a tumour or urine and negative connotations of these kinds of tissue are likely to intersect negatively with the more positive associations of a gift.

²³ INVOLVE is a UK national advisory group set up in 1996 to support active public involvement in NHS, public health and social care research. It is funded by the National Institute for Health Research (NIHR) which is primarily funded by the Department of Health and Social Care.

Health Research (NIHR) has also undertaken a campaign with the strapline “I am research: Be part of the solution” (NIHR 2017). Employing a wide variety of strategies to enable people to “shout about how fantastic research is”, this campaign directs people to consider their individual responsibility within a framework of collectivism. In addition to traditional style public engagement formats of public debates, film screenings, and other events, people are also encouraged to contribute their online personal stories tagged to the ‘iamresearch’ Twitter and Facebook social media accounts. ‘Thunderclaps’ whereby people are asked to post a prescribed message at the same time and day have been another online social media activity. These social media campaigns sit within an integrated online suite of appeals for recruitment to studies as well as involvement in research processes. However, these are not just public engagement ‘activities’, they can be viewed as social mechanisms to galvanise and heighten the idea that support for research is widespread and socially accepted.

Institutions may choose to employ some of the involvement strategies because of a desire to involve people in the decision-making process of research but also because funders now insist on having public involvement, engagement and impact within research proposals. An alternative perspective is that these involvement strategies enable a way in to discuss the possibility of taking part in the research or to disseminate participation to others.²⁴ A limited amount of research has shown that one of the things that involvement *has* improved is increased participant recruitment rates (Ennis and Wykes 2013).

In analyses of participatory discourse, Tutton (2007) has argued that the UK’s Biobank institutions have aligned with and appropriated discourses of partnership, community involvement, and active citizenship in order to galvanise the provision of tissue samples and personal information from the UK population. More recently, Patrick Woolley and colleagues (2016) call for a critical analysis of such activities,

²⁴ From INVOLVE’s mission statements, they aim to promote involvement in research but also to involve *everyone*, thus downplaying the burden of involvement that requires the development of skills, expertise, and experience in addition to addressing issues of power imbalances, accessibility, and inequalities (Branfield and Beresford 2010).

arguing that research organisations have embraced a rhetoric of engagement, community involvement, and citizen science because of their need for more participants, arguing that the purported role of involvement lacks clarity and is part of more widespread uncritical usage in order to cultivate a sense of civic duty towards participating in government-sponsored research.

There is a bigger question, however, than whether or not these activities reflect desires to improve knowledge generation or whether they are social mechanisms for making people feel valued in exchange for securing funding or increasing recruitment. Drawing on the work of Irwin (2006), and his analysis of public debate and consultations surrounding genetically modified foodstuffs in the early 2000s, allows the question to be asked about whether these participatory activities are just rhetorical flourishes, ritualistic and diversionary. At that time, the rhetoric of public consultation and participation as a means of the new governance of science was at its peak. Rather than simply criticising these attempts at a new form of governance, Irwin demonstrated that an analysis of the evidence reflected the uneasy relationship between science and society at that time because of tensions between old and new assumptions about people's relationship to science. Irwin's approach demonstrates that these activities related to psychiatric genetic research participation and the actions of potential participants should not only be critiqued but they also indicate science-public relations that are worthy of sociological investigation. One area of this relationship that is repeatedly debated is the idea of participation as a duty or moral obligation.

1.6 Research as a Moral Obligation

Research participation is predicated on balancing the benefit to research against the risk of harm to individuals and, in the UK, obtaining informed consent is generally sought prior to participation. Some have argued that the emphasis on securing and maintaining individual consent is actually detrimental to the greater public good and disproportionate to the risks to the individual (see, for example,

Coleman et al. 2003; Walley 2006). In fact, since the late 1990s²⁵ there have been growing claims that research is being hindered by the ethical constraints that surround participation in research (Hoedemaekers et al. 2006; McGuire and Beskow 2010; Rhodes 2010). Rosamond Rhodes has argued that research ethics based on prioritising the welfare of the individual participant at the expense of the public good is protectionist, paternalistic, and unjustifiable (2010). The argument is that the practical administration of legislation errs on the side of caution, and that the public is more supportive of research and more amenable to taking part than the legislation permits.

In both the UK and the US, there have been calls for research participation to be compulsory or viewed as a moral obligation (Harris 2005; Schaefer et al. 2009; Rhodes 2010). These opinion pieces from bioethicists, all based within scientific institutions, advocate for a societal change on how research participation is viewed, to challenge “the presumption of suspicion about medical research” (Harris 2005, p. 242) and to support the view that participation should be a duty or moral obligation. Owen Schaefer and colleagues (2009) draw on empirical research to argue that the prevailing view in the UK is that participation is seen as a good thing but not morally required. Consequently, they propose there should be a change in mindset to focus on the moral obligation as a member of society rather than on the personal benefits to the individual.

Whilst these views received much criticism at the time, others have also asked when such a view might actually be considered morally acceptable (For example, see Ursin and Solberg (2008) and (Hoedemaekers et al. 2006)). Chadwick and Berg (2001) have previously asked why the individual’s right to refuse to take part in genetic research should override the benefit of research to others, arguing that a case for solidarity is particularly strong in genetic research whereby family members of participants may benefit in the future, even though the current participant

²⁵ Researchers had started to complain back in the 1980s about the burden of overregulation on researchers and research and this persisted but in the 1990s there became more focus on the impact on participation rates and its impact on the progress of research.

doesn't.²⁶ Following Chadwick and Berg (2001), Hoedemakers and colleagues (2006) ask under what conditions are alternative forms of informed consent more ethical that are less restrictive for research and more justifiable on the grounds of the public good. Hoedemaekers and colleagues (2007) claim that, in certain circumstances, solidarity can be used to justify reducing individual control over how tissue samples and personal information are used, on the grounds that public benefits outweigh individual risks of participation when these risks are small and adequately controlled. More recently, geneticist John Mulvihill and his bioethics colleagues (2017) have repeated the call for prioritising the public good over individual rights and for emphasising solidarity as an ethical principle for genetic research and technologies. This repeated call by Mulvihill and colleagues is a result of the emergence of CRISPR-Cas9 gene-editing technology that can alter and correct DNA. CRISPR-Cas9 has been described as a 'disruptor' technology (Ledford 2015) because the specificity, ease of use, and low cost of this technology means that genetic research will be able to move at a much quicker pace. Consequently, ethical issues will need to be addressed more rapidly.

Returning to Tauber's arguments about the need for a greater moral relationship between the individual and their governing state, a question remains about whether we can be *obliged* to incur costs, in the context of genetic research, by giving up time and tissue samples to benefit future patients. If the answer to this is yes, then such moral arguments will need the setting of conditions regarding reduced consent, the balance of control over tissue samples, and sufficient overseeing of this control, especially for patients with severely reduced autonomy

²⁶ Genetic research and genetic databases, along with the storage of tissue samples, have raised particular ethical problems that have been widely debated and are predicted to escalate in the future (See, for example, (Biesecker and Peay 2003; Knoppers and Chadwick 2005; McGuire and Beskow 2010; Caulfield and Murdock 2017). Genetic research, with the collection of tissue samples and concerns about commercialisation, has complicated the traditional process of informed consent and control over samples. This complication is also due to the need for larger scale collaborative projects whereby it is necessary to extend the possibility of a donation's use to research projects other than that for which its collection was originally intended. Different consent models have been proposed and attempted but there is still confusion about the best way to go about this, especially for large-scale collections of genetic samples such as biobanks (Caulfield and Murdoch 2017).

and social functioning (Hoedemaekers et al. 2007). This setting of conditions has been explored in a study concerning the reuse of health data in which there was public support for its use for purposes beyond clinical care, as long as it is expected to further the public good (Skovgaard et al. 2019). Thinking about the ethics of large-scale collections for genetic research would therefore need to do so within a new framework of *doing* public good (Cordell 2011) rather than persisting with makeshift versions of the traditional form of informed consent.

Some STS scholars question whether ideas of individual autonomy and empowerment are actually a bit of a façade. Anne Kerr (2003) suggests that changes in how genetic research participation is framed does not necessarily mean there has been any change in the balance between the entitlements of professionals and the obligations of patients or publics, simply that the apparent mechanisms of taking part in genetic research have shifted. She argues that DNA repositories such as the UK's Biobank, in which publics donate according to an undercurrent of obligation to the public good whilst also bearing a devolved responsibility through the ethics of informed consent, is a process that is still governed by the entitlement of professionals to judge the research's ethics and merits towards the public good. According to Kerr, the devolving of responsibility to individuals has circumvented what would be a more socially just process of governing genetics that safeguards responsibilities towards socially excluded groups. These groups, whose challenging lives means they may not be able to exercise the proclaimed rights to choice and to voicing their wishes and concerns through public debate, can get overlooked.

To sum up so far, previous studies of participating in biobanks or genetic research for conditions other than mental illness demonstrate that altruism and the public good predominate as reasons for participation. Even so, although it is likely that many individuals will conform to the belief that medical research is a public good that will provide the best therapeutic opportunities, this may not be a universal view. For example, people who have had negative experiences with the medical profession and, in particular, with psychiatry may feel very different about

biomedical approaches. As a result, such deliberations about participation are contextually situated within the specificity of particular conditions and the socio-political circumstances within which the potential participant must make their decision.

1.7 The significance of psychiatric genetic research participation

Overall, genetic approaches to understanding psychiatric conditions have been disappointingly slow, a delay that supporters of such research put down to a greater than expected complexity than was understood at the time of the initial hopes and promises (Burmeister et al. 2008; Merikangas and Merikangas 2019; Smoller 2019). Early excitement in the 1970s and 1980s quickly revealed that findings were not reproduced by other researchers, with a subsequent impact on the promissory landscape (for a detailed genealogy of psychiatric genetics, see Arribas-Ayllon et al. 2019).

Key critics argue that, along with neurobiology, psychiatric genetics has failed in its search for clinically reliable and valid biomarkers which is “probably futile” (Rose 2019, p. 183) and has meant that attention and funding has prioritised it over research on the environmental and social determinants of mental ill health (Joseph 2012; Rose 2019). On the other hand, psychiatric genetic researchers still regard molecular genetics as one of the few tools available for understanding the aetiology of these conditions (Sullivan et al. 2012; Smoller 2019) and that we have finally entered a “golden age of research into the fundamental basis of severe mental illness” (Sullivan et al. 2018, p. 25).²⁷ Furthermore, the expansion of registries and biobanks are seen as providing great opportunities for future research, responding

²⁷ There is no internationally recognised definition of severe mental illness (SMI) but the most widely used is that by the National Institute for Mental Health and includes schizophrenia, depression and bipolar disorder (see NIMH 1987; Schinnar et al. 1990; Ruggeri et al. 2000).

to the so far limited successes in translating research knowledge into reducing the 'burden'²⁸ of mental ill health in the population (Merikangas and Merikangas 2019).

Sociologists who have engaged with the history of psychiatry (Rose 2019), and psychiatric genetic research in particular (Arribas-Ayllon et al. 2019), argue that psychiatry and its biomedical research counterparts have shaped and sustained how we know and treat psychiatric conditions. Nikolas Rose (2019) questions the high and increasing statistics on mental disorders, arguing that these statistics include extraneous diagnoses that represent mental distress as a result of essentially social problems; a claim supported by epidemiological studies (Baxter et al. 2014). According to Rose, these statistics have served a more political purpose to galvanise the global mental health movement whilst at the same time reframing mental disorders as brain disorders, primarily in need of biomedical treatment underpinned by biomedical research. These developments are significant in a number of ways but three consequences of relevance to this study are: (1) the current primacy of biomedical research over other kinds of research for mental health; (2) the impact of problems ascertaining phenotype²⁹ on the need for participants; and (3) the effect on the identities and subjectivities of participants, their willingness to take part in psychiatric genetic research and how this affects their relationships with researchers and recruiters.

The prioritisation of particular kinds of research ties in with government plans for the UK to compete within the global biomedical and life sciences industry (Adams and McKeivitt 2015); science has acquired strategic political value in which the future-oriented expectations from scientific research also has political and economic currency (Borup et al. 2006). The promise of science is therefore not just about realising public health benefits from science but about realising the public financial investment (Murtagh et al. 2011).

²⁸ The description of mental ill health as a burden has become regularly used within the presentation of national and global statistics, as it has for all diseases and conditions.

²⁹ A phenotype refers to an organism's observed physical and biochemical characteristics influenced by the environment and/or genotype, the DNA sequence of an organism (Health Education England 2019).

Additionally, within the UK, the process of gaining access to mental health services affects what it means to have a particular psychiatric condition. A perceived hierarchy of disease severity leads to potential patients actively seeking to 'upgrade' their diagnosis from a moralised psychological behaviour to a more medicalised condition, believed to hold greater legitimacy and currency within the help-seeking process of mental health services in the UK (Grue et al. 2015; Lane 2019). The impact of psychiatric conditions and their categorisations has become linked with their economic 'burden' to the UK and whether the UK workforce is able to compete within a globally functioning economy and government (Wahlberg and Rose 2015). These effects on diagnostic categorising are important, not only within mental health care but also within psychiatric genetic research because analyses depend on phenotypic as well as genotypic data and problems with phenotypic classification persist, affecting the validity of the phenotype and adding to the complexity of understanding these conditions (Owen and Cardno 1999; Burmeister et al. 2008; Merikangas and Merikangas 2019).

Michael Arribas-Ayllon and colleagues (Arribas-Ayllon et al. 2010; Arribas-Ayllon et al. 2019) argue that the rhetoric of complexity by researchers has allowed psychiatric genetic research to be resilient to uncertainty and criticism in order to maintain a reconstruction of promises and marshalling of resources. Psychiatric genetic research has needed a relationship with its multitude of public groups to attract funding, and to raise and maintain its status as a discipline, but also, crucially, to recruit research participants who donate a blood sample and complete a questionnaire about their condition. Researchers need large numbers of participants in order to explore the scientific complexity of the conditions, which is further complicated by the politics of diagnosis. Furthermore, increases in the scope of the genetic material that the researchers are investigating, involving small effects across a multitude of genes, has also increased the number of participants needed such that the whole process of participant recruitment has had to be dramatically up-scaled. Consequently, psychiatric genetic research has become 'big biology'

(Weinberg 1961; Weinberg 1999) in which research participation and recruitment are now a fundamental component.

However, unlike the physics kind of 'big science' in which the large physical scale of its apparatus is a key aspect of what makes it big, what is important in the context of psychiatric genetic research is the contribution of the extremely large numbers of participants who are needed to give up time and tissue.³⁰ Big biology also emerged at a time of a new social contract³¹ between science and society in which the benefits from basic scientific research were no longer assumed and funding applications needed to demonstrate clear societal benefits (Vermeulen 2016). The idea of autonomous university researchers carrying out pure research to generate knowledge, from which societal applications were then identified, was being replaced by models of scientific knowledge production embedded within its societal applications and inseparable from its societal consequences (Gibbons 1999; Nowotny et al. 2003). Taking into account this history of psychiatric genetic research as a form of big biology, we can see how it has developed as a decentralised and necessarily collaborative kind of science that is not only reliant on, but is also increasingly held accountable *to*, society.

Consequently, psychiatric genetic research is not just a science of detailed laboratory work and biostatistical analysis, it is also explicitly a social endeavour, dependent on the considerable social interaction necessary in order to bring the required human data and human tissue into the research process and environment. Furthermore, this human data does not manifest itself in some neatly attainable way; it is hindered by a combination of a lack of awareness of such research,

³⁰ Additionally, big biology, of which the human genome project was the first example, relies on collaboration; in contrast to the large-scale physics projects already established at the time, the human genome project was funded and organised in a decentralised fashion in which funds were dispersed to support many small-scale research projects all contributing to the bigger goal of mapping the human genome (Balmer 1996; Kevles 1997; Vermeulen 2016).

³¹ I will discuss the social contract between science and society in greater detail in Chapter 8 but a brief definition is of an unwritten agreement regarding rights and responsibilities among individuals and groups in their social environment.

personal difficulties faced by individuals and specific barriers such as the stigma of psychiatric conditions and a suspicion of researchers (Woodall et al. 2010). One way to deal with these barriers and recruit participants is through public engagement and, in order to achieve a high number of participants, there are various social mechanisms³² that organisations may utilise such as public engagement events and the use of research champions who have already taken part and actively encourage others to do so. How people get in to psychiatric genetic research participation will be discussed in the next section but I would first like to discuss the sociological contributions to a word that has been used a lot when researchers motivate, and talk about, psychiatric genetic research participation: hope.

A social engineering based around hope?

As discussed above, psychiatric genetic research has grown as a discipline since its modest expansion as a form of big science in the 1960s, with key elements of its development resting firmly on ideas of hope and expectation. Arribas-Ayllon and colleagues (2019) describe the public engagement of psychiatric genetics as a form of social engineering based around hope. Utilising a rhetoric of complexity and cautious therapeutic optimism, researchers have been able to create imaginaries of hope in order to manage expectations, maintain hope and, therefore, support in the face of an uncertain future (Arribas-Ayllon et al. 2010; Lewis and Bartlett 2015). In the sociology of expectations, the 'future' is used as an analytical object that enables us to think about the work that the future, and associated concepts such as hope, do in terms of managing uncertainty and mobilising resources (Brown and Michael 2003). Imaginaries of hope also have to contend with competing future orientations and, for psychiatric genetic research, this is potentially a future in which biomedical approaches to treating mental illness have less of its current power.

³² By social mechanism, I mean entities and the activities surrounding them that regularly bring about change (Hedström and Yikoski 2010). An interest in social mechanisms is an interest in the explanatory power of social theory to analyse what causes social events rather than just providing a description.

What is particularly important here is that these are not just the imagined hopes and expectations of individuals, the social organisation of research participation is a systematic way of drawing people together, people who have a stake and input into this possible future. In this way, hope becomes collective. Returning to the work of Marcel Mauss (2002) and Nik Brown (2003), what is useful to think about is the idea that these expectations carry with them a value and as such can be exchanged or traded amongst the relationships that constitute this collective hope. Hope of better therapies in the future can be offered by researchers in exchange for information and tissue samples by participants in the present, who in turn can draw in other potential participants through their various networks. Drawing people together requires work and, in the context of psychiatric genetic research, funding was provided for ambitious public engagement programmes to engage with the various publics that it needed in order to carry out translational research,³³ not only to reach their potential participants but also those publics who might be a barrier to reaching those participants (Lewis and Bartlett 2015).

1.8 How do potential participants get into psychiatric genetic research and why do they participate?

Attitudinal studies suggest the UK population are generally enthusiastic about biomedical research, optimistic about genomic-based medications, support research that advances knowledge despite no immediate benefits, and would be very willing to allow access to their genetic and mental health information for research (Armstrong et al. 2007; Castell et al. 2014; Skinner and Shah 2014; Steen et al. 2019; BEIS 2020). However, these same studies also suggest that people have concerns about potential negative outcomes of scientific research including concerns about its governance, albeit to a lesser extent. Furthermore, public

³³ From the year 2000, the term ‘translational research’ gained traction as a way to place the perceived gap between biomedical research and clinical practice on government agendas (Butler 2008; Machado-Vieira 2012). In the UK, government funding for the Medical Research Council rapidly increased between 2007 and 2010 in order to fund translational research as a way to cross this “valley of death” and overcome the disconnect between basic biomedical research and the needs of patients (Butler 2008, p.840).

attitudes about genetic research, not just in the UK, have been found to be contradictory and highly contextual (Condit 2010) and participation “a highly varied social process with multiple meanings” (Haimes and Whong-Barr 2004, p. 57).

Existing understanding about why people may or may not participate in *psychiatric* genetic research is very limited. Much of our current understanding about why people would take part in psychiatric genetic research comes from studies about participating in genetic research for conditions other than mental illness or contributing to biobanks (for example, Hoeyer et al. 2004; Tutton 2007; Dixon-Woods and Tarrant 2009; Lipworth et al. 2011; Ryan et al. 2020). Only a limited number of studies have specific relevance to psychiatric genetic research participation (Trippitelli et al. 1998; Turney and Turner 2000; Jones et al. 2002; Illes et al. 2003; Meiser et al. 2005; Laegsgaard and Mors 2008; Rose et al. 2015).

There is a small amount of questionnaire-based research looking at attitudes towards biomedical research for psychiatric conditions, mostly based on people with a diagnosis of bipolar disorder as well as unaffected individuals. This has shown that, of people who responded, many were found to be in favour of psychiatric genetic research and generally in favour of genetic testing although much less so for prenatal testing (Trippitelli et al. 1998; Jones et al. 2002; Laegsgaard and Mors 2008).³⁴ A large-scale study in Germany found that members of the public, patients and families were generally favourable about psychiatric genetic research but with reservations about its applications; respondents felt that information from any testing should be kept private and had mixed feelings about the moral implications of prenatal testing and possible pregnancy terminations (Illes et al. 2003). Except for the study by Franciska Illes and colleagues, none of these studies provided the opportunity for qualitative data so the information gathered is restricted to whether or not respondents expressed a positive attitude to the statements on the questionnaire.

³⁴ Of these, the study by Laegsgaard and Mors was a larger study, although all the participants were pre-existing participants in a genetic study and presumably already in favour of psychiatric genetic research.

There has been a qualitative study based on in-depth interviews with pre-existing participants involved in a genetic study of bipolar disorder but this focused only on attitudes to genetic testing (Meiser et al. 2005). Attitudes were generally positive but demonstrated variations according to the test's predictive value and the treatability of the condition; there was little interest in prenatal testing. A further study asking six interested groups to speculate on the implication of improved genetic knowledge, specifically about schizophrenia, suggested a diversity of views across geneticists, psychiatrists, community psychiatric nurses, general practitioners, carers and people diagnosed with schizophrenia (Turney and Turner 2000). Other than the geneticists, other groups perceived the value of genetic information in contradictory ways, influenced by their view of the condition within a context of complex family struggles. These groups viewed the use of genetic testing with a sceptical willingness because of concerns about public attitudes, stigma and a step towards negative eugenics. Another study, exploring views of mental health service users and carers, demonstrated "considerable enthusiasm" for psychiatric biomarker research that might lead to stratified medicine and an interest in this kind of research participation, on the grounds of altruism (Rose et al. 2015). However, this same study also highlighted their concerns that biomarker research might be prioritised over research on psychosocial causation and treatments.

Although these studies provide some related information on overall attitudes towards psychiatric genetic research, the focus is often on genetic testing and we know very little about why people would take part or not, or what participation means to them. In their editorial review, Felicity Callard and Til Wykes (2009) called for more research into how causal beliefs about mental health problems affects willingness to participate in research involving biomarkers. We also know little about how this participation might come about so further research is needed to gain a greater understanding of how this is socially organised. Similarly, Singh (2015) has argued there is a gap in how we understand the way in which people with illness negotiate the decision to take part in a genetic database and, in turn, to participate in genetic research. In line with work by Dixon-Woods and Tarrant

(Dixon-Woods et al. 2008b; 2009) which demonstrates that participation is more socially organised, Singh's research suggests that decisions about participation are made based on the more macro-level structures and actions of policies and institutions that determine availability and access to services and care rather than traditional bioethical concerns related to the individual, i.e. those of informed consent, participant autonomy and privacy. Similarly, research in Sweden has previously called for attention to be diverted away from issues around the informed consent of individuals towards institutional and social factors that contribute to the diversity of donors' views (Hoeyer et al. 2005; Hoeyer and Lynöe 2006; Hoeyer 2010).

1.9 Conclusion

My review of the relevant literature demonstrates that psychiatric genetic research is increasingly significant as an area of sociological study, not just because of the important potential consequences of its science but because it is very much a social endeavour: public participation is crucial to its accomplishments. However, psychiatric genetic research as a discipline has a challenging relationship with its different publics because of its link to past and present controversies within both psychiatry and genetics.

Nevertheless, an increased demand for participants has necessitated much public engagement work which, for psychiatric genetic research, has been described as a form of social engineering based around hope (Arribas-Ayllon et al. 2019). Thinking about these issues through (broadly) sociological concepts of individualism, collectivism, citizenship, communitarianism and solidarity help bring to the fore what social challenges are faced by research recruitment and to consider what alternatives might be possible, and in need of further consideration and research. These debates are relevant for how participation and individuals are framed when recruiting the necessary human resources for psychiatric genetic research and, in

the context of this thesis, provide a conceptual framework against which to think about the socially organised features of different people's accounts of psychiatric genetic research participation.

The literature demonstrates that individuals' decision-making process of taking part in research is a socially negotiated experience and not necessarily based on a rational assessment of information provided in resources such as participant information leaflets and consent forms (Cox 2002; Sharp 2004; Dixon-Woods et al. 2007; Carter et al. 2015). Indeed, these resources have become viewed as 'symbolic tokens' of trustworthiness of the research process in which science, medicine, and publics are perceived as a hybrid community, relying on trust, solidarity, shared values, etiquette, and reciprocity, (Dixon-Woods et al. 2008b), (McDonald et al. 2008; Lemke et al. 2010)

The purpose of this chapter has been to provide relevant background to the area of psychiatric genetic research participation and to evaluate what has already been learnt about research participation generally, and specifically in the context of psychiatric genetic research participation. This has highlighted the limited number of in-depth qualitative studies relevant to psychiatric genetic research participation, especially studies that are able to understand participation from a variety of perspectives. Furthermore, we do not know how research participation is framed and organised in the specific context of psychiatric genetic research and thus there is a pressing need to empirically explore its processes and its politics.

This chapter has provided the context for the research including an evaluation of the relevant literature for psychiatric genetic research participation whereas Chapter 2 provides a historical sociology of the 'participant' and shows that, since the change in terminology from research 'subject', it now seems timely to ask what 'participant' might come to mean in the future. The end of Chapter 2 concludes with a justification for the study and a clear statement of the research questions. Chapter 3 details the methodology and justifies the use of Q methodology to produce and analyse the data. Chapter 4 presents an overview of the results,

demonstrating the elicitation of four distinct styles of thought³⁵ concerning psychiatric genetic research participation, broadly categorised as ‘untroubled’, ‘strategic’, ‘concerned’ and ‘cautious’. Chapters 5 to 8 explore the results in much greater detail, including interpretation of the data to produce four key findings. Taken together, the four styles of thought and the four findings suggest that psychiatric genetic research participation is undergoing change and moving away from appeals for altruistic donations that rely on autonomous informed consent. Chapter 9 discusses these results and findings, relating them back to the research questions and the relevant literature. From this I argue there is a need and appetite for exploring a solidarity-based conceptualisation of psychiatric genetic research participation, and I consider some implications of this for the governance of participation along with some final conclusions in Chapter 10.

³⁵ I have used the phrase ‘styles of thought’ to denote different groups of collective thinking and talking about psychiatric genetic research participation. This will be discussed in Chapter 4.

Chapter 2: Historical sociology of the research participant

2.1 Introduction

This chapter draws together literature on research participation in order to map out the historical developments that have enabled various re-framings of research participants as a particular kind of person. It provides a historical sociology of the research 'participant' as a kind of figure that appeared on the landscape of scientific, medical and health research in the UK since the late 1990s.

Up until the late 1990s, those in the UK who have taken part in research have been denoted as research 'subjects' but there has been a shift towards use of the term 'participants' (Corrigan and Tutton 2006). This chapter focuses on evaluating what the historical literature from the fields of STS, bioethics, health & social care research, and patient & public involvement can tell us about this development and how changes within science, the medical profession and society have led to the social production of 'participants' as particular kinds of people within a process of potentially competing and contradictory aims. Whilst acknowledging the multiple meanings assigned to the term 'participant', I pay particular attention to the view that people are a resource needing social mechanisms to initiate and maintain goodwill and the willingness to take part in research. In doing so, it should provide a framework to think about what being a psychiatric genetic research participant could come to mean in the future.

2.2 Participant as a historically rooted category and socially produced identity

In 2006, sociologists Corrigan and Tutton critically examined the shift in the UK from the use of the term research 'subject' to research 'participant'. Acknowledging the mainstream use of 'participant' since 1998, Corrigan and Tutton proposed a guide for when it might be appropriate to use the terms participant or patient activist and

when it might be more appropriate to return to using the terms subject and healthy volunteer subject. In doing so, they brought attention to a turning point in the UK's development of participant as a historically rooted category but, more significantly, in the reframing of and resistance to what it means to *be* a participant.

The year 1998 is significant because this is when a UK advisory group set out the aims and values of 'consumer' involvement in the NHS research and development programme (NHS_Executive 1998). The advisory group was establishing itself during a political transition between conservative and labour governments in 1997, when market-led competition was seen by both governments as a way to modernise the NHS, providing patients with consumer choice. The advisory group was to provide independent advice to the NHS on "the best ways to involve consumers" and represent their interests "at the very heart of NHS decision-making about research" (ibid, p.4).

The authors of the report recognised there was a problem in having to use a single word in order to define a collection of people to be involved in the research process but decided to use 'consumer' in preference to the existing terms of 'user' and 'lay person'. Importantly at the time, the term 'consumer' signified that these NHS users were presented as, and possibly perceived themselves as, having rights in a similar way to consumers of products and services. Furthermore, the very use of the term 'consumer' highlights the nature of the relationship between NHS management and those using NHS services at that time, existing as it did within a shifting policy landscape governed just as much by political and economic considerations as by health care (Mold 2010). Government thinking had been promoting an increase in the role of the private sector within society in order to reduce spending by the welfare state and this thinking proliferated into most aspects of UK policy and society. The advisory group report made a distinction between 'subjects' of research and people with an active involvement in research, who contribute to decisions about the research process. However, the semantic lack of a single noun to denote 'involved people' was problematic and this may be why research 'participants' later became the preferred terminology.

Despite the 1998 advisory group calling for a commitment to involve people as *active* participants in the research process as opposed to simply being ‘subjects’ of research, some responses to this recommendation focused more narrowly on the terminology of what people should be called (see Boynton 1998; Chalmers 1999; Jackson 1999). In order to align research practices with the recommendations of the NHS advisory group, Petra Boynton called for changes in terminology by highlighting that 99% of the previous year’s Medline abstracts of international biomedical journal articles used the term ‘subjects’ rather than ‘participants’. Although Boynton claimed this change was needed to “reflect the role of people in the research process” (Boynton 1998, p. 1521), there was little reflection on, nor evidencing of, whether those roles did indeed represent active *involvement* in the research process. Boynton’s article was published in the *British Medical Journal* (BMJ), and simultaneously endorsed, by its then editor.

Iain Chalmers, the then director of the NHS Research & Development Centre, congratulated the BMJ’s subsequent decision to change to using ‘participant’ in their publications (1999), but his reflections on his apparent lack of ability to persuade other people to change in the ten years prior seem to be misguided. Chalmers’ long career in health services research allowed him to draw on many compelling examples for why ‘lay people’ should be involved in all stages of the research process and this led him to suggest the need for gathering formal evidence to support this involvement taking place (Chalmers 1995). However, in the process of supporting this change from subject to participant, he confounds the very purpose of renaming. His argument for changing the name became focused instead on the need to give due respect to individuals for agreeing to be the subjects of research, rather than changing the name because it actually reflected a change in working practices whereby more people were involved in the research process itself (See Chalmers 1995, 1999). Chalmers did actually attempt to draw the campaign group ‘Consumers for Ethics in Research’ (CERES) into a debate about more suitable alternatives for the newly proposed term ‘participant’ but their ambivalence reflected the feeling, at that time, that the new term did not align with the number

of available opportunities for getting involved in research beyond simply giving consent as a research subject (see Chalmers 1999; Corrigan and Tutton 2006).

So, we see that, even at this early stage, there is a sense of misgiving in the appropriateness of the term 'participant', or rather in the appropriateness of its usage, and of a mismatch in what different parties might understand by the term as a concept. Therefore, critiquing this position within the medical and health research community, I argue these concerns about terminology glossed over an in-depth consideration of genuine public involvement and resulted in embracing only its sentiments. Indeed, in both 2001 and 2005, the Department of Health defined 'participants' within research governance to be "patients, users, relatives of the deceased, professional carers or members of the public *agreeing to take part in the study*" (DoH 2001, p. 20; 2005, p. 22). What is revealing is that these documents also include an acknowledgement that, in law, some of these same participants are known as subjects.

At the time of Boynton's BMJ publication calling for a change in terminology, some concerns were raised about the ambiguity of the term 'participant' and whether, in so using, authors to journals would profess the presence of a more involved form of participation despite a lack of substance to the claim (Jackson 1999). Such concerns appear to have gone unheeded given that, seven years later, sociologists were arguing that the mainstream acceptance of this term had taken place without due consideration of whether it reflected what was actually happening in practice (Corrigan and Tutton 2006). Indeed, on the basis of published articles, it appears that a seemingly small interaction between Boynton, Chalmers and the editor of the BMJ consolidated a change in practice that went almost completely unchallenged, at least publicly so. Consequently, the use of the term 'participant' became prolific in the publications and documents of various UK organisations related to research (for details, see Corrigan and Tutton 2006, pp. 101-102; Tutton 2007, p. 174).

In analysing the discourse of participation within the context of genetic databases, Tutton (2007) has highlighted a preference for the use of 'participant' over 'subject'

in the various academic literature such as that of bioethics, social science, and medicine. However, Tutton does not explicitly distinguish this use between the research cultures of different countries such as that of the UK and the US. In analysing the references in Tutton's statement about terminology preferences, those who have used 'subjects' are all researchers based in the US whereas those who have used 'participants' are primarily based in the UK and Europe. My reading³⁶ of research 'participation' literature to date concurs that the use of 'subject' has been retained in the US to a much greater extent than in the UK, thus reflecting the contextual nature of this change in terminology. In the US, the debate over subject versus participant persists, both in terms of terminology but also the role that distinguishes a subject from participant (Bromley et al. 2015).

In the ten years since Corrigan and Tutton suggested that the term research 'subject' be reinstated where appropriate, the favoured term has continued to be participant. This has not, however, been unproblematic. Those authors who have acknowledged the work of Corrigan and Tutton, have either reluctantly taken up the term 'participant' for pragmatic reasons of compatibility (See McDonald et al. 2008; McDonald and Cox 2009) or, in examples where US and UK researchers have collaborated, have favoured alternatives such as 'volunteer' in order to avoid the ambiguity caused by cross-country cultural differences in understandings of what 'participant' means (See, for example, Morris and Schneider 2010).

Looking back at the 1990s and 2000s, what is particularly significant about this shift in terminology in the UK is that the call for respect by Chalmers and others were an attempt to reframe the positioning of the research subject in the eyes of the research community and beyond, a position in which the research subject had increasingly come to be seen as vulnerable and exploited. Indeed, respect has been a key ethical consideration within informed consent procedures for clinical and medical research (Faden and Beauchamp 1986; Emanuel et al. 2000) and current

³⁶ This is limited to journal articles for the purposes of this PhD study rather than a systematic review of articles on research participation generally.

guidelines outline the need to respect an individual's decision on whether to take part, their privacy, and their right to withdraw without reason.

2.3 Reconfigured identities and reimagined relationships: Reframing the research 'subject' as vulnerable and exploited

In addition to the change in terminology of subject to participant, a more longstanding, though equally important historical development has been the reframing of the research subject as someone in need of autonomy³⁷, to freely and actively *choose* whether and how to take part in research. This choice is predicated on consent that is given as a result of understanding and evaluating information, provided by the relevant research organisation, on the benefits and risks involved, i.e. informed consent. Therefore, continuing to use the terminology of research subject, with its associated connotation that individuals are unwillingly or unwittingly *subjected* to research, would contradict the idea of a considered and voluntary action. Although there is some evidence that the act of gaining consent has taken place for centuries in a clinical setting and since the early 1900s in a research setting, the mobilisation of this in shaping legal judgements about research values towards human experimentation began in the US in 1914, with ethical codes concerning informed consent emerging after the Second World War (Faden and Beauchamp 1986; Jefford and Moore 2008). Bioethics is often country specific, addressing different topics and with different working practices, but the US has been considered to be the forerunner of both informed consent and the discipline of bioethics (Montgomery 2016).

One consequence of the 1947 Nuremberg trials, in which doctors were sentenced to death for their part in the Nazi's human experimentation on prisoners, was the formulation of a code of conduct. This code, which focused primarily on the need

³⁷ Philosophers have defined autonomy as a process of personal reflection to make self-directed choices but also to live life according to one's own values and standards, developed through an active engagement with societal forces and influences (Barclay 2000; Friedman 2000).

for consent to be voluntary and informed, became incorporated into US law in 1957 as a set of 'informed consent standards' (Jefford and Moore 2008). Further guidelines around the world, including the Declaration of Helsinki in 1964 and the Belmont Report in 1979, expanded the code to advocate both adequate protection from exploitation within *non*-therapeutic research and the opportunity for individuals to make the decision to take part without coercion or undue influence. The details of these developments have been discussed elsewhere (Faden and Beauchamp 1986; Emanuel et al. 2000; Berg et al. 2001; Jefford and Moore 2008; Rhodes 2010; Beauchamp 2011) and highlight the on-going debate and the contradictions that have arisen and still arise within issues of informed consent. Much of this debate concerns balancing idealism with the pragmatism of respecting autonomy, or rather, of *demonstrating* respect for autonomy, given that actual practice has been claimed to fall short of this ideal (Corrigan 2003; O'Neill 2003; Hoeyer et al. 2005; Koski 2010).

It is important to note that communitarians and feminist theorists have focussed much critical attention on autonomy and its meaning, claiming that autonomy has become confounded with individualism and promoted according to masculine ideals in a way that ignores the social and historical context in which a person might develop autonomy (for a historical discussion, see Mackenzie and Stoljar 2000a). Initial advocacy in the mid 20th century for patient autonomy as a means to overcome medical paternalism resulted in a narrow focus on individualised informed consent, detracting attention away from the effects of medical, social and familial practices and pressures on a person's capacity for autonomy (Dodds 2000).³⁸

³⁸ *Relational* autonomy, as an attempt to reconfigure the traditional concept of autonomy, can provide a focus on the complex socially embedded nature of the individual and on how relationships impact on a person's autonomous development (Mackenzie and Stoljar 2000; Donchin 2001; Christman 2004). This is relevant for the conceptualisation of research participation because reconfiguring autonomy in this way helps to foreground the need to think about what conditions and relationships promote or constrain autonomous capability, including the need to provide a more supportive framework when such conditions make the decision about research participation particularly challenging. Whilst relational autonomy has received much theoretical attention in the past, its practical application has, so far, been limited but is gaining attention (Dove 2017).

Consent based around ideas of being fully informed has its origins in both a legal and moral point of view, evolving from within the field of US medicine in and around the 1950s (Faden and Beauchamp 1986). The primary concern of US and UK medical ethics at that time was to maximize medical benefit to the patient through the careful management and disclosure of information to the patient in order to 'do no harm'. However, the possibility of lawsuits for damaging medical outcomes brought in a legal perspective on the need for informed consent and, in this respect, the focus was on protecting the practicing physician rather than the patient. Discussions concerning patient autonomy developed from the 1950s to the 1970s but there was still resistance from many physicians because of a prevailing paternalistic view that informed consent was inconsistent with good patient care. However, concerns in the 1960s in the US about the social implications of bioscience, such as the genetic modification of humans, and broader social concerns during the 1970s regarding civil and human rights is considered to have galvanised the development of US bioethics including that of medical ethics (Jecker et al. 2011; Evans 2012). In contrast to the initial more legal point of view that principally protected researchers and their organisations, attention was turning towards enabling choice for the individual based on the provision of information supplied by the relevant professional out of a moral rather than a legal duty.

Heightened public sensibilities towards unequal power relationships in the US galvanised the awareness of questionable experimental medical practices into US 'scandals', and the medical researchers' fear of public concerns became influential in the setting up of ethical committees in the US (Faden and Beauchamp 1986; Stark 2011). These concerns were not, however, in response to needs to protect research subjects but originated from the fear that funding would be withheld or that the funding bodies would be sued for unethical activities by grant-holders. Whilst the lawyers of funders at the US National Institutes of Health were keen to make grant-holders responsible for their own ethical conduct, research scientists resisted the imposition of gaining informed written consent but also the prospect of externally

imposed regulation. Instead, researchers set up local ethics committees that satisfied the legal concerns of funders whilst maintaining self-governance, thus basing their ethics upon the pre-existing moral code of medical practice.

Meanwhile, in the UK, the Nuremberg code of conduct had failed to have much of an impact on the medical profession who chose to introduce their own discretionary code in the midst of some rogue researchers prioritising research over patient wellbeing (Hazelgrove 2002). The Nuremberg code of conduct had laid the foundations for securing some international guiding principles of research ethics but not before research became “identified as a potentially deviant activity” distinct from that of medicine (Dixon-Woods and Ashcroft 2008, p. 382). Medical research became viewed separately from medical practice because it was perceived as increasingly risky and not complying with the accepted ethical conduct of medical practice. According to Mary Dixon-Woods and Richard Ashcroft (2008), encouraging the UK medical profession to regulate itself with respect to research had failed to provide sufficient protection for participants due to the persisting paternalistic nature of a medical profession that was unchallenged by dependent patients and a powerless government.

The Declaration of Helsinki by the World Medical Association and the CIOMS³⁹ guidelines had been drawn up as extra guidelines to protect those who take part in research. Official UK regulations on Research Ethics Committees began in 1991 and gradually developed to provide a research governance framework. Dixon-Woods (2011) suggests that a series of scandals resulted in the overthrow of UK medicine’s self-regulation but Adam Hedgecoe (2009a, 2016) argues that these regulatory changes occurred more because of funding related factors and that the impact of UK research scandals on the development of research ethics review has been limited. This evidence suggests that the initiation of the ethical review of research in the UK came about because of medical researchers’ needs to satisfy the ethical

³⁹ CIOMS is the Council for International Organizations of Medical Sciences, a nongovernmental organization established in 1949 to facilitate the international activities of the biomedical sciences.

requirements within US funding bids rather than as a result of widespread UK public concern about medical research (Hedgecoe 2009a). In doing so, the conduct of UK research has shifted over time from an internal reliance on moral codes of conduct, borrowed from general medical practice, to externally regulated safeguards deemed necessary to protect the public from possible misconduct but, primarily, to fulfil the stipulations of funding bids.

Over the period of these developments, the UK government's Department of Health (DoH) had initially attempted to distance itself from the responsibility of ethical governance and made clear their opinion that ethical decisions were to be made solely by the medical profession (Hedgecoe 2016). However, standardisation of ethics arising from concerns about the lack of patient consent for research related practices taking place in *clinics* was then extended to research ethics in general. This resulted in increased procedural work for researchers and tensions arose in the 1980s because of discussions about the need to alleviate the burden of overregulation on researchers; these tensions between protecting participants and regulating researchers have persisted (Coleman et al. 2003; Shaw et al. 2005; Koski 2010; Salman et al. 2014).

By considering these historical developments, we see that changing guidelines on informed consent and associated debates have been important for shaping the production of research participants as either needing or gaining a greater say over their own bodies, at least from the perspective of the participant. From the perspective of the researchers, the literature above suggests that instigation and development of informed consent has produced a somewhat different framing. From within research, instead of being a system designed to respect the autonomy of those taking part, informed consent has become seen as a complex burdensome system. It is also a system that has developed under a resistant medical paternalism, the profession's social norms of self-governance, and the requirement to negotiate with funding bodies. So, whilst the view for participants may be one of greater autonomy, others may see the system as bureaucratic and self-serving.

Nancy Campbell and Laura Stark (2015) have argued that the civil rights movements of the 1960s and the bioethics debates of the 1970s served to reframe people as vulnerable and exploited; their argument is important for thinking about the development of 'participant' from the subjects' position. These movements and debates allowed some people to reconfigure their relationship to research and reconstruct their identities such that what it then meant to be a 'subject' was a production of those historically reconfigured social interactions. Consequently, this then potentially changes how those people behave. This is what Ian Hacking refers to as the "looping effect" (Hacking 1995) in which people become aware of the category and the criteria through which they are being categorised and subsequently, deliberately or subconsciously, change their behaviour. This, in turn, changes the category and the ways in which people might then intervene in aspects of the category. These are then 'kinds of people', but specifically what Hacking refers to as 'human kinds' in which their properties are constructed and reconstructed in the process of making up particular categories of people, kinds that do not naturally exist but are contextually specific (Hacking 1986; Hacking 2007). So, research subjects became reframed by civil rights movements and bioethical debates as vulnerable and exploited, in need of autonomy and, after the change of title to participants, anticipated to be in demand of greater involvement in the research process.

Around the same time as this reframing of the research *subject* as someone who was vulnerable and exploited, what it meant to be an active *participant* was emerging. Publics are known to organise themselves around techno-scientific objects and "matters of concern" (Jasanoff 2014, p. 23) and, in the US, particular forms of civil rights movements, such as the 1980s activism by AIDS patients, demonstrated that people were extremely capable of exercising their rights in the face of scientific and medical power. AIDS activists mobilised large and effective demonstrations to communicate and claim what they considered to be their ethical right to assume the risk of scientifically unproven treatments in the face of terminal illness (Epstein 1995, 1996). This was a challenge to the traditional relationship between researchers and research subjects. However, AIDS activists, rather than

using traditional strategies of political activism to ‘confront’ expertise, developed ways of presenting and demonstrating themselves as credible sources of knowledge. In doing so, they gained sufficient competence to align themselves with the scientists whilst clearly signalling they represented a large collective who could, if necessary, withhold participation in research trials. The activists’ arguments and strategies were morally and scientifically justified, powerfully presented and difficult to discredit.

The “legacy of AIDS activism” has been that alternative modes of working are possible for knowledge building that do not need to conform to hierarchical constructs of power that has been the dominant view of relationships with science (Epstein 1996, pp. 346-353). Consequently, AIDS activism provided a model for other health-related activists on how to engage with and democratise biomedical science and reconfigure what being a research ‘subject’ *could* mean in the production of scientific knowledge. It also demonstrated that patients had a voice, a voice that had a newfound power that could be heard above that of the research community and was widely disseminated as a model for other patient activism through the increased use of digital media (Petersen et al. 2019). Nevertheless, whilst participants play a role in shaping the active participant so can governments and research organisations.

In the 1980s, the framing of people as active citizens was widespread within government policies and practices in the UK, (Marinetti 2003). However, community involvement and citizenship, so the argument goes, have become a strategizing tool and form of political rhetoric, allowing governments to carry out their duties with legitimised authority whilst deliberately shaping the dispersed activities within society rather than under the more obvious appearance of interventions coming from a centralised state (Marinetti 2003; Tutton 2007). This opened up the opportunity for the research participant to be reframed as an active *citizen*. Indeed, the uncritical displacement in the use of ‘consumer’ and ‘subject’ to a seemingly active but often more misleading and ambiguous terminology of ‘participant’ also reflected the workings of government policy that had been taking

place on a wider scale within the UK (Mold 2010). This idea of the self-governing individual was also set against a backdrop of strained science-public relations throughout the 1990's due to the BSE crisis and public concerns over GMO's⁴⁰ alongside the government's drive towards greater transparency on scientific evidence within policy decisions and the growing rhetoric of public engagement, participation and involvement (Irwin 2001, 2006, 2014).

Internationally, public consultation and participation for scientific and technological decision-making was gaining increasing interest, although the political context within each country meant there were variations in the speed at which this occurred (Einsiedel and Kamara 2006). In recent years, STS has reflected greatly on the question of increased participation and asked for what kinds of decisions is public participation appropriate and at what phase(s) of S&T development (Collins and Evans 2007; Irwin 2014). The key question, according to much of this literature, is whether the people involved have sufficient expertise and interest. In the UK, controversy within public participation has been both higher than in most countries and also highly visible, with criticisms from some sociologists arguing that public deliberation has consisted of appeasing and *placating* rather than that of genuine deliberative consultation (Einsiedel and Kamara 2006); a process viewed as public relations exercises for decisions already made. Within the context of psychiatric genetic research, there have been calls to move from this rhetoric towards implementing and evaluating the involvement of service users and patients in all phases of research, including the initial phases, normally reserved for scientists and funding bodies (Baart and Abma 2011; Callard et al. 2011). However, such involvement was found to be limited and lacking adequate support and investment.

⁴⁰ These strained science-public relations were largely as a result of how the science was mediated and implemented by politicians (see Irwin 2001 for details). The Bovine Spongiform Encephalopathy (BSE) or "mad cow" crisis spanned the late 1980s through the 1990s, quickly followed by public concerns about food safety in relation to genetically modified organisms (GMO's). Politicians dismissed public concerns as irrational and emotional, thus reflecting poorly managed relations between the public and politicians' use of scientific advice. By the late 1990s, the UK government underwent significant changes in its commitments towards greater openness, public dialogue, and public participation regarding scientific developments and uncertainties.

It highlighted the disengaged attitudes of researchers towards patient involvement, researchers who were happy with the vision of involvement but not when it needed to be put into practice (Abma et al. 2015).

Returning to the work of Corrigan and Tutton (2006) and thinking about their work in relation to the above mentioned developments, their empirical evidence suggests that enthusiasm for participant ‘involvement’ was predicated on the need for maintaining willing recruitment to research projects rather than researchers acknowledging its democratic value and potential for improving the quality of research. Furthermore, the enthusiasm for a more respectful, and seemingly more involved, terminology may have been largely sustained by this increased need for recruitment. One field of research we can learn from is health and social care research, in which involvement has been heavily advocated and evaluated.

2.4 Participation as involvement and the rejection of ‘participant’: The view from health and social care research

Within health and social care research, ideas about patient input, public participation (PP), patient and public involvement (PPI), and public involvement activities (PIA) have been heavily utilised, rapidly expanding from around the early 2000s, and also explored in great depth (see Brett et al. 2014 for a review). This is because participatory or action research has gained a strong holding within areas of research that are closely tied to services. Practitioners within this field are keen to develop best practice about how to utilise experiential knowledge from service users but also tend to have a different kind of relationship with public groups, possibly because they wield less authority than researchers within the field of medicine. Involving people and communities within the process of carrying out research on the provision of services is grounded in the idea that experiential knowledge can provide useful expertise that potentially adds value to the research design and outcomes.

From the late 1990s, the UK government's NHS reforms encouraged the involvement of patients and publics in various aspects of the research process, resulting in the proliferation of activities and producing the ideal of an active and involved participant within health and social care research (Mold 2010). However, differential uptake and problematic definitions of the role of participants hindered the realisation of this ideal (Williamson 2014; Madden and Speed 2017). Meaningful involvement has been described as rare with many activities regarded as "window dressing", resulting in calls for involvement to be taken more seriously or risk "tokenism" (Wilson et al. 2011, p. 603; Snape et al. 2014, p. 1). As such, the literature in this field suggests that the weak evidence base for its efficacy has compromised the support for PPI (Staniszewska and Denegri 2013; Pollard et al. 2015; Knaapen and Lehoux 2016). Consequently, there have been greater efforts to evidence the beneficial impact of participation on research quality and the generation of new knowledge, over and above the benefits of empowerment to those involved as participant researchers.

Nevertheless, INVOLVE⁴¹ and other government led initiatives for increasing involvement in research have meant that PPI has been increasingly prolific in the UK on the *assumption* that it is beneficial to research (Staniszewska and Denegri 2013; Pollard et al. 2015). My reading of INVOLVE related online documents and strategic plans, spanning 2001-2016, shows that in 2001 there was still much disagreement about both the terms 'consumer' and 'involvement' with a particular dislike for consumer. By 2007 the strategic plan had moved to using the term 'public' involvement. From this we see that research participation, in the specific field of health and social care research, acquired the alternative terminology of 'involvement' by referring to participation as Patient and Public Involvement (PPI) and Public Involvement Activities (PIA) and less so as Public Participation (PP). This can be viewed as a rejection of the term 'participant', possibly because of its ambiguity but also because it still conjures up a passive attitude towards research.

⁴¹ INVOLVE is a UK national advisory group funded by the National Institute for Health Research (NIHR). The purpose is to promote public involvement in NHS, public health and social care research. It evolved from the 1996 'Consumers in NHS Research' group and became part of NIHR in 2006.

Significantly, by 2016, INVOLVE's strategic plans and the language of involvement within health and social care research was then clearly shifting towards that of 'partnership' and 'co-production'. However, as Oli Williams and colleagues warn, co-production is another term that risks misappropriation as a result of an "appetite for participatory research practice and increased emphasis on partnership working" (Williams et al. 2020, p. 1).

What this means is that, on a wider scale, the persisting calls for rigour and a stronger evidence-base after twenty years of participatory research involvement opens up the question of how and why the rhetoric of public participation has been sustained up until this point. Despite its weak evidence base (Brett et al. 2014), involvement as a form of participation is still being pushed forward by funding bodies and through government policies and initiatives. A similar question to this has also been raised by sociologists Mary Madden and Ewen Speed (2017, p. 3) who have asked why the drive for PPI has become ubiquitous "despite this on-going lack of clarity about its practices, processes, and means of evaluation".

The view from health and social care research, therefore, suggests that the trajectory of government led initiatives regarding greater input in the research process does not depend on the evidence base of its efficacy. Furthermore, we have seen that the terminology of 'participant' is not fixed in time other than its emergence in 1998 and its terminology, nor the validity of its meaning, has not been settled. However, one particular and more universal framing for what it means to be a research participant that has received a lot of sociological attention has been the becoming of participant as responsible citizen.

2.5 Development of the empowered autonomous responsible citizen

As outlined in Chapter 1, a further development since the late 1990s has been the framing of the participant as an autonomous *citizen* with rights and responsibilities. Contemporary use of the term citizenship invokes ideas of non-passive ways of

existing within a larger group whilst having individual responsibilities towards a collective infrastructure such as the welfare state. Drives towards the production of the empowered autonomous responsible citizen have been discussed in both scientific and health research.

In the late 1990s, sociological interest was emerging about the possibility of new forms of identity related to citizenship. Particularly relevant are claims that were made about the significance of biological, and specifically genetic, ways of understanding human life but also the politics of life, its social organisation and effect on people's identities and subjectivities. Ian Hacking, Paul Rabinow, Carlos Novas and Nikolas Rose were particularly influential in thinking about how the biological and social interact to constitute individual and collective identities. The role of the biosciences in potentially creating new categories, groupings and the 'making up' of people had been predicted to have a profound effect on the future of self-identity and the social relationships that might develop amongst the people acquiring this new identity (Rabinow 1996; Hacking 2006; Gibbon and Novas 2008).

Rabinow (1996) had argued, following the Human Genome Project, that genetic risk markers for disease might prompt people to think of themselves as a particular kind of person such that new social groups would gather on the basis of genetic risk, rather than some already manifested disease or condition. Rabinow named this 'biosociality' and used it as a concept to think with, at a time of considerable technoscientific changes to our understandings of disease (Gibbon and Novas 2008). Hacking, on the other hand, focused much more on how new biological contributions to classifications bring into being a new kind of person who is conceived of, and who experiences a particular way to be, that kind of person. Work related to this was that of Novas and Rose who focused on the impact of biological science on identity and personhood and how these ideas potentially added to existing theorising about citizenship and citizens.

The term biocitizenship, or biological citizenship, emerged in the early 2000s after Adriana Petryna (2002) used it to describe how individuals, in the wake of the

Chernobyl disaster in 1986, exercised their rights on the basis of a biologically damaged status in order to make claims to medical care and state welfare. Some form of liberal democracy and harsh market-led forces were co-emerging in the Ukraine at that time, providing the circumstances for the production of an active biological citizen, contextualised as a consumer with individual rights. Early attempts to define biological citizenship postulated not only the uniqueness of biological information in affecting identity and gathering people together but also its dominance. Biological and genetic citizenship were also used in order to describe individual contributions towards collective action and became associated with individual empowerment and activism. New alliances were formed between patients, families, scientists and biotech companies, for example, activists lobbying government to increase genetic research funds or working alongside researchers to fast-track the research (Leach et al. 2005; Rose and Novas 2005; Heath et al. 2007).

In their conceptualisation of biological citizenship, Rose and Novas (2005) described its action as both collectivising and individualising. The individualising action works whereby individuals see and conduct themselves more and more in biological terms. In the context of both genetics and citizenship, the argument goes that when a condition is described as having a genetic component, it invokes consideration of 'genetic responsibility' within the individual that is both personal and familial, including present and future family (Novas and Rose 2000; Leefmann et al. 2017).

Critics had argued that 'new medical genetics' was leading to undue focus on the isolated individual but Novas and Rose disagreed, commenting that the impact of genetic thinking on identity "has to be located in a more complex field of identity practices" (Novas and Rose 2000, p. 491). Significantly, Novas and Rose argued that these individuals, 'genetically at risk', would interact with networks not of society but of community. In doing so, Novas and Rose attempted to make a distinction between the two and how the individual would interact with community level networks in order to navigate their choices, responsibilities, and obligations. However, they also described these genetic practices of selfhood as allied to "contemporary norms of selfhood that stress autonomy, self-actualization,

prudence, responsibility and choice". Consequently, this aligned their position more so with an idea of citizenship that has been seen as problematic for people not in a position to actualize those choices and responsibilities (Plows and Boddington 2006). Individuals may not be able to, or *feel* able to, engage with their communities. Similarly, those communities may no longer exist, if indeed they ever did.

Some scholars have argued that biological citizenship is a broad concept applied with varying meanings, most likely as a result of its emergence from various disciplinary sources around the same time (Plows and Boddington 2006; Cooter 2008). Its definition by Rose and Novas (2005), was criticised as reductionist and overly optimistic, overlooking the complexity of multiple publics and their relationships to biomedicine and biotechnology, that risked being co-opted by biotechnology, "serving to create and amplify inequalities" (Plows and Boddington 2006). Rose and Novas themselves pointed out that not all citizenship is equal and similar points have been made that genetic citizenship may constrain as well as facilitate democratic possibilities (Heath et al. 2007). Similarly, the concept of genetic responsibility has also been criticised as vague with a multiplicity of meanings, many of which relate to ideas of more general 'responsibilisation' in which individual 'citizens' are encouraged to take action upon themselves rather than relying on the centralised action of government to manage health care and risks (Leefmann et al. 2017).

Biocitizenship as a concept then came to be understood more generally as a form of identity in which individuals not only actively mobilised around some common biomedical identity, with rights and responsibilities, but did so within the context of changes in the traditional understanding of citizenship and a more consumer-driven culture of choice (Kerr 2003; Rose and Novas 2005). However, this economic climate of choice was also emerging within the existing structure of the welfare state and NHS and, as we will see, the opportunity and choice of citizenship sits uncomfortably with existing ideas of duty and obligation.

In line with government led initiatives to promote involvement in research, as described in the previous section and in Chapter 1, the UK's National Institute for Health Research (NIHR) has, over the last decade, also encouraged people to take part in research. This is to help develop a culture of research and to increase participation rates and has included extra staff funding for UK hospital trusts to identify and approach patients about research opportunities (Wienroth et al. 2018; Wienroth et al. 2019). At the same time, NHS healthcare delivery has been realigned as a means to generate income in response to the precarity of NHS funding but also as an opportunity to generate public money within a competitive global market. A document analysis of sources related to NIHR recruitment campaigns concluded that NHS patients have been framed as having entitlements and benefits as both a resource and an asset (Wienroth et al. 2019). In their analysis, the authors demonstrate that research participation is appealed to in exchange for the consumption of NHS services, thus setting up a contractual obligation. Highlighting that being an NHS patient means individuals are also part of the NHS research system facilitates this obligation. The possibility to help save lives is then promulgated as a moral advantage to participants but, as a citizen, these same individuals are framed as having a *right* to know about the opportunity to participate and be empowered through their involvement in research, as well as having a shared responsibility with researchers and government to, as stated in the NIHR's mission statement, "improve the health and wealth of the nation through research" (NIHR 2006). Ideas of rights, opportunities and responsibilities then compete with the pre-existing ideas of contractual duties and obligations. As discussed in Chapter 1, citizens have minimal responsibilities. Though confusing and nuanced, these distinctions are important and significant.

Additionally, attention has turned away from governing the health of the population and governments have recalibrated their sights on the economic contribution of individuals' biological characteristics, their 'biovalue' (Waldby 2002) or, more specifically, the knowledge-value to be generated from the biological

material of individuals⁴². These biological materials and the associated structures and labours of knowledge production are assets waiting to be realised and, as such, hold potential economic value that may, in the future, be translated into a commodity (Birch and Tyfield 2013). This is something that psychiatric genetic researchers, who are familiar with the need to justify resources to fund research, may be more aware of compared to their potential participants. As such, potential participants may not appreciate the biovalue of their donations to research and may not see themselves as involved in an economic transaction. On the other hand, there is evidence that some participants are aware of the potential commercial value of their participation in biobanks, lending support for arguments that biobanks need to consider their reciprocity towards participants (Busby 2006; Haddow et al. 2007).

As research participants, most patients and publics in the UK therefore provide free or barely-remunerated labour, either knowingly or unknowingly, for generating revenue through research knowledge production and then transfer ownership of this asset to the NHS. Patients and publics are not encouraged to see themselves as providing economic value to the NHS but rather to actively benefit the research system and public good on moral grounds as part of an obligation in exchange for their consumption of NHS services.

Therefore, calls for people to contribute to the public good under the existing social contract embedded in the NHS sit alongside this relatively recent construction of participants as active, empowered, responsible citizens. And yet, Corrigan has suggested that despite the historical transition in perception of the participant as passive subject, through vulnerable victim, to empowered autonomous citizen, individuals come to inhabit all three of these at some point during the participation process (Corrigan 2004). This can partly be explained by Tutton (2007) who has

⁴² STS derived conceptualisations of biovalue, bioeconomy, biocapital and 'life as surplus' have been criticised by Birch and Tyfield (2013) for a fetishisation of the 'bio' and under-theorising without due attention to pre-existing economic understandings of value, economy and capital. Although I disagree with aspects of their critique, their perspective provides a useful specificity to these concepts.

suggested that the shift in the perception of research ‘participants’ as active partners rather than as passive subjects, and the nature in which that perception has been constructed, is an institutional response to public ambivalence towards the value of scientific research and public distrust in those institutions. According to Tutton, this response has involved a borrowing of the language of citizenship to alleviate some of this ambivalence; yet it might also be said that an act of citizenship enables the co-option of a sense of responsibility to the state or UK population at large and directs the request for participation away from the institution itself. This might be especially important for institutions and organisations that have a troubled relationship with their publics.

2.6 Citizenship: the rejection of responsibility and the possibility of opportunity within research participation

One aspect of citizenship is the idea that individuals have responsibilities as well as rights. However, in the context of research participation, Klaus Hoeyer (2003) and Ulrike Felt and colleagues (2009) have argued that there is a resistance to the imposed responsibility that informed consent procedures administer. Based on fieldwork in Sweden, Hoeyer found that consent to take part in a genetic study did not revolve around a considered response to the information sheet but around a sense of obligation towards the generalised need for research and a duty towards helping others. Based on his observations, he concluded that when donors did not read the information sheet, it was a way of absolving themselves from adjudicating on whether the research is good or bad, rather than having to assume the less desirable responsibility of no research by refusing to donate. Reading and assessing the information would place them in a dilemma of either not contributing at all or having to evaluate and judge the research; participating without taking on the information therefore produces a route out of this dilemma. Consequently, donating in that manner absolves participants of taking on this moral responsibility but, looking at it from this perspective, they are neither active nor citizens. Indeed, offloading responsibility to individuals through a process of informed consent

ignores the lack of capacity or interest that is required to become an informed decision-maker, and simultaneously prioritises the autonomy of the individual.

However, even if the information sheet is read, the rights and responsibilities of individuals implicit within the informed consent process have been regarded as insufficient when it comes to promoting the public good. According to Sue Weldon (2004, p. 168), the process requires an additional duty in which the individual is a member of society with “an active role in promoting wider social interests”. She argues that, to participate as active citizens, there needs to be a role created alongside researchers in order for a negotiation to take place to determine science’s license to practice. From this view, research participants cannot be seen as responsible active citizens simply by giving informed consent. However, it remains unclear what these wider social interests refer to and whether ideas associated with citizenship, as it has developed, are still appropriate.

Such issues with the informed consent process, and the shortcomings of genuine active involvement, problematise the proffered concept of participant as citizen. Consequently, critical understandings of the usage of citizenship, its appropriation and the way it has developed under market forces, make the ‘citizen’ an unlikely candidate for participant identity in future visions of how to proceed with research participation if pursuit of the public good is the aim. We have seen that citizenship has become characterised by autonomy and a consumer-driven culture of choice. Therefore, in the context of genetic research, even when there is a focus on the responsibilities of the active citizen, this is done so within the context of their rights, entitlements and the economic value of their contribution to research projects and biobanks. In this way, participants potentially view themselves, and are constructed and viewed as, involved in an enterprise of goods, services, and business rather than as altruistic donors (Tutton and Prainsack 2011).

This particular entrepreneurial kind of participant subjectivity potentially competes with other subjectivities such that the rights and opportunities of the individual are prioritised over the public good, fundamentally changing the relationship the

traditional participant has with research. Tutton and Prainsack (2011) demonstrate how the different subjectivities of enterprising and altruistic selves are constituted by comparing recruitment practices between the commercial model of research participation by US company 23andMe and the publicly funded population based UK Biobank. Altruistic selves, constituted by the terms of conditions to participate in the UK Biobank, give freely and expect nothing in return. On the other hand, the enterprising self in 23andMe takes part in a commercial transaction and sees themselves as a consumer and entrepreneur entangled within ideas of an empowering democratised rights-based alternative to traditional research knowledge generation. What Tutton and Prainsack's analysis of these recruitment practices shows is the way in which commercial initiatives such as 23andMe facilitate a platform and process whereby benefits for the individual and helping others are not necessarily mutually exclusive endeavours and that the individual's relationship to research is framed as one in which they are in control by voting on prioritising health research directions. What is not clear though is how dependent the success of this symbiotic interchange between enterprising and altruistic selves is on the capacity of potential participants to enact the enterprising component, given that these activities require funds and access to the platform.

Such issues about capacity are not restricted to commercial approaches to recruiting to research. Changes in how research is organised has led to changes in how informed consent is practiced and broad consent for any future research, such as that practiced by UK Biobank, has raised concerns about whether this reduces participants' trust in the process. Technology-facilitated dynamic forms of consent, that allow an on-going relationship between research and participant, purport to enable active empowered informed participants within a transparent system (Kaye et al. 2012) but have significant challenges to overcome in terms of the inherent assumptions made about IT literacy, affordability, and motivation on the side of participants.

2.7 The multiplicity of 'participant' ...

As we have seen, the single term 'participant' has a challenging job when representing people's level of commitment and relationship to the research endeavour in addition to their disease status and social identity from other aspects of their lives. This demonstrates that the terminology of taking part in research is complex and contextual; different fields of research and practice perceive participation and involvement differently, and also sometimes interchangeably. Even if it can be clearly defined within a group or field of research(ers), those outside may interpret the name very differently by bringing their own experiences and understandings to bear on its meaning. Interestingly, individuals who have worked alongside researchers will themselves have their own opinions about this differentiation between terminologies. For example, one research advocate of over 20 years recently described himself as a research 'collaborator', distinguishing this from simply being a participant which he sees as more aligned with the term research 'subject' (Mayer 2012). As this example demonstrates, the labelled may well come to reject the label of the labeller, even when the new terminology is considered to be more respectful.

Nina Hallowell and colleagues (2010) have pointed out, from their study of patient's motivations when participating in genetics-related research, that personal, familial and social motivations are interdependent, prompting the authors to conclude that debates based on the dichotomy of self versus other is too simplistic. So, when we think of individuals as certain kinds of participants, we should also try to understand what their reasons are for taking up or rejecting a particular identity and how it might overlap and compete with other aspects of their identity (Lehoux et al. 2012a). In addition to identities related to disease status, e.g. as patients, carers, patient activists, or healthy volunteers, individuals can be understood according to their relationship to the research process, e.g. as active, cost-benefit, passive or reluctant participants (Haines and Whong-Barr 2004).

As we have seen in this chapter, ethical debates and civil rights movements of the 1970s and 1980s created the opportunity for the participant to re-emerge as a particular kind of person, a vulnerable victim whose autonomy needed to be respected and privileged over the public good. This helped to transform the traditional research subject into a series of re-framings of the 'participant'. However, as the literature suggests, since the UK's renouncement of research 'subject' in 1998, research 'participation' and 'participant' have been variously and poorly conceptualised with a lack of clarity as to their purpose (Corrigan and Tutton 2006; Lehoux et al. 2012b; Martin 2012; Rose 2014), particularly when considering the generation and quality of new knowledge. Defining what is meant by the term participant has been problematic, often with a lack of distinction made between individuals as patient, service user, carer, interest group member, or disinterested citizen (tax-payer or otherwise) (Martin 2012; Hainz and Strech 2014).

2.8 Conclusion

Since the late 1990s, there has been a shift in the UK from the use of the term research 'subject' to research 'participant'. Subsequent advocacy by the NHS and the *British Medical Journal*, a lack of suitable alternatives, and widespread uncritical adoption of the term 'participant' has since led to a prolific increase in its usage. Its ambiguity has led to a problematic diversification in its meaning within different research contexts and according to different socio-political motivations.

Over the last thirty years, government initiatives and many research organisations have promoted public engagement, scientific citizenship, and involvement in research as democratising and empowering. Scholarship within STS argues that many initiatives have been institutional strategies to increase participation in research and carry on with business as usual; evidence from public involvement activities in health and social care research also suggests this is so. Similarly, the traditional form of informed consent as a means of giving participants control over whether or not to participate in research has been described as ethically empty, bureaucratic, burdensome, a façade and imposition.

Over time, participants have been viewed as needing respect for their autonomy and protecting from harm but have also been framed as active citizens with rights and responsibilities, as involved research partners, or as entrepreneurs. In this chapter, I have discussed how the framing of participant as citizen, in the way that citizenship has developed and come to be understood, creates a tension within the UK's existing welfare state. The conflation of responsibility within a citizenship framing and obligation within the pre-existing framing of the NHS and its social contract has become problematic.

As discussed in Chapter 1, previous empirical studies on (genetic) research participation suggest the need for greater understanding of the social processes taking place within the decision to participate, or cooperate, in research (Dixon-Woods and Tarrant 2009; Hallowell et al. 2010; Singh 2015). This current chapter

has provided a historical sociology of the research 'participant' and an understanding of how the concept has been shaped by individuals, societal events, governments and research organisations. Given the various framings of the research participant over the last twenty years and the outstanding need for specific kinds of participants in psychiatric genetic research, despite an intensive period of public engagement, it seems timely to ask what 'participant' in this particular context might come to mean in the future.

In this study, I explore why some (potential) participants are keen to take part in psychiatric genetic research whereas others resist, or refuse, and then move onto considering how this is affected by social mechanisms related to research participation. In doing so, this empirical exploration will provide an analysis of the socially negotiated way into participation and ask how the future of psychiatric genetic research depends on what it means to be a participant.

Chapter 3: Methodology

3.1 Introduction

The following chapter makes clear the rationale for data collection and sets out an argument for the use of Q methodology to study the variety of subjective views about psychiatric genetic research participation. I begin the chapter by discussing what other research methods are available and justify the use of Q methodology before describing the various stages of data production and strategies to gather appropriate data. I detail the analytical approach and method of analysis along with reflections on their strengths and limitations, and on how the methodology has enabled me to answer the research questions.

Previous empirical studies on (genetic) research participation suggest the need for greater understanding of the social processes taking place within the decision to participate in, or cooperate with, research (Dixon-Woods et al. 2008b; Dixon-Woods and Tarrant 2009; Singh 2015) and such studies have generally produced social knowledge about participation as a result of conducting and analysing semi-structured interviews. To date, these studies have focused on understanding specific groups of individuals such as scientists, patients, or professionals. The distinctive aspect of this study is to bring these individuals together without any pre-conceived ideas that their views are to be understood from within the perspective of these groupings. Furthermore, psychiatric genetic research participation is to be analysed in terms of how it is socially organised, using what participation as a process means to different people in order to understand the sociological work that these processes do within participation. As it stands, psychiatric genetic research participation has not yet been explored in this way and primary data collection is necessary.

Scholars have recently reiterated the value of the social sciences and humanities to intervene within biomedical practice in order to draw attention to the inherent social and ethical matters of concern when dealing with human problems and health (Pickersgill et al. 2018). And yet, the challenges of maintaining a co-productive relationship, conducive to productive dialogue and research, reside within a background of historically critical sociological scholarship on psychiatry and its practices (Pilgrim and Rogers 2005; Pickersgill 2012). Undertaking social research that draws attention to views that are in opposition to the vision and associated rhetoric of psychiatric genetic research(ers) may well be received by some psychiatric genetic researchers as part of a persisting and unwelcome challenge to their beliefs and values. However, it was necessary to use a methodology that could take into consideration the idiosyncratic nature of what psychiatric genetic research participation means whilst explicitly soliciting people's responses to the wide variety of other views that are currently known to exist, including those views that challenge the status of psychiatric genetic research.

Q methodology is a research approach and method that is becoming increasingly applied in various fields with researchers advocating for its use but also acknowledging its interpretative demands (Cross 2005; Eden et al. 2005; Baker et al. 2006; Akhtar-Danesh et al. 2008; Davis and Michelle 2011; Wright 2013; McCrum et al. 2015; Lundberg et al. 2020). It is considered particularly useful for participants who find some research approaches challenging or for complex social problems involving 'thorny' contentious issues about which there is little consensus and that risk producing 'messy' data, requiring understanding from multiple voices (Stainton Rogers 1995; Donner 2001; Focht 2002; Rayner and Warner 2003; Ellingsen et al. 2010; Shemmings and Ellingsen 2012). Using statistical tools, it provides a structured approach to aid interpretation of various subjective accounts of a topic, enabling the identification of any distinct groups of people and the characterisation of what perspectives make up those groups. By applying Q methodology to the accounts of psychiatric genetic researchers, mental health professionals, and potential participants to psychiatric genetic research, the study will aim to answer the following questions:

Research Questions

- Why do people take part in psychiatric genetic/genomic research and why do others resist or refuse?
- How do social mechanisms⁴³ related to research participation affect this decision-making process?

A number of concepts and ideas frame this study and help me to think about what psychiatric genetic research participation means to different people and the inherent social relationships embedded within its practices. These were presented in Chapters 1 and 2, and draw on what has already been discussed about these concepts within the academic literature. Key concepts are research 'participation', participation as a 'gift', collectivism, community, citizenship, solidarity, and the public good.

Based on these existing concepts and ideas, I am interested in whether a number of distinct groups of people exist within which similar views are held about psychiatric genetic research participation, and whether those shared views differ from the views of other groups.

Mental illness is a contested concept (Rose 2019). As such, views about the existence and causation of mental illness are likely to affect the decision making process of potential participants to psychiatric genetic research, making it an area worthy of research (Callard and Wykes 2009). The decision as to whether or not to take part in psychiatric genetic research will likely depend on the person's point of view about the existence and causation of mental illness. As such, this decision is subjective and will differ between individuals despite the same circumstances and will differ over time for an individual.

⁴³ As a reminder from Chapter 1, what I mean by social mechanisms are entities and the activities surrounding them that regularly bring about social change (Hedström and Yikoski 2010). An interest in social mechanisms is an interest in the explanatory power of social theory to analyse what causes social events rather than just providing a description.

The method therefore focuses on the construction of meaning and its significance, with the aim of generating new ideas about research participation *through* the data, grounded in the experiences of a purposely chosen diversity of individuals. My analytic thinking uses abductive reasoning in which discovery and indeterminacy is valued and in which connecting and generating ‘plausible’ ideas takes precedence over describing and confirming a pre-existing hypothesis (Reichertz 2007; Timmermans and Tavory 2012; Reichertz 2014; Akhtar-Danesh and Mirza 2017).

3.2 Research design and methodology

Investigating the views of psychiatric genetic researchers, mental health professionals and potential participants, in particular people with psychiatric conditions,⁴⁴ provides an opportunity to produce and analyse data based on diversely positioned perspectives. Q methodology provides a systematic way to investigate and group people’s subjective views about a topic on the basis of these views, making no prior assumptions about groupings based on socio-demographic attributes.⁴⁵

The analysis of attitudes and subjective opinions has been an area of research for many years, originating from within social psychology in the 1920s (Cross 2005) and drawing on research techniques developed from the positivist views prevalent at that time. Positivism restricts its view to what can be observed and objectively measured with the purpose of explaining cause and effect (Williams 1996). The development of attitude research therefore has a positivist tradition of quantitative methods using questionnaires and self-reported attitude rating scales that are

⁴⁴ It should be noted that the lack of a medical diagnosis does not preclude people from taking part in this study because I accept that individuals may neither seek nor recognise a formal diagnosis by a psychiatrist. However, many of my participants with a psychiatric condition did have a formal diagnosis.

⁴⁵ Note that some Q methodology studies have found that including distinct groups of people in the same Q-sort analysis has resulted in the need to analyse the groups separately because their views are tightly linked to their prior group status (For example, see Ellis et al. 2007). Such a finding, however, would still be informative about the distribution of views.

summed or averaged over a series of measures taken from a large number of survey respondents. Although quantitative methods were traditionally used for the research of attitudes and can be quick and relatively easy to analyse, an uncritical use of such methods has often been criticised for not providing a deep understanding of the process by which people acquire values or attitudes (Hammersley 1989, pp. 111-134; Stainton Rogers et al. 1995).

A critical engagement with method and how things are 'measured' is just as relevant now as it was when survey approaches were first criticised, irrespective of the quantitative and qualitative paradigms to which one might align and for whatever reason (Oakley 1999; Blaikie 2016; Cicourel 2016; Smith and Atkinson 2016; Uprichard 2016). More broadly, all forms of social research need to ensure there is a link between social actors' talk and actions and the typical sociological representations we create that enable the development of valid theories and understanding, whilst "avoiding overly subjective interpretations of social phenomena and the arbitrary application of crude categories to complex forms of organisation" (Smith and Atkinson 2016, p. 99). My choice of method, therefore, is situated somewhere between these extremes and in keeping with the complexity of the topic.

The multitude of ways, but transient nature, in which deliberations about psychiatric genetic research participation could be experienced would make it difficult to gather qualitative data through observational techniques such as ethnography. It would be possible to attend public engagement events but my own past experience as a public engagement practitioner within psychiatric genetics and mental health has suggested that very little data would be gatherable from such interactions, given the nature of the events.⁴⁶ On the other hand, psychiatric genetic research is unlikely to be a mainstream topic of naturally occurring discussion within mental health support groups and other mental health

⁴⁶ A study participant substantiated this observation. They described how the explicit mental health component of their public engagement events is deliberately downplayed, in order to attract more attendees and provide a pleasurable experience.

organisations. Furthermore, whilst the research aims to understand social interactions, some of which are likely taking place at a level above that of the individual, some individuals may have mobilised themselves into a group whereas others may not. The unit of analysis was therefore selected to be individuals rather than some larger level of analysis that would involve undertaking a case study or ethnographic observations of an organisation.

Another possible method would have been to ask individuals to imagine or recount a personal experience of being approached to take part in psychiatric genetic research and to use a biographical narrative method in which interviewees recount a story completely uninterrupted. Whilst allowing interviewees complete freedom to articulate and develop this story, the approach may not result in sufficient information directly relevant to the research topic. Although it is possible to ask people, through the use of an unstructured or semi-structured interview, about what psychiatric genetic research means to them and what their reasons are for why they would or would not take part, this may not yield the necessary data since participants may not be able to articulate their reasons when asked directly.⁴⁷ Reflecting on these debates, I decided I needed an approach that enabled a way to explore individuals' multiple meanings of psychiatric genetic research participation whilst determining whether these could be systematically typified before expanding into some broader findings. As a starting point, I needed to operationalize, i.e. make observably discernible, people's reasoning about 'participation'. One approach that *can* be observed is to provoke people's relative judgements about a set of statements that prompt them to consider participation in relation to a number of aspects such as their relationship to psychiatric conditions, genetic research, and to the social context in which decisions about participation rest.

The generation of data for this study has been through the use of Q methodology which attempts to elucidate socially shared views about a topic through a process

⁴⁷ This is not specific to psychiatric genetic research participation but is a criticism of interviews in many other settings. Assumptions that interviews are capable of 'mining' or 'digging' beneath the surface to reveal some stable truth have long been critiqued (Benney and Hughes 1956; Heyl 2001; Platt 2012; Brinkmann and Kvale 2015).

of the sorting and discussion of statements. My initial approach was to undertake a combination of Q methodology and the visual research method of photo-elicitation, an approach that uses visual images to elicit discussion during an interview. However, photo-elicitation provided very little useful data compared to Q methodology.⁴⁸

Q methodology was first introduced by William Stephenson in 1935 and originated from psychology (Stephenson 1935). The approach was controversial and a challenge to the predominant positivist approaches, resulting in little uptake at the time but has seen a revival since the 1980s (Watts and Stenner 2005; Brown 2006; Stenner et al. 2008). Criticisms have originated from researchers who have compared it against the quality criteria of quantitative methods and have, not surprisingly, been strongly rebuked by the Q methodology community as a misunderstanding of its underlying philosophy (Kampen and Tamás 2014; Brown et al. 2015). At face value, Q methodology appears to have a more positivist ontology largely because its tools encompass very quantitative techniques of hypothesis testing and data reduction procedures based on correlations in the data. This is to facilitate the identification of groups of people with similar views and to be able to characterise the groups based on which statements show similarities and differences between the groups.

David Shemmings and Ingunn Ellingsen (2012) reflect that Q methodology provides some improvement on interviewing techniques, especially when engaging with participants who might find interviews quite challenging. Other authors have also highlighted the participatory, non-threatening and empowering nature of Q methodology when studying marginalised populations, arguing that Q methodology can be useful for providing valuable insights on subject matter that is sensitive,

⁴⁸ Visual research methods have utilised imagery and creative practices for learning about the social world and been found to be particularly useful when working with marginalised groups (Stanczak 2007; Mannay 2016; Rose 2016). Following a pilot session of photo-elicitation and one session of photo-elicitation prior to Q methodology with a mental health support group, I decided that photo-elicitation provided insufficient data relevant to the study and no additional data that Q methodology did not elicit.

controversial and difficult for some to articulate (Donner 2001; Rayner and Warner 2003; Brown 2006; Ellingsen et al. 2010).

By presenting a series of statements based on a wide range of views, individuals essentially self-categorise themselves through the process of sorting statements. Q methodology enables participants to reflect on and prioritise their own position in relation to statements that not only represent their own views but those put forward by others. The participant decides what's meaningful to them, evaluates and ranks the statements relative to each other statement and in accordance with their own views and experiences.

On a practical level, this sorting of statements has operationalised the gathering of views. On a theoretical level, by approaching the co-production of data in this way, it demonstrates a critical stance to the idea of an objective researcher having unmediated access to a knowing participant who is able to articulate their views directly to the researcher (Brown 1980; Gubrium and Holstein 2012; Edwards and Holland 2013). I argue that Q methodology potentially facilitates a greater feeling of co-production of the data in that, whilst the researcher provides the statements for consideration, the participant is in full control of their relative positioning; this positioning then structures the discussion. Furthermore, both researcher and participant use the statements as anchor-points with which to raise discussion about the choices they made: choices of statement selection by the researcher and choices of statement positioning by the participant.

Some studies involving Q methodology have applied it in a way that utilises a self-completion format that is remote from the researcher. Often such applications are performed by researchers with an ontological stance of objectivity, assuming that quantifying the statement sorting is sufficient for understanding people's views.⁴⁹

⁴⁹ To familiarise myself further with the different philosophical approaches to Q methodology, I interviewed three researchers at Cardiff University who had used Q methodology extensively in their research and I also travelled to interview Simon Watts and Paul Stenner, authors of numerous publications on the process. I organised a symposium at Cardiff University that was attended by 19 people who had either used Q methodology or

Such an approach potentially decontextualizes the process and may limit the richness and validity of qualitative data that could be achieved through interacting with the researcher. Consequently, I decided to undertake the sorting and discussion of the statements face-to-face.⁵⁰ This reflects my own stance that Q methodology is aligned to a qualitative philosophy that utilises quantitative tools to provide analytical structure to the interpretation of qualitative data. As will be seen in how I have interpreted the data, I have made a conscious decision to foreground the qualitative data and to do so in a way that has links to the interpretive tradition, focusing on people's interpretation of participation and understanding what it means to them. Having participants undertake the same task does, however, provide advantages in that there is some commonality in the production of data, despite the diversity of the participants.⁵¹

3.3 Q methodology: The stages of data construction, collection, and analysis

Q methodology begins with the construction of a set of statements about the research topic. Each participant then arranges the set of statements, according to how much they agree or disagree with the statements, on a scale from most disagree to most agree (see Image 1). This configuration of sorted statements is then analysed across all the participants.

were interested in its application to their research. One key learning from exploring the usage of Q methodology was the striking epistemological differences in how the method of Q was applied by different researchers, ranging from a positivist attitude that prioritised the quantitative data to a much more qualitative sensibility that prioritised the subjective nature of the discussion about participation as prompted by the statements.

⁵⁰ This decision was also as a result of previous investigations by me that highlighted a loss of data quality when Q methodology was carried out using alternative more remote formats such as self-reporting via a questionnaire or dedicated software, even with post-sort discussions via telephone, video call or via email (Thomas 2016).

⁵¹ Combining approaches helps facilitate greater input from participants into research knowledge production and combines the depth of qualitative data with the tools of quantitative approaches, enabling the study of what typifies and distinguishes diverse views within complex social problems (Gómez 2014; Mertens 2015).

Image 1: Participant sorting Q-statements

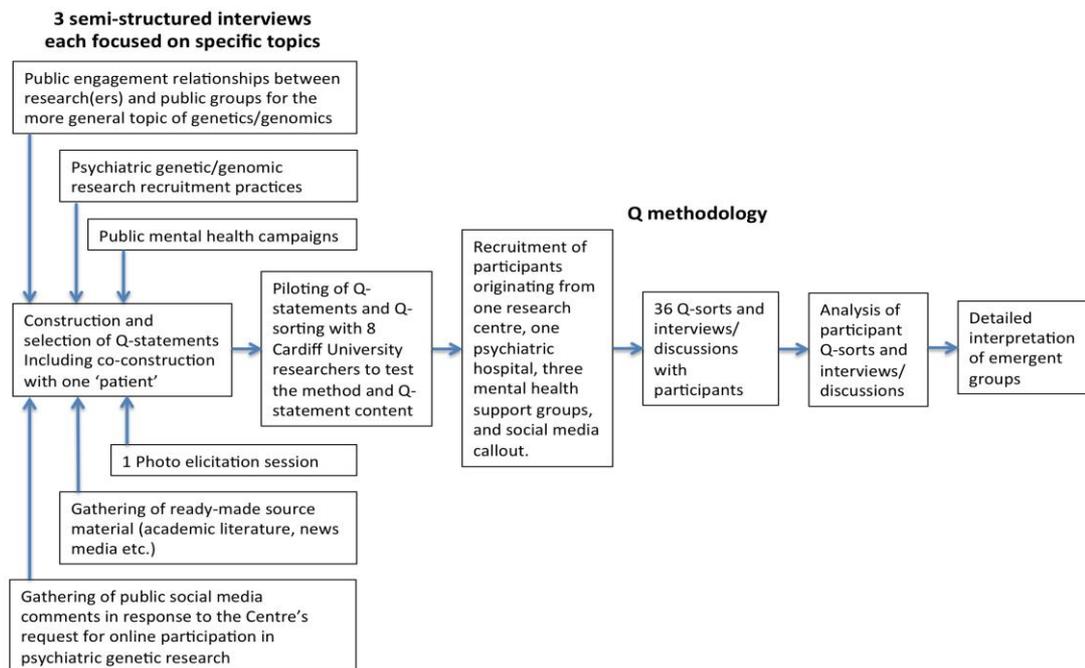


Q methodology involves the following six stages:

1. Construction and selection of Q-statements
2. Piloting and refining of statements
3. Recruiting participants
4. Obtaining participant Q-sorts and associated qualitative data
5. Q-sort analysis to identify groups
6. Interpretation of emergent groups

An overview is shown in Figure 1 and the six stages described in detail in the following sections.

Figure 1: Overview of Q methodology process



3.3.1 Construction of Q-statements

This section describes how statements were generated from source material in keeping with a Q philosophy (Brown 1980; Watts and Stenner 2012; McKeown and Thomas 2013). This involved reviewing information gathered from ready-made sources (Watts and Stenner 2012; McKeown and Thomas 2013) such as the academic literature, news media, social media, and notes from psychiatric genetics public engagement events. Three semi-structured interviews, specifically aimed at helping to generate the statements, were also conducted to gather additional information, centring on (1) psychiatric genetic research recruitment practices, (2) public engagement relationships between researchers and public groups, and (3) public mental health campaigns. Three interviewees were recruited on the basis of their expertise and experience within one of these areas and, as such, were senior members of staff with considerable knowledge of the selected area. All three interviews were audio-recorded. These ready-made sources, the pre-Q interviews and pilot photo-elicitation session facilitated the development of a collection of

statements to represent all that has been 'said' (the discourse)⁵² about psychiatric genetic research participation.⁵³

Statements were created that responded to the phrase: 'Psychiatric genetic research participation ...' and worded to be of reasonably similar length, suitable for printing on hand-held sized cards. To generate possible statements, phrases were constructed based on actual quotes or a précis of information from within the source material. In line with advice from previous Q methodology studies (see, for example, Donner 2001), statements that everyone might agree or disagree with were avoided or rephrased in order to be less generic, enabling the statement to be a plausible competitor of choice amongst other statements. For example, a statement like "needs more resources to be put into understanding mental health" is likely to be agreed on by the majority of people whereas the statement "needs government and funders to focus more attention and money on this kind of mental health research" is likely to tease out views about how resources should be distributed according to different approaches to understanding mental health. The revised statement may also provoke a discussion on biomedical versus psychological approaches to understanding and treating mental ill health.

A good Q-item within the collection of Q-sort cards should be constructed such that participants feel they can bring their own meaning(s) to the text on the card. Simon Watts and Paul Stenner (2012) argue that the text is less of a statement and more of a suggestion or provocation. From this perspective, the aim is to draw a reaction out of the participants that will allow the sorting process to differentiate them in

⁵² Here, I refer to discourse as a representational system that includes the social activities and textual/verbal/visual accounts that affect how we think, communicate and interact in society. Within the different discourses available are embedded the moral and productive properties that constitute and perform shared knowledge, some discourses of which have greater power than others. This follows the discursive approach to research questions and methodology advocated within critical social psychology (see Stainton Rogers 1996) that rejects the idea of discourse as revealing some stable privileged underlying essential truth. Thus, within the use of Q methodology, discourse relates not only to the language used and spoken within participant sessions but also the discourse and discursive practices pertaining to psychiatric genetic research participation outside of those sessions.

⁵³ In the terminology of Q methodology, this is called the Q-concourse (see Stephenson 1978).

terms of their point of view. This viewpoint is characterised by that particular participant's beliefs, values and experiences about the subject matter. The whole set of these items, the Q-set, needs to cover the breadth of opinions on the subject matter in order to be able to locate a participant's viewpoint profile in amongst all possible points of view.

Removing repeats and statements of fact resulted in 106 possible statements. The Q-set, a set of statements providing sufficient coverage of the total discourse, was selected as follows (see Stainton Rogers 1995; Watts and Stenner 2005 for further details on this process). I categorised the research question into a number of themes and the aim was then to select a fairly representative selection of statements from each theme whilst constructing a cohesive set of statements. I identified the following eleven themes from the collection of source material:

- Knowledge and understanding (of genetic component of psychiatric conditions)
- Diagnosis, care and treatment
- Concepts related to social organisation (e.g. collectivism and individualism)
- Research recruitment
- Research and researchers
- Beliefs about causation of mental illness
- Public, disclosure and stigma
- Funding and support
- Hopes and fears
- Personal experience
- Trust and relationships

According to Watts and Stenner (2005, pp. 75-76), the reduced set of selected statements need only be broadly representative and contain a "representative condensation of information." This is because the purpose of the Q-set is focused more on the propensity to generate robust engagement with the whole set and to

prompt detailed reasoning from participants about the statements. I discussed the 106 possible statements with someone who is aware of psychiatric genetic research and has a diagnosed psychiatric condition. I did this to provide an initial assessment of the choice of language, breadth of statement items, along with optimal number of statements. I then selected 48 statements as a result of this discussion and advice from within the Q methodology literature.

Researchers who have used Q methodology generally choose between 35 to 80 statements; too few statements risks insufficient coverage of the subject matter whereas too many risks jeopardising the validity of the data by overwhelming the participant (Stainton Rogers 1995; Watts and Stenner 2012; Zabala et al. 2018). I selected at least two statements from each of the eleven themes in order to ensure a broad representation of the source material. For the remaining 26 statements, I selected ones that would create a cohesive set of relevant statements for the purposes of answering the research questions rather than, for example, ensuring the same proportion of statements from each theme.

The set of statements should mean that participants do not feel limited in how they are able to represent and express their views. Consequently, it is important to have a rigorous piloting stage for Q methodology. Note that at the end of each Q-sort session, whenever possible, I asked participants how they felt the session had gone and this often included asking about the number of statements and the language used in the statements.

3.3.2 Piloting the Q-set statements

I undertook extensive piloting to provide rigour in the final selection of statements, the choice of wording and procedure of how to administer the Q-sorting. I carried out piloting with the following people:⁵⁴

⁵⁴ I audio-recorded the sessions, except for session 1 due to technical difficulties.

1. an individual who has a diagnosed psychiatric condition and is familiar with psychiatric genetic research
2. a group of seven researchers (mostly social scientists) familiar with qualitative research methods
3. an experienced researcher who is familiar with research methodologies and has particular expertise in the sociology of psychiatric genetics and genomics

I checked statements for clarity and coverage. I checked the Q-sorting process and post-sort interview to make sure the language I intended to use would enable the participant to feel able to put their view forward. When piloting with the group of social researchers, I asked them to note when statements were unclear, particularly difficult to place, or whether a statement would be better replaced with some alternative, more relevant, statement. I explored this latter check on the statements in greater detail when piloting with the researcher who has expertise in the sociology of psychiatric genetics.

Piloting with the individual diagnosed with a psychiatric condition was extremely useful for highlighting language that would be unfamiliar and potentially problematic for any study participants whose poor mental health may have affected their educational opportunities throughout life or whose poor mental health at the time of Q-sorting may interfere with their attention span. This was countered by advice from the researchers who suggested that some words such as 'eugenics' were necessary to retain because of their resonance with psychiatric genetic researchers and with some patients who have been particularly active within the field of mental health research. Based on this advice, I agreed that I would have definitions of certain words available in order to clarify their meaning when necessary rather than omitting them completely. Piloting with the researchers also highlighted the need to moderate some statements that might influence how people would respond to the statements because of their normative phrasing. Such phrasing might have limited the responses because of a feeling that there was a right or wrong way to respond.

After revising the language and procedure of how to administer the Q-sorting, I finalised 48 statements and printed them onto hand-held cards (Figure 2), along with pre-sort and post-sort schedules to structure the discussion (see Appendix I).

Figure 2: 48 statements for Q-sort activity

48 statements completing the phrase ‘Psychiatric genetic research participation ...’

Statements were presented to participants as a shuffled pile of cards with the following format.

<i>isn't going to help because these conditions are too complex</i>	<i>demonstrates the need for a more scientific approach to mental health</i>	<i>heightens the relevance of genetics for people's everyday experiences of understanding their condition</i>	<i>is a responsible thing to do to improve the understanding of psychiatric conditions</i>
<i>is pointless because mental illness is not a genetic illness</i>	<i>means challenging the diagnostic criteria of the past</i>	<i>means having better access to diagnosis, care and treatments</i>	<i>is vital for developing new treatments and overcoming the shortcomings of current therapies</i>
<i>is an empowering and positive thing that helps the individual</i>	<i>is a generous act for the future benefit of others</i>	<i>means being part of a collective working towards a better future</i>	<i>means having a sense of belonging to a cause</i>
<i>needs to inspire volunteers so that research can move forwards</i>	<i>means coming together to wage war on mental illness</i>	<i>doesn't address the things needed to deal with psychiatric conditions now</i>	<i>means giving up time for no personal gain</i>
<i>should be a moral obligation for the benefit of the greater good</i>	<i>is only focused on extracting scientific data from human resources</i>	<i>is no different to taking part in research about other health conditions</i>	<i>takes advantage of the altruistic intention of potential participants</i>
<i>challenges the belief that people are the instigators of their psychiatric condition</i>	<i>means accepting the biomedical model of mental illness</i>	<i>helps psychiatry to recognise its current limitations and uncertainties</i>	<i>needs greater public debate about the implications of future technologies from this kind of research</i>
<i>means being part of informing and educating people about the causes of psychiatric conditions</i>	<i>should be publicly shared to encourage other volunteers</i>	<i>is more known about because of the increase in public discussions about mental health</i>	<i>is likely to stimulate discussions within families about psychiatric conditions and their heritability</i>
<i>gives people more reason to label someone as 'a risk'</i>	<i>needs government and funders to focus more attention and money on this kind of mental health research</i>	<i>needs public resources to shift from addressing mental distress to that of severe mental illness</i>	<i>needs to overcome mental health specific barriers that hinder people from taking part in research</i>

Figure 2 (continued): 48 statements for Q-sort activity

48 statements completing the phrase ‘Psychiatric genetic research participation ...’
Statements were presented to participants as a shuffled pile of cards with the following format.

<i>is the only way we're going to make things better for people in generations to come</i>	<i>opens up opportunities for commercial pharmaceutical companies to exploit research and individuals</i>	<i>does not safeguard personal data from being passed onto unauthorised companies</i>	<i>is promoting an idealised vision of scientifically perfected human beings</i>
<i>is a short step towards eugenic practices for improving the mental health of society</i>	<i>will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems</i>	<i>is based on a fragmented and incomplete account of someone's psychiatric condition</i>	<i>provides a sense of ownership over the research</i>
<i>means being part of a realistic hope of treating mental illness</i>	<i>incorporates knowledge from people who are experts in their own condition</i>	<i>needs a united commitment from both researchers and those with psychiatric conditions</i>	<i>means someone is really listening and trying to understand psychiatric conditions</i>
<i>means people overcoming a distrust of research(ers)</i>	<i>is a complex decision that depends on many factors</i>	<i>provides vast amounts of data that will give us many answers in the future</i>	<i>has implications for whole families and not just the individual participant</i>

3.3.3 Recruitment of participants

Eligibility Criteria

Wherever possible, participants were recruited from the South Wales region for ease of travel costs/time for both the participants and myself. Participants were a mix of psychiatric genetic (PG) researchers, mental health professionals and adults (18+) with mental health problems, focusing on those people with personal experience of schizophrenia, bipolar disorder, or depression. This diagnostic focus is because these are the main psychiatric conditions that are studied within the Centre from which the psychiatric genetic researchers were recruited.

Mental health services inpatients and those currently receiving support or awaiting support from a mental health crisis team (either from GP referral or self-referral) were excluded from the study. In line with the mental capacity act (Mental Capacity Act 2005), potential participants with mental health problems were assumed to have capacity until it was judged that they did not have the capacity to take part, or that participating would be detrimental to their wellbeing.

Number of study participants

The number of study participants traditionally used for Q methodology lie somewhere between those of qualitative and quantitative methods but are relatively small compared to survey approaches (Stainton Rogers 1995; Watts and Stenner 2012). The aim is not to predict how many might hold a particular point of view in some larger population but to find out about a variety of views in great depth. Q methodology therefore does not aim to generalise from a sample to a population and the number of participants do not need to meet some statistical criteria for carrying out parameter estimation or hypothesis testing. However, a sufficient number of participants are needed to enable the identification of distinct groups with shared views and Watts and Stenner have suggested an initial guide of six participants for every group that might be identified (2012). Q-methodologists recommend that capturing a wide breadth and diversity of viewpoints might require numbers of around 40-60 participants whereas, in practice, numbers are normally around 30-40 participants (Stainton Rogers 1995; Watts and Stenner 2012; Kampen and Tamás 2014; Zabala et al. 2018; Lundberg et al. 2020). Q methodology has also been successfully carried out with less than 20 participants.

I was keen to have a reasonable spread of people from psychiatric genetic researchers, mental health professionals and people with a psychiatric condition, including those who had taken part in psychiatric genetic research and those who had not. Given the specificity of psychiatric genetic research, I initially aimed for at least 40 participants. However, there came a point at which the information provided during the post-sort discussions was reaching a saturation point whereby no new insights were obvious

from including further participants in the study. A preliminary analysis of the Q-sort data at this point also suggested that distinct groupings were already identifiable from the quantitative data.

Consequently, for this study, 36 people were recruited between March and December 2018 with the following breakdown:⁵⁵

- 8 Psychiatric genetic research professionals
- 11 mental health professionals (e.g. psychiatrists, clinical psychologists, community psychiatric nurses, mental health researchers)
- 9 adults with a psychiatric condition, who had never been approached to take part in PG research
- 2 adults with a psychiatric condition, who had been approached to take part in PG research but had not taken part
- 7 adults with a psychiatric condition, who had been approached to take part in PG research and had subsequently taken part

Recruitment technique

I recruited psychiatric genetic research professionals by identifying a cross-section of researchers with varying levels of expertise from within a large psychiatric genetic research organisation, identified from previous public engagement activities in conjunction with publications in this field. My recruitment targeted those individuals involved in public engagement, or with a reasonable level of experience, who might be more likely to be aware of some of the relevant issues within psychiatric genetic research recruitment and the researcher-participant relationship.

I recruited mental health professionals and mental health researchers after promoting the study within particular research groups at a local University, and via snowballing after initial recruitment of a personal contact from a previous mental health public engagement project. I used a strategy of purposive and snowball

⁵⁵ Note that these numbers do not add up to 36 because one of the professionals also had a psychiatric condition and was eligible to take part in PG research.

recruitment following the initial broader invitation to participate. I invited individuals to request further information if they felt they might have a reasonable grasp of the relevant issues; in practice Q methodology relies on individuals being able to demonstrate an opinion on the topic.

To recruit people with experience of psychiatric conditions, I approached local mental health organisations in order to promote the research to potential participants.⁵⁶ An information sheet and invitation to participate was distributed via email, social media, and printed flyers through the appropriate contact. I also offered to provide an informal brief presentation at mental health organisations in order to make service users aware of the study and its aims. I was successful in being invited to three mental health organisations to talk about the study and subsequently attended some of the open support group sessions in order to develop rapport with potential participants. This was particularly useful in assessing people's prior knowledge about psychiatric genetic research and their capacity to be able to carry out the Q-sorting.

Recruitment consent

I obtained written consent prior to the participant undergoing any activities that were specifically for the purposes of the study. I gave the information sheet and consent form to potential participants at least one week in advance to give them time to read and consider them. At the beginning of the session, we discussed the written consent form in case of any questions, and two copies were signed at the start of the session; I gave one copy to the participant and I retained the other copy.

Ethical considerations⁵⁷

I attempted to reach people with severe mental illness in order to include their views but, ethically and quite rightly, this could only be at times when they were well enough to do so. A few participants pulled out or rearranged the day when

⁵⁶ Ethical approval was granted by Cardiff University's school Research Ethics Committee (REC) rather than through NHS research governance procedures because participant recruitment was via non-NHS routes.

⁵⁷ Regulatory requirements regarding ethics are included in Appendix II.

they could do the research but, as far as I could tell, this was more to do with their daily struggles rather than a reluctance to take part in the research itself and I was sensitive to possible signs of those struggles. As an example, one person was due to take part in the study but I observed a change in their behaviour during my weekly visits to the support group and, having expressed some concerns to their support worker, it was decided to postpone their participation; shortly afterwards they were admitted to a psychiatric unit and they never took part in the study. This highlights the difficulties of carrying out research with those whose lives are severely challenged by their psychiatric condition but also highlights the significant advantage of developing relationships with potential participants so that harm is not caused by undertaking research at a vulnerable time.

Some participants were invited to undertake activities as a small group during the early experimental phase of the study, either the photo-elicitation sessions or group Q-sorting sessions. Whilst this does not reveal a mental health diagnosis, their taking part may associate them with having mental health conditions/problems and this consent to take part may be something that they could later regret. This problem of post-research regret is not unique to research involving mental health issues but past experience has suggested that some people with mental health problems can make decisions that are more likely to need confirming at a later date because of impaired judgement at the time the decision was made.

Discussions during the activities had the potential to trigger memories of difficult personal experiences and/or anger as a result of poor experiences with mental health services. I had previously carried out a mental health first aid course and had been actively involved in dealing with situations of mental distress through previous public engagement work. If an individual became distressed, I gave them the opportunity to take a break from the session and asked how they would like to proceed. Sessions took place in university buildings or buildings linked to local mental health services and support group premises at specified times when there were staff around who could provide additional support. I gave participants the option to bring a companion to the session if they felt they might become

distressed as a result of the process, in which case companions were required to sign a consent form. Participants in small group sessions were made aware of the need to respect each other's anonymity about what was discussed during those sessions.

3.3.4 Obtaining participant Q-sorts and associated qualitative data

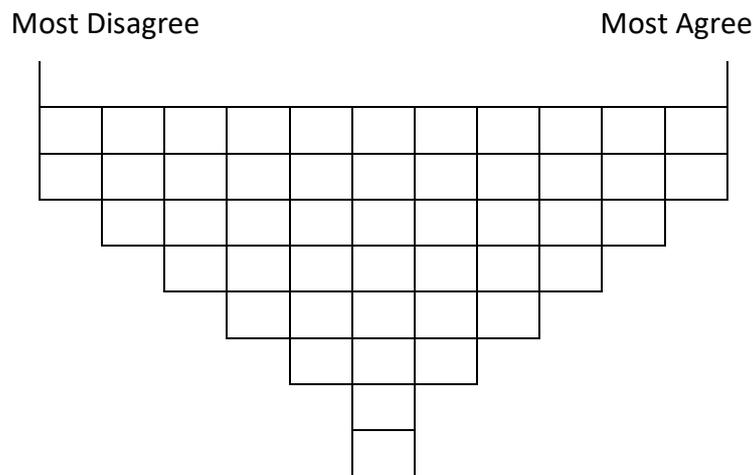
I collected demographic information prior to the Q-sorting session in order to determine eligibility to participate (see Appendix I). This was collected either in person, via telephone or email and included an optional question regarding whether participants have a formal mental health diagnosis.

Q-Sort Data Production

I informed participants that statements had been gathered from interviews, a photo-elicitation session, a review of the research literature, public documents, news media, public events, and both online and social media. I asked participants to read the statements and sort them according to the following stages:

1. Sort into three piles of agree, disagree, and unsure.
Participants could have as many or as few statements in each pile as they wished. During this stage of the Q-sort, I reassured participants that this was a preliminary sorting and that they would have further opportunities to reconsider or refine their choices.
2. Take each pile in turn (agrees, disagrees, and then unsorted) and populate the empty boxes of each column with the set of 48 statements, resulting in ordered columns of statements from most disagree on the left to most agree on the right (see Figure 3).
3. Make any further changes to the relative positioning of statements until participant is happy with the final Q-sort.

Figure 3: Q-sort framework for 48 statements



Note that each box in the figure represents a statement.

I recorded the developing configurations of statements as photographs during the various stages of sorting. This ensured I captured which statements were in the agree, disagree and unsure piles, plus any changes in the Q-sort until a final configuration was decided. The demographic questioning, the sorting process and post-sort discussion were all audio recorded unless the participant refused, in which case written notes were taken instead.⁵⁸ Observation enabled me to gather information about which statements were seemingly easy or particularly problematic for the participant and these were raised during the post-sort discussion. At the end of the Q-sorting sessions, I asked participants whether the set of statements had enabled them to express their views on the topic, if there were any statements they felt were missing or superfluous, and consequently whether they had any further comments.

Q-sorting generally takes between 30 minutes and one hour depending upon the speed at which a participant sorts and arranges the statements; the post-sort discussion also takes around an hour depending on how much the participant has to say about the topic; some participants also talk through the sorting of statements or

⁵⁸ Only one person refused to be audio-recorded on the grounds that they felt they would be too conscious of the recording and it would inhibit their discussion.

3.3.5 Q-sort analysis to identify groups

Within Q methodology, the analysis of Q-sorts focuses on the degree of agreement or disagreement between a number of individuals by using the complete set of statement rankings, i.e. the profile across the statements, rather than between each statement separately. The resulting correlation matrix contains correlation values each of which are the correlation of one individual against another, and consequently of one profile of Q-sort rankings against another profile. High correlations amongst a number of individuals suggest the presence of a group of people with similar sorting profiles. Analysis involves an iterative process of choosing how many distinct groups to identify, aiming to find the most parsimonious solution that captures the diversity of views in the whole dataset with the smallest number of groups. Those within a group should be highly correlated and distinct from other groups.

The choice of the number of groups involves examining the statistical output against criteria described below but also from deciding what consequences the decision on number of groups would have on the interpretation. For example, it may be that analysis of the quantitative data from the Q-sorts suggests the majority of psychiatric genetic researchers could be aggregated within one group with fairly weak evidence for splitting this into two groups. However, analysis of the qualitative data may suggest that these researchers have quite different views about certain key, and also statistically significant, statements that would be lost if they were retained within one group. The idea is thus to allow a story to emerge for each group but a story that makes each group distinctive from other groups (see Watts and Stenner 2012; McKeown and Thomas 2013).

The R software calculates the correlation matrix, showing the correlation between each possible pair of Q-sorts. The analysis then proceeds as a modified form of the statistical technique of factor analysis (for details, see Watts and Stenner 2012)

whereby the resultant factors⁵⁹ are essentially groups of Q-sorts reflecting common views across certain statements. Factor loadings are also provided, expressed as a correlation coefficient ranging between 0 and 1, and these provide a measure of how much a particular individual's Q-sort is associated with each possible factor. The loadings are calculated according to researcher input on the number of factors to extract, choice of extraction, and choice of factor rotation of the data. Factor extraction provides a means of data reduction, from the total number of Q-sorts to a smaller number of groups of Q-sorts, and factor rotation searches for the simplest observable structure such that Q-sorts load more distinctly onto factors. Rotation does not affect the relationships between Q-sorts, it merely provides a different way of looking at the data.

In this study I used the PCA⁶⁰ method of extraction because unlike factor analysis, which uses the assumption of some underlying construct in order to make predictions for some generalised population, the PCA method is a data driven method of extraction. The number of factors to extract is selected on the basis of the following key recommendations by experienced Q-methodologists (Brown 1980; Watts and Stenner 2005; McKeown and Thomas 2013):

- Select factors with an eigenvalue⁶¹ greater than 1.0
- Select factors with at least two significantly loading Q-sorts

This study used the varimax rotation procedure, rotating the data to find the simplest solution that maximises the differences explained by the groups. This was

⁵⁹ Factor analysis is a data reduction technique to reduce a larger number of variables to a smaller number. For the purposes of explaining the statistical analysis, I will refer to these preliminary groupings as factors in order to distinguish them as resulting from the statistical analysis and to retain the standard language used in Q publications.

⁶⁰ In two reviews of Q methodology studies, most studies used Principal Components Analysis (PCA) extraction and varimax rotation, resulting in 3 or 4 factors (Zabala et al. 2018; Lundberg et al. 2020). In these studies, the number of participants was around 35 and used around 40 statements.

⁶¹ In the context of Q methodology, an eigenvalue is the sum of squared factor loadings for each factor (Brown 1980, p. 40) and represents the amount of variance that can be explained by that factor.

chosen for its simplicity and reliability: technical details can be found in Watts and Stenner (2012) and Brown (1980).

As a result of interpreting statistical output, similar and dissimilar Q-sorts can be differentiated and this helps to identify groups of Q-sorts presenting with similar views. This enables the identification of the Q-sorts that load significantly onto each factor and the relevant qualitative comments from the post-sort discussions can be identified to help interpret the factors.

3.3.6 Interpretation of emergent groups

Interpretation of Q-sort data involves considered attention to understanding the views reflected in the data, encapsulated within both the decisions made during Q-sorting, and an account of those decisions made evident during the post-sort discussion. Once the number of factors has been decided, typical Q-sort configurations can be produced for each factor and the R software statistical output provides a guide with which to interpret the configuration of Q-statements that best characterises each factor (see Watts and Stenner (2012) for details). Statements with large loadings in a factor that differ significantly from all other factors are regarded as distinguishing statements for that factor and some statements may show differences across some but not all factors; those that are non-significant across all factors are considered consensus statements.

However, interpretation should aim to understand the *whole* configuration of Q-statements. To do this, close attention to the accounts given within the qualitative post-sort discussion is essential. Watts and Stenner (2012, p. 150) suggest producing a 'crib-sheet' as a systematic way to "help the researcher deliver genuinely holistic factor interpretations" and I used this approach for this study. In the next chapter I provide an overview of the results, through which this stage of the interpretation will become clearer.

Building on the interpretation of the identified factors, developed by following the standard approach of Q methodologists, I then extended this by looking for ideas that differentiated and connected these new groupings. I generated findings through a two-stage process:

(1) Coding extracts of qualitative data from the Q sorts within each group using thematic analysis (Braun and Clarke 2006; Nowell et al. 2017), focusing on those individuals identified with high loadings from the statistical analysis

(2) Further coding to generate higher-level themes across the groups and linking these themes with the academic literature to help generate findings and understand their significance.

In linking these themes to the literature, I was interested in how participation is achieved and whether the rhetoric involved in this is distinguishable between different groups of people. I paid particular attention to the way in which participants and participation were framed during the discussions.

Before going on to provide some methodological reflections in the next section, I here acknowledge that discourses on a topic are inconsistent and fragmentary, arising from unstable discursive practices that are reflected in the, sometimes contradictory, nature of accounts given by research participants. I am not assuming some single coherent underlying response and, as such, there will be some overlaps across groups and heterogeneity within groups. The approach draws on the alternative discourses about psychiatric genetic research participation that people may identify with, though not necessarily uniquely so. As such, Q methodology as a particular form of critical discourse analysis attempts to identify and describe the key features within this landscape of available discourses, promoting the hearing of a diversity of 'voices' rather than that of a single dominant discourse (Stainton Rogers 1995; Stainton Rogers et al. 1995, pp. 225-254).

3.4 Methodological reflections

Gaining access to participants, the nature of data production, and the foregrounding of qualitative analysis constantly caused me to reflect upon my own background, relationships and epistemological assumptions. I often worried that my former careers as a biostatistician and then artist and curator within the public engagement of psychiatric genetics meant that some of my participants, whom I had previously come into contact with as a consequence of my work, held prior assumptions about what I might expect them to say. I sought to differentiate my own research from the research of the psychiatric genetic researchers and, whenever it was not obvious, explained that I was not connected to the Centre or, when relevant, was no longer connected to the Centre. Throughout the whole process of recruitment, data production, analysis and interpretation, I often felt that I was constantly sliding along the spectrum of insider/outsider researcher positioning (Le Gallais 2008). At the time, this left me perpetually unsteady but, on reflection, I think it allowed me to become more reflexive.

It was also important to educate people about the method, including why there were potentially critical statements in the set, because there was the potential for gatekeepers to block the recruitment process on account of feeling uncomfortable with some of the statements or feeling it would be too challenging a process for some people. I am aware that there could be some limitations to the study that may have arisen as a result of not gaining access to people who are particularly critical of psychiatric genetic research or by holding the sessions in an environment that could limit what people say, such as sessions within a person's place of work. As will be shown in the results chapters, I managed to speak to a diverse range of people and I am confident that the study has captured a variety of perspectives on psychiatric genetic research participation. One limitation is that my participants were all of white ethnicity, a problem in mental health research that is not limited to this study. Research suggests that the stigma of mental illness is more of a barrier for ethnic minorities, many of whom tend not to access mental health services (Woodall et al. 2010). Anecdotally, one of the interviewees in this study commented

on the absence of people from ethnic minority backgrounds at public engagement events for mental health.

The data in this study includes a number of people who disclosed their diagnosis of bipolar disorder and one who disclosed a diagnosis of schizoaffective disorder but nobody with schizophrenia. This study has included the views of people who have supported those with schizophrenia such as clinicians, psychiatric nurses, social workers, mental health support workers, and parents. This provides views relevant to schizophrenia but a possible limitation of this study is inevitably that there may be views missing from those people diagnosed with schizophrenia themselves.

On reflection, I think my former careers afforded me the initial rapport I needed to gain access and allowed me a variety of insights that helped me to probe deeper into some aspects of the topic, facilitated by the engaging and sometimes challenging nature of the Q-sorting activity. One of the strengths of Q methodology is the structured nature of the activity and the propensity of a conversation to develop about the subject matter through being engaged in a process that allows the participant to order their thoughts. The process enables them to state their views on what they agree and disagree with but also to articulate their uncertainties. Another strength was how it engendered opportunities to avoid the well-rehearsed story, especially when talking to psychiatric genetic researchers who have routinely been interviewed about their research or talked about it at public engagement events.

Based on their research related to recovery and social integration of people with severe mental illness, Philip Yanos and Kim Hopper (2008) argue there is a need for competent interviewers to employ active, methodical listening and close attention to performative speech within interviews. They suggest there is a need to avoid well-rehearsed performances and “to move both the interviewer and interviewee to uncharted ground” (Yanos and Hopper 2008, p. 234). Some social researchers, most noticeably from ethnography, also warn that methodological claims to

authenticity should be treated with suspicion and view all actions, and talk about actions, as potentially performative (Atkinson and Coffey 2001; Jerolmack and Khan 2014a, b). Indeed, my participants may have been no less performative in their positioning of the Q-statements than they might have been when talking in an interview. Viewing the interview as part of a game in which power and resistance play a role, Karl Nunakoosing (2005) counsels that the interviewer needs to use their research skills to help generate new stories rather than risking no story or the regurgitation of popular well-rehearsed stories. But as Patricia Adler and Peter Adler (2001, p. 527) warn: “if researchers are too aggressive in their requests, they may scare or threaten respondents.”

Note that some small group Q-sorting sessions were also trialled because I had previously carried out Q methodology with small groups of genetic counsellors and demonstrated that valuable additional qualitative data on some of the more problematic/contentious statements can be achieved by carrying out Q methodology with small groups compared to individuals (Thomas 2016). These small group sessions were non-researchers at one of the mental health support groups. Whilst small group sorting has advantages in terms of the possibility of extra data, it can often be difficult to schedule participants into mutually convenient times. Drop-in support group sessions make this even more challenging, especially when these sessions are time-limited and, quite rightly, utilised as an opportunity to catch up with each other’s struggles and achievements from week to week. Consequently, one cannot rely on a sufficient number of small groups to generate the data required for Q methodology. Analysis of the qualitative data from the first two small group sessions suggested that there was little extra information to be gained from this format, structured as it was within the end of a regular mental health support group gathering but also because participants often digressed to ask about a mutual friend or some previous incident.

In these circumstances, I often felt conflicted between the opportunity to gather data and respecting my participant’s purpose for being at the support group session; other researchers may have pushed to gather more data but it felt

important to me not to spoil their support group experience and I was very grateful for them giving up their time. Consequently, some sessions did not provide data but were extremely good learning experiences for how to approach future sessions. I subsequently decided that Q-sorting would take place only with individuals and Q-sort sessions worked best within support groups in which whole afternoons or evenings were available for the support group to use. In these situations, individuals were happier to temporarily break away from the group in order to take part in the research, knowing that there would still be time to catch up with their friends. One aspect of recruiting participants from support groups that I was not quite prepared for was the extent to which I embedded myself within the activities that took place in these sessions, and how I often felt I should open up my own vulnerability in terms of sharing personal experiences when encouraged to do so. This was done in the spirit of having been welcomed into the support group and my sharing may account for greater recruitment success at that organisation. However, they were encounters that I had not anticipated and, given my private nature, I had to work hard at managing my own emotions during these recruitment activities, what sociologist Arlie Hochschild described as the emotional labour of certain occupations (Hochschild 1983, 2012).

3.5 Conclusion

In this chapter, I have presented an argument for the use of Q methodology and detailed the approach and methods involved. It was necessary to use a methodology that could take into consideration the idiosyncratic nature of what psychiatric genetic research participation means whilst explicitly soliciting people's responses to the wide variety of other views that are currently known to exist, including those views that challenge the status of psychiatric genetic research.

Particular consideration has been given to the status of the qualitative data in this approach by foregrounding the detailed reasoning provided during discussions with my participants. My reflexivity, research approach and interactions with people,

combined with the particular engagement that Q methodology enabled, has produced a certain kind of data, data that allows me to understand some problematic social relations and processes from various perspectives. I am confident the rich nature of the data produced enables me to answer the research questions with claims grounded in a diversity of perspectives about psychiatric genetic research participation, utilising quantitative tools to provide analytical structure to the interpretation of qualitative data.

In the next chapter, I provide an overview of the results from this approach to demonstrate and outline four distinct styles of thought about psychiatric genetic research participation.

Chapter 4: Results Overview

This chapter provides an overview of the results from my analysis of the Q-sort data, with detailed analysis and interpretation following in Chapters 5 to 8. I begin by showing how groups of people with similar views were selected, highlighting a few problems that arose, before moving onto describe how the results provide a robust interpretive framework. I conclude with an overview of four distinct styles of thought on psychiatric genetic research participation that have emerged from this study.

4.1 Data quality and selection of groups

36 Q-sorts were generated alongside audio-recorded discussions about psychiatric genetic research participation, resulting in both quantitative and qualitative data for analysis. Each Q-sorting and discussion took from 50 minutes to 2 hours 44 minutes but on average lasted around 2 hours⁶². This meant that it was possible to gather extensive qualitative data about why individuals had chosen to place the statements in a particular configuration, what statements they felt particularly captured their views and to have an in-depth discussion about specific statements. Of the 36 individuals, eight were psychiatric genetic researchers, four were other types of mental health researchers, seven were mental health professionals and 17 did not fit into these categories but were also individuals with mental health problems, many of whom had a medical diagnosis of a psychiatric condition.

The individuals in this study commented that the number of statements presented to them had been *“about right”* and that the process was engaging, saying *“I thought it might be a bit of a chore [...] but it’s thought provoking stuff”* and *“so much better than just speaking”*. After asking how they’d found the process, many said they’d found it okay and not as taxing as anticipated: *“an interesting way to do*

⁶² This is the median length of time to undertake the Q-sort session, including Q-sorting and discussion.

things” that “*makes you question everything that you think about all of it*”. When some of the statements were controversial, there were times when I, as the researcher, felt that the discussion could close down but the use of statements, recognised as having been constructed from found resources, deflected the proposition away from me as the researcher and enabled discussion to progress. This is evidenced from comments made such as: “*I suppose these are the arguments for the opposition aren’t they*”, “*I can see people saying these things*”, and “*Yes, it’s very hard not to kind of read behind [...], you know, second-guess the intentions of the person who made the statement*”.

After discussion of the Q-sort statements had been completed, all individuals had been given the opportunity to add further to the discussion and everyone declared they had nothing further to add, suggesting that as full a discussion as possible had taken place with comments like, for example, “*I think it’s been a pretty full on robust discussion*” and “*I think this is a good replete spread of how I feel, there’s no big gaps in my thinking that this doesn’t fill in, no I think it’s, it’s about spot-on*”.

These responses demonstrate how much participants were engaged in both the sorting process and discussions. Except for one mental health professional, who was called away during the post-sort discussion, participants talked until they felt they had nothing further to add to the discussion. This level of engagement and gathering of extensive qualitative data provides evidence towards the credibility of the data produced (Charmaz 2010).

I identified three Q-sorts as potentially problematic; two were undertaken by individuals who struggled with some of the wording in the statements, which they described as being due to low levels of schooling, some of which was a result of their mental health condition at the time.⁶³ However, these words or phrases were explained during the sorting session and there was no reason to believe that this

⁶³ Note that during piloting, I received feedback that a few words on the statements might be challenging for some people but important to keep for other people. These words were retained on the basis that I would be able to describe the meaning of these words because of carrying out face-to-face Q-sorting.

impacted on the positioning of the statements in a way that would warrant excluding their Q-sorts from the dataset. One other individual was quite anxious about making decisions regarding their level of agreement or disagreement and tended to put a lot of statements as unsure and found it hard to describe why statements were placed in certain spaces. Again, it was difficult to justify excluding this Q-sort from the analysis because, although the Q-sort would not be as informative as other Q-sorts, there was no reason to believe that its inclusion would bias the interpretation. Looking at the loadings⁶⁴ of these three individuals, none of them loaded particularly heavily on the groupings identified from the statistical analysis and their qualitative data was also not heavily influential in terms of the interpretation and conclusions. In summary, the inclusion or exclusion of these three Q-sorts did not affect the overall conclusions of the study and all 36 Q-sorts were considered of sufficient quality for analysis.

As described in Chapter 3, the quantitative data from the 36 Q-sorts were analysed with R statistical software using principal components analysis and varimax rotation, resulting in four groups explaining a total of 58% of the variance in the data (explained variance in the four groups were 23%, 19%, 9% and 7%). This percentage of explained variance is considered to be an above average outcome for data reduction purposes in Q methodology (Zabala et al. 2018). These four groups each had eigenvalues above 1.0 and at least two significantly loading Q-sorts, meaning each group contributed towards the overall objective of data reduction by reducing the 36 Q-sorts to a smaller number of interpretable groups. A solution with fewer groups did not tease out the nuances that were evident within the qualitative data and a solution with more groups resulted in groups with only one significantly loading Q-sort. I considered this four-group solution to be the most parsimonious number of groups that best reflected both the quantitative and qualitative data.

⁶⁴ As described in Chapter 3, the loadings represent how typical an individual Q-sort is of a particular group. Similar to a correlation coefficient, loadings range between -1 and +1 such that loadings close to ± 1 would be given greater weight when calculating a typical configuration to represent the group.

Table 1 shows the loadings of the Q-sorts on each of the four possible groups along with which group each Q-sort was then allocated to. Shaded cells show the loadings that are significant with at least 5% significance level; very highly significant ($p < 0.0001$) Q-sorts are also highlighted in bold. All 36 Q-sorts loaded significantly ($p < 0.05$) onto at least one of the four groups. Using statistical criteria detailed in Chapter 3, 29 Q-sorts could be allocated to a group whereas seven were confounded, i.e. loadings were split between two or more groups and it was difficult to determine an allocation on the basis of the quantitative data alone.

Detailed inspection of both the quantitative and qualitative data suggested that Q-sorts 20 and 26 shared similar views to those individuals allocated to group 3 and there were justifiable grounds for including them in this group. Inspection of the qualitative data provided justification to group together Q-sorts 7 and 8 with the remaining five confounded Q-sorts, something that was not so clear from the quantitative data. Whilst confounded individuals within this fourth group could not be allocated cleanly within any of the three groups already discussed, their overall configurations of the statements did not draw them together as a group either. Two people (Q-sorts 7 and 8) had been originally identified as potentially forming a cohesive but very small group and the remaining five had some overlapping views, mostly of those in either group 1 or group 2. Even though the fourth group had only two Q-sorts and there were five unallocated Q-sorts, this does not mean their views are not important to consider. It means that their viewpoint does not align neatly with the viewpoint of other individuals and specifically does not align on the basis of the quantitative representation of their statement configurations.

These individual viewpoints could have been left as idiosyncratic but assessment of the qualitative data suggested there were some striking commonalities amongst these seven individuals that justified both a combined analysis and discussion of their views. On this basis, four groups were identified from the analysis and used to develop the interpretation. In order to guide the interpretation, it was useful to look at what statements distinguished the groups and what statements were

similarly placed by all four groups, including those for which there is consensus, i.e. no significant differences from any other group.

Table 1: Loadings according to potential group and final allocated group

Final Allocated Group	Potential Group				Notes on allocation	Q-sort
	1	2	3	4		
1	0.765	0.269	0.202	0.001	High loading & clear ⁶⁵	25
1	0.745	0.108	0.165	-0.084	High loading & clear	35
1	0.727	0.314	-0.023	0.136	High loading & clear	32
1	0.691	0.235	-0.290	-0.006	High loading & clear	3
1	0.634	0.187	0.209	0.340	High loading & clear	19
1	0.604	0.155	-0.034	0.053	High loading & clear	9
1	0.578	0.340	-0.004	0.373	High loading & clear	13
1	0.572	0.317	-0.117	0.323	High loading & clear	17
1	0.717	0.438	-0.071	-0.030		29
1	0.673	0.410	-0.151	0.077		33
1	0.599	0.501	-0.303	0.036		14
1	0.490	0.235	0.208	0.155		1
1	0.459	0.040	-0.075	0.334		6
2	0.338	0.768	-0.007	0.099	High loading & clear	4
2	0.115	0.728	0.155	0.181	High loading & clear	16
2	0.319	0.678	-0.195	0.273	High loading & clear	27
2	0.373	0.637	0.108	-0.206	High loading & clear	24
2	0.445	0.641	0.102	-0.025		36
2	0.510	0.593	-0.213	0.108		31
2	0.451	0.569	0.064	0.088		21
2	0.502	0.558	-0.017	0.159		30
2	0.094	0.548	-0.179	0.309		12
2	0.379	0.531	0.318	-0.040		23
3	-0.146	-0.003	0.807	-0.176	High loading & clear	22
3	0.111	0.231	0.573	0.126	High loading & clear	10
3	0.013	-0.390	0.610	0.287		28
3	-0.075	0.061	-0.385	0.317		5
3	-0.182	0.473	0.589	0.371	Confounded ⁶⁶	26
3	0.256	0.000	0.467	0.399	Confounded	20
4	-0.006	0.151	0.169	0.715	High loading & clear	8
4	0.385	0.152	-0.074	0.665		7
4	0.522	0.539	-0.003	0.141	Confounded	34
4	0.516	0.521	0.280	0.255	Confounded	2
4	0.497	0.375	-0.491	0.137	Confounded	11
4	0.495	0.489	-0.011	0.330	Confounded	15
4	0.360	0.442	-0.322	0.188	Confounded	18

⁶⁵ High loading and clear refers to an allocation where one loading is very highly significant ($p < 0.0001$) and all other loadings are non-significant at the 5% level.

⁶⁶ Confounded refers to the situation where the highest loading is statistically significant ($p < 0.05$) but is not distinguishable enough from all other loadings according to the criteria given in R software (Zabala 2014, p166 and Brown 1980).

4.2 Distinguishing and consensus statements

The estimated statement placing along the most disagree to most agree scale, depicted as z-scores⁶⁷, is shown in Figure 5 with z-scores plotted by statement and group. Statements exhibiting large differences feature towards the top of the plot whereas those with small differences are towards the bottom. Detailed statistical test results of pairwise⁶⁸ comparisons between each group are provided in Table A3 of Appendix III. For a particular statement, symbols that are very spread out indicate a wide range in placement between the different groups. For each statement, filled in symbols indicate when a group is significantly ($p < 0.05$) distinguishable from *all* other groups in terms of the placement of that particular statement. If a symbol is not filled in, at least one paired comparison is non-significant and the group cannot be distinguished from at least one other group.

Only two statements produced consensus; placement of these two statements resulted in no statistically significant differences between pairwise comparisons across all four groups. All other statements demonstrated a significant difference between at least two of the groups. These consensus statements related to whether participation needs public resources to shift from addressing mental distress to that of severe mental illness (sta_31 in Figure 5) and whether participation heightens the relevance of genetics for people's everyday experiences of understanding their condition (sta_3 in Figure 5). From the qualitative data, most people slightly agreed that participation heightens the relevance of genetics but simply did not consider it as important as many of the other statements. The shifting of public resources on the basis of distress versus severe mental illness was one of the statements that people often found difficult to place. Many believed that there should be funding available for researching both distress and severe mental

⁶⁷ Z-scores represent the estimated placement of a statement along the most disagree (-5) to most agree (+5) scale, standardised to take into account the loading of each Q-sort and the number of Q-sorts in each group. This is to help make visual comparisons between groups and statements fairer. Note that z-scores for group 4 are based only on the two Q-sorts for which the quantitative data was considered of sufficient clarity for inclusion.

⁶⁸ Pairwise involves each possible pair. With four groups, pairwise comparisons involves six pairs (1,2);(1,3);(1,4);(2,3);(2,4);(3,4).

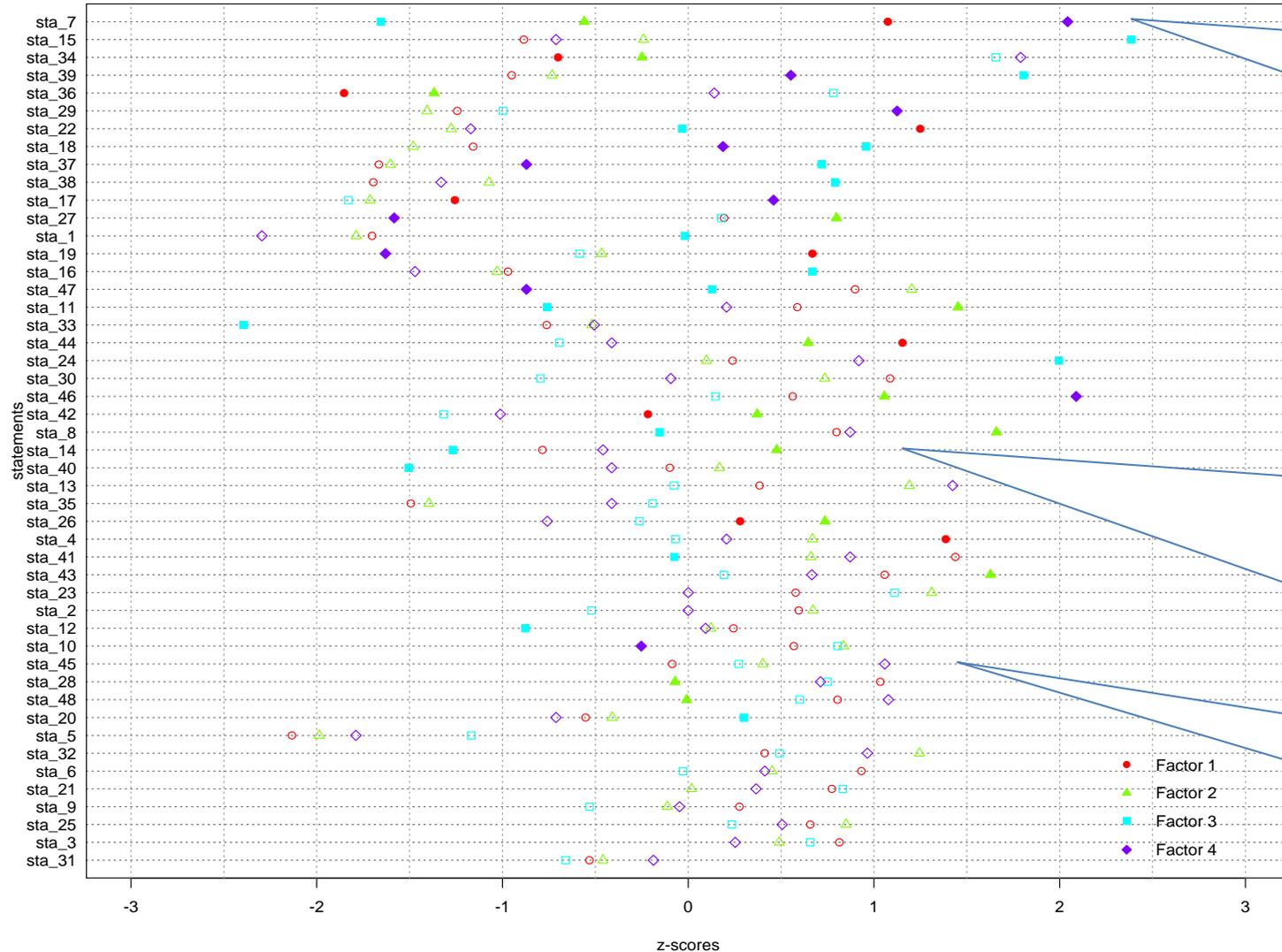
illness whereas others questioned the distinction between these two depictions of mental ill health in terms of seriousness and societal impact. Consequently, many individuals placed this statement on the basis of being unsure and it scored around -1 on the -5 to +5 scale.

Fourteen statements showed significant differences between at least one paired comparison; while this meant there was not consensus, these differences did not statistically distinguish a group from *all* the other groups. Conversely, the remaining 32 statements, identifiable in Figure 5 by at least one solid filled in symbol across the four groups, were useful for statistically distinguishing between the groups. One of these statements significantly distinguished between all four groups because there were very different views on whether participation means having better access to diagnosis, care and treatment. Reading of the relevant qualitative data showed this was largely due to temporal aspects, with some people arguing that participation in itself does not lead to better access *now* and others arguing that participation now will lead to better access *in the future*. Overall, group 1 had the fewest statistically distinguishing statements, largely because of some similarity with group 2 whereas group 3 had the most distinguishing statements highlighting their very different perspective compared to the other three groups.

The distinguishing statements, combined with the estimated Q-sort configurations, resulted in detailed crib sheets for each group.⁶⁹ These four crib sheets provided the structure for analysing the qualitative data; placement of 44 of the 48 statements have been informative for characterising the four groups. This quantitative data provided a great deal of structure for analysing the qualitative data. Similarly, the qualitative data provided detailed clarifying information for deciding on the number and nature of the groups. This iterative approach to the analysis, integrating both quantitative and qualitative data, resulted in the robust characterisation of four distinct groups.

⁶⁹ The distinguishing statements, each recognisable by having at least one filled in symbol across a row in Figure 5, are detailed in Table A3 in Appendix III. The crib sheets were created using the approach described in Chapter 3 and are presented in full in Tables A4-A7 in Appendix III. Estimated Q-sort configurations for groups 1 to 3 are provided in Figures A5-A7, also in Appendix III.

Figure 5: Z-scores by statement number and group (group denoted by factor in the R software output)



For statement 7 (sta_7), all symbols are filled in, meaning each group is significantly different from *all* other groups.

For statement 14 (sta_14), groups 2 and 3 are filled in, meaning each of these groups is significantly different from *all* other groups. Groups 1 and 4 are not filled in because they each have at least one group that they are not significantly different from.

For statement 45 (sta_45), no symbols are filled in, meaning there is no group that can be distinguished from *all* other groups.

4.3 Four styles of thought about participation

From the Q-sort analysis, I have proposed what Q methodologists would ordinarily refer to as a four-factor solution. However, in the application of Q methodology, I have given greater emphasis to the qualitative data than most Q methodologists would do. Consequently, I will refer to these as four different *styles* by drawing on Hacking's 'styles of reasoning' (Hacking 1982, 1992) but more so on Ludwik Fleck's thought collectives in which collective ideas are bonded by a specific mood (Fleck 1979). This mood then represents an emotional readiness to interpret psychiatric genetic research participation through the thought style of the collective to which a person belongs. Styles of reasoning have been used to understand the scientific *practice* of investigating the world, enabling the identification of broad patterns but also differences within that practice. A more suitable approach in the context of this study, however, would be to think in terms of different styles of meaning-making whilst paying attention to talk concerning the social practice of research recruitment and participation. This draws attention to the social interactions taking place when the different people involved think and talk about what participation in this kind of research means to them. We can then use the comparison of these four styles to gain a deeper understanding of people's perceptions of, and values towards, psychiatric genetic research participation as a social practice.

For each group, I prioritised the interpretation of qualitative data from high loading and clear Q-sorts, focusing on the statements identified in the relevant crib sheet. For example, interpretation of group 2 prioritised qualitative data from Q-sorts 4, 16, 27, and 24 (see Table 1) and focused on the 18 statements in Table 2, in particular the nine distinguishing statements highlighted in bold. This resulted in a highly structured approach, essentially weighting the qualitative data by those individuals who typified the group. These four groups were subsequently named as particular thought styles, the style having been derived from this combined interpretation of both quantitative and qualitative data. A summary of the groups is shown in Figure 6 and forms the basis of the next four chapters.

Four very distinct groups have emerged as a result of analysing the Q-sorts and discussions. The data suggests that all four groups regard psychiatric genetic research participation as providing an important contribution towards a better understanding of psychiatric conditions. However, whereas groups 1 and 2 are very much in favour of psychiatric genetic research participation, group 3 has a much more critical stance on the value and prioritisation of the research and group 4 calls for greater debate about its research applications but feels much more strongly than other groups that participation should be a moral obligation.

Figure 7 shows the numbers of individuals included in each group. Groups 1 and 2 represented almost two thirds of the individuals in this study; however, all four groups were of a reasonable size such that it was possible to characterise the groups on the basis of a substantial amount of qualitative data. Age ranges were comparable across the four groups. Of the eight psychiatric genetic researchers in the study, five were allocated to group 2, the socially engaged strategists. All four mental health researchers were allocated to group 3, the concerned critics; a group that was also predominantly female. Mental health professionals and individuals recruited on the basis of having mental health problems or a diagnosed psychiatric condition were fairly evenly distributed across the four groups. Of the seven in the study who had previously taken part in psychiatric genetic research, five were allocated to group 1, the untroubled progress-seekers.

Figure 6: Four styles regarding psychiatric genetic research participation (PGRP)⁷⁰

1: The Untroubled Progress-Seekers
 PGRP is a proactive, responsible, unproblematic process providing realistic hope for the future. Eager to see action and progress.

Key distinguishing statements: “psychiatric genetic research participation...

- means accepting the biomedical model of mental illness
- is no different to taking part in research about other health conditions
- is a responsible thing to do to improve the understanding of psychiatric conditions

2: The Socially Engaged Strategists
 PGRP *should* be part of a united collective of researchers, mental health professionals and those with psychiatric conditions.

Key distinguishing statements: “psychiatric genetic research participation...

- means being part of a collective working towards a better future
- is more known about because of the increase in public discussions about mental health
- needs a united commitment from both researchers and those with psychiatric conditions

3: The Concerned Critics
 PGRP is part of a strategy that gives primacy to an ill-conceived biomedical vision for treating psychiatric conditions. Critical stance.

Key distinguishing statements: “psychiatric genetic research participation...

- doesn't address the things needed to deal with psychiatric conditions now
- will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems
- isn't going to help because these conditions are too complex

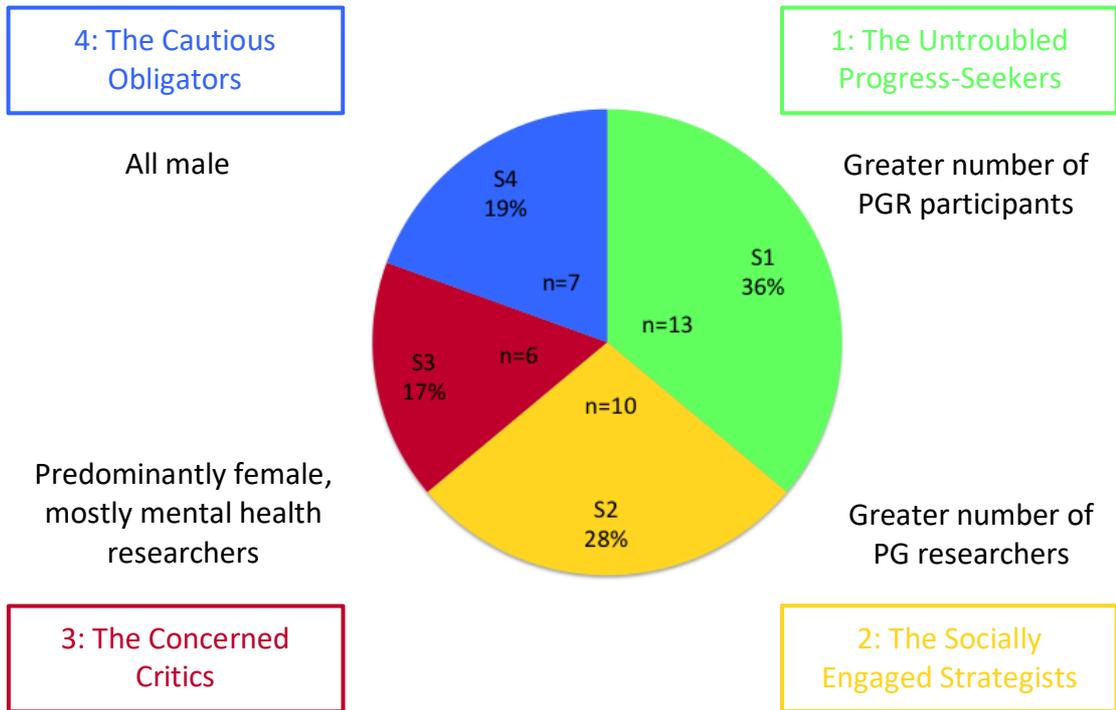
4: The Cautious Obligators
 PGRP should be a moral obligation and is beneficial but research applications need more sophisticated debate.

Key distinguishing statements: “psychiatric genetic research participation...

- gives people more reason to label someone as 'a risk'
- should be a moral obligation for the benefit of the greater good
- [strongly disagrees] is more known about because of the increase in public discussions about mental health

⁷⁰ Key distinguishing statements for group 4, the cautious obligators, are based only on Q sorts 7 and 8.

Figure 7: Allocation of 36 individuals to four styles and notable demographics



As discussed in Chapter 3, the analytic strategy did not start with pre-assumed groups of categories such as seeking to find differences in views between psychiatric genetic researchers versus those with psychiatric conditions. The approach of Q methodology means that groups emerge as a result of the similarity in people’s views. Although one group has a large number of psychiatric genetic researchers and another consists of predominantly mental health researchers, other individuals are spread across the four groups.

4.4 Conclusion

Q methodology has provided a useful and structured analytical procedure, integrating both quantitative and qualitative data. 44 of the 48 statements (92%) were found to be useful for characterising the groups with 32 of the 48 statements (67%) statistically distinguishing between the groups. Consequently, I have identified four distinct styles of thinking, and talking, about psychiatric genetic

research participation and what that means to different people, especially in the context of the social world in which the research is embedded and how participation is achieved. The four styles can be very broadly described as (1) *untroubled*, (2) *strategic*, (3) *concerned*, and (4) *cautious* in their orientation towards psychiatric genetic research participation. Having provided an overview, I now present a detailed interpretation of the four styles in Chapters 5 to 8 and I begin with the socially engaged strategists because it sets the scene for all four chapters.

Chapter 5: The Socially Engaged Strategists

5.1 Introduction

In this chapter, I present the socially engaged style of thought, people oriented towards the public sharing of research participation, collective working and a united commitment between researchers and those with psychiatric conditions. The analysis is based on Eleanor, Debbie, Charlotte, Agnes, Chloe, Alice, Zoe, Steve, Andrew and Tony. Five are psychiatric genetic researchers and two are mental health professionals. Four individuals disclosed a mental health diagnosis and one had taken part in psychiatric genetic research. The key statements that characterise and distinguish this group are shown in Table 2.

People with this style of thought typically see psychiatric genetic research participation as ‘vital for developing new treatments and overcoming the shortcomings of current therapies’. In section two I demonstrate that, despite the view of the research as vital, people account for this view in very different ways, highlighting a breadth of imagined hopes for the future. Although socially engaged, we see this engagement arises from a variety of motivations. In section three, I describe how psychiatric genetic researchers have perceived a barrier to their potential participants as a result of disciplinary conflicts and what they see as a culture of resistance to research, and to psychiatric genetic research in particular.

I argue in section four that, for the psychiatric genetic researchers, there is a desire to give something back to those with mental health problems in exchange for participation, but that this is entangled with the need to achieve recruitment to research. Within their accounts of what psychiatric genetic research participation means, we see the strategic nature of their activities. This is evidenced from their attempts to bypass powerful mental health service gatekeepers and reach potential participants through public engagement, constructing ‘community’, and downplaying the mental health content of public engagement events. I argue that researchers’ attempts to create ‘community’ was a way to give something they

perceived to be of value to participants, and to do so in exchange for participation. However, we see that potential participants can also intervene by their rejection of these attempts. Lastly, in section five, I introduce evidence that researchers have identified a tension in trying to appeal for participation as a good thing to do without going as far as a moral obligation. This, along with their pursuance of using anonymised data without gathering informed consent, suggests that participation and what it means to be a participant is once again changing.

On the basis of findings in this chapter, I argue that what we can learn from the 'socially engaged strategists' style of thought is that participation is not only socially organised but is open to strategic interventions by psychiatric genetic researchers, interventions that are also shaped, however, by potential participants. The breadth of future hopes, the failed strategy of building 'community', and the entanglement demonstrated in this chapter highlights challenges that complicate the reciprocity and relationship between psychiatric genetic researchers and their potential participants.

Table 2: Estimated position of statement agreement/disagreement and distinguishing statements for group 2 ‘Socially Engaged Strategists’

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
8	is vital for developing new treatments and overcoming the shortcomings of current therapies	2	5	-1	2	*	Distinguishes gp 2
43	needs a united commitment from both researchers and those with psychiatric conditions	3	5	1	2	**	Distinguishes gp 2
Other statements (those ranked higher in group 2 than in all other groups)							
11	means being part of a collective working towards a better future	1	4	-2	1	***	Distinguishes gp 2
32	needs to overcome mental health specific barriers that hinder people from taking part in research	0	4	1	3		
47	provides vast amounts of data that will give us many answers in the future	2	3	0	-2		
25	means being part of informing and educating people about the causes of psychiatric conditions	1	3	1	1		
26	should be publicly shared to encourage other volunteers	0	2	-1	-2	*	Distinguishes gp 2
27	is more known about because of the increase in public discussions about mental health	0	2	0	-4	**	Distinguishes gp 2
2	demonstrates the need for a more scientific approach to mental health	1	2	-1	0		
14	means coming together to wage war on mental illness	-2	1	-3	-1	*	Distinguishes gp 2
42	incorporates knowledge from people who are experts in their own condition	-1	0	-4	-3	**	Distinguishes gp 2
40	provides a sense of ownership over the research	-1	0	-4	-1		
Other statements (those ranked lower in group 2 than in all other groups)							
21	challenges the belief that people are the instigators of their psychiatric condition	2	0	3	1		
48	has implications for whole families and not just the individual participant	2	0	1	3	*	Distinguishes gp 2
28	is likely to stimulate discussions within families about psychiatric conditions and their heritability	3	0	2	2	*	Distinguishes gp 2
18	is only focussed on extracting scientific data from human resources	-3	-4	3	0		
Statements ranked at -5							
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		
1	isn't going to help because these conditions are too complex	-4	-5	0	-5		

5.2 The multiple imagined futures of vital research

As can be seen from the estimated positioning of the statements in Table 2, this style of thought is exemplified by *disagreeing* that participation ‘is pointless’ and ‘isn’t going to help because these conditions are too complex’ but also distinguishable from other groups by *agreeing* that participation is ‘vital for developing new treatments and overcoming the shortcomings of current therapies.’ People in this group talk about the prevailing lack of effective treatments for mental health problems and the side effects of medication, resulting in what Eleanor describes as a “pressing need to develop better treatments.” Eleanor works closely with the Centre’s field team, which recruits participants and gathers data, and comments that she sees genetics as just one approach amongst many others and “the hope is that, in the future, that you can come up with treatments that work better for people basically.”

This view of a pressing need to develop better treatments is a particular feature of this group and many talked about this in relation to the ineffectiveness of medications for psychiatric conditions. For example⁷¹, Debbie has a diagnosis of bipolar disorder and described her experiences of struggling to function whilst on strong sedating medication for her condition. Debbie’s concerns regarding long-term medication for mental ill health highlight her feelings about the shortcomings of current medication-based therapies:

... I worry about how that maybe really affects people who are on it for most of their lives and whether that should be kind of the first point of call. I feel like it is at the moment because of issues with resources and therefore it’s like ... it’s kind of the better option in trying to keep people safe in some circumstances but that ... that level of sedation is also something that is a big limitation for people potentially.

(Debbie, research champion) P36

Debbie views limited mental health resources as a reason why medication is preferentially offered as a starting point to keep people “safe”. In her view,

⁷¹ In Chapters 5 to 8, excerpts will be included and use the following syntax: pauses in what is said are denoted by ..., superfluous comments that have been removed are denoted by [...], added words to improve clarity are denoted by [added words for clarity].

medication is often considered to be the initial choice of therapy as a short-term measure for financial and practical reasons but that people cannot function in this way on a long-term basis.⁷² This suggests that Debbie's support for psychiatric genetic research is centred on the development of treatments not restricted to medication, or for medication with fewer side effects better suited to long-term use.

Charlotte, a mental health pharmacist, says there's been very little change in medication within psychiatry:

... it's terrible really that all this time has gone passed and there is ... you have to start to look at other organisations that are gonna do it and the genetic research is being done in a way that they're looking at people with mental health illnesses and they're looking at people without and they're actually looking at it sensibly rather than just trying to find a drug, concentrating on the drug, they're doing it the other way round, trying to work out what's causing it so that they can think about where they can target the treatment, which to me makes much more sense but it's going to take longer.

(Charlotte, mental health pharmacist) P27

Indeed, large pharmaceutical companies have increasingly withdrawn from psychiatric drug development as a result of being unable to bring new, profitable, and more effective drugs to market, such that drugs are no different to those used 40 years ago (Nutt and Goodwin 2011; Insel and Sahakian 2012; Rose 2019).

Charlotte argues that, despite the length of time that psychiatric genetic research takes, she sees it as a more "sensible" approach compared to a persistent reliance on medications that simply alleviate symptoms without understanding the aetiology. Noticeably, her support for psychiatric genetic research is rooted in her perceived lack of change in alternative approaches, as suggested by her statement that "you have to start to look at other organisations that are gonna do it."

⁷² The UK's Improving Access to Psychological Therapies (IAPT) initiative for anxiety and depression, introduced in 2008, was later extended to severe mental illness following pilot studies between 2012-2015. However, according to Pickersgill (2019), IAPT is neither re-centring psychological approaches nor challenging the dominance of biomedical approaches.

Agnes is a retired psychiatric nurse with many years experience working in a psychiatric hospital and as a community mental health nurse. In response to whether the research is vital, she reflects on the current trial and error approach to both diagnosis and treatment:

... you can't just wave a magic wand can you, unfortunately, and you have to try the cocktails of drugs in order to find the one that suits you and you've also got to get the right diagnosis. I know this because my husband was told he was bipolar and somebody said no, it's not, and then someone else said yes he is; and the drugs that we went through were unbelievable.

(Agnes, psychiatric nurse) P12

When asked about her views on different kinds of approaches to *treating* psychiatric conditions, Agnes draws largely on her belief in a fundamentally biological approach, despite previously discussing the multifactorial aetiology of psychiatric conditions. She says: "I honestly think the building block to treatment and illness has got to be genetic, you've got to do the bloods." However, when discussing gene editing, Agnes states "there's a limit to ethics, to what we should be doing with DNA", demonstrating her objection to making changes to what "God created" and what such technology might lead to. Unsurprisingly, therefore, Agnes much prefers drug development to gene therapy, saying: "I'd be a lot happier of them developing a drug that would stop somebody from developing it than to cut it out of their DNA."

Here we see that Agnes finds the idea of gene editing very problematic and she draws a clear boundary between using knowledge, generated from psychiatric genetic research, for improved drug development versus using it to inform gene-editing therapies. Consequently, her support for psychiatric genetic research is contingent on how the resulting research might be utilised in the future, with targeted drugs regarded as much more acceptable than gene editing.

Steve, a social worker who has worked in mental health across adult and child services for over 20 years, strongly disagrees with the Q-statements that psychiatric

genetic research participation 'is pointless' and 'isn't going to help' but is unsure how vital psychiatric genetic research is:

I just think that it all needs to be quite seriously considered and what is it that we're trying to do, to what impact, you know, and if we do find something that we could ... then how do we deal ... how do we introduce this? How do we introduce it into society and how do we even introduce it to politicians because politicians ... we live in a five year span of politicians, don't they, who are thinking about the next election just after they've won the last one so they're always looking for a quick fix and a headline.

(Steve, social worker) P16

Steve sees the research itself as being beneficial but contemplates the difficulties of introducing any proposed treatments into society and how such implementation would need to be carefully thought through as part of a long-term strategy, but also how this is at odds with dealing with the short-term gains demanded by those in political power. Fundamentally, however, Steve questions the very basis of the need for a scientific approach. He argues that science is often perceived as the preferred option because changing how we organise ourselves as a society is relatively more challenging than scientific solutions. He says:

... that's harder for us to challenge and look at than [for] university scientists or scientists to come up with a solution. It's a bit like we create a problem and then we wait for science to ride to the rescue and solve it, whereas if we changed the way we did things in some way then we might not create so many of those problems anyway.

(Steve, social worker) P16

Steve also said that he "wouldn't dismiss" gene therapy or attempts to eradicate the most severe kind of mental illness, but he was concerned about the repercussions of scientific approaches for less severe mental health problems:

I always think a lot of this stuff, technology, we'll find a solution one day with the technology, it's all a bit quick fix stuff, because that would be lovely for all of us wouldn't it? You know, oh we'll modify the human genome and we'll get rid of all these diseases and we'll get rid of all that, which would be great, especially for degenerative physical diseases but it's all a bit ... yeah science has come up with a solution so that's okay now. Whether we'll *pay* for everybody to have the solution, we'll forget about that ...

(Steve, social worker) P16

Here, Steve draws attention to a disconnect between scientific progress and considerations of social inequalities that its resulting technologies may foster. He also compares the difficulties of biological approaches to addressing mental ill health with tackling the social problems and inequalities that contribute to the development of some of these conditions in the first place. Similarly, despite their enthusiasm for the therapeutic possibilities of psychiatric biomarker research, service users and carers have expressed concerns that this kind of research might be prioritised over psychosocial research (Rose et al. 2015). Such a reflection ties in with the changing sentiments about the primacy of science and technology to address mental disorders, calling for a new psychiatry grounded in its social context (Bracken and Thomas 2001; Bracken et al. 2012; Rose 2019).

Whilst many people in this ‘socially engaged strategists’ group agree participation is vital, they account for this view in very different ways. Some look to psychiatric genetic research as hope for more tailored medications in the future, others for greater understanding such that we can move away from the reliance on medication. Debates about gene editing ranged from refusal on religious grounds to resistance, except for very severe conditions, because of potential social inequalities in accessing such technologies but also the fundamental basis for its necessity. This demonstrates that this view of participation as vital is relative to the availability and progress of alternative approaches, as well as being contingent on the fundamental aims of the research in terms of its applications in society. Nevertheless, these disparate views, even amongst those who support psychiatric genetic research, highlight the breadth of imagined hopes for the future between researchers, mental health professionals and potential participants. Sociological work on regimes of hope,⁷³ imagined communities, and how public engagement is a form of social engineering based on hope, help us to understand the significance of hope and future expectations (Brown 2003; Brown and Michael 2003; Moreira and

⁷³ The phrase ‘regimes of hope’ has been used to describe systems invested in the view that the future holds promise beyond the limits of the present situation (Moreira and Palladino 2005). These systems are distinguished by their subtle embedding within and across networks and practices, and in this way they are less vocal and more subtle than the discourses of hope.

Palladino 2005; Martin et al. 2008; Arribas-Ayllon et al. 2019). However, if this hope becomes eroded, dissected and less powerful, these disparities in imagined futures potentially complicate the idea of collective working built on regimes of hope.

People in this group *disagreed* that psychiatric genetic research participation wouldn't help because these conditions are too complex, but the researchers talked about how this isn't a widely held view. Tony, who has worked in psychiatric genetic research for many years, says: "I think there's been a tendency to sort of give up hope and think these are too complicated." His colleague Andrew agrees with him and says: "I think that's a very prevalent opinion that I very strongly disagree with, these things are incredibly complex and very very difficult but that's no reason to give up."

Within the broader academic literature, however, critics argue it is time to admit psychiatric genetic research is a failed endeavour, is "probably futile", and that, despite years of funding and promises, we are no nearer to linking genetic sequences with mental states and should redirect attention to other approaches (Joseph 2012; Rose 2019, p. 183).

Giving up on the grounds of complexity is significant because, as Arribas-Ayllon and colleagues (Arribas-Ayllon et al. 2010; Arribas-Ayllon et al. 2019) have argued, so far the rhetoric of complexity has maintained the resilience of psychiatric genetic research and the marshalling of its necessary resources, including participants. However, as we see in the next section, complexity is not the only factor within these critiques; there are also disciplinary, ontological, economic and political issues at stake.

5.3 Conflict and resistance to (psychiatric genetic) research

The most prominent feature distinguishing this group, both in terms of the positioning of statements (see Table 2) and how much they were talked about in the Q-sort discussions, reflects desires for collective working and a united commitment between researchers and people with psychiatric conditions. However, this is often seen as problematic and possibly an idealistic vision. Although a number of individuals in this study talked about disciplinary conflicts and resistance to psychiatric genetic research, the researchers amongst the 'socially engaged strategists' talked about this in detail. Andrew, a researcher, outlines the problem from his perspective as follows:

There's a very ... in mental health in general the problem we have is of a ... not a shared understanding of what underpins these conditions so ... there isn't a shared belief that research is a positive good, will bring positive benefits.

(Andrew, psychiatric genetic researcher) P4

There are two key points in this short excerpt. One concerns the lack of a shared understanding about the aetiology of psychiatric conditions and the other is about the lack of a shared *belief* in research. Whilst the former signifies differences of opinion, the latter is much more fundamental and rejects the value and centrality of any kind of research but, as we will see, this may be for specific kinds of research.

Tony, another psychiatric genetic researcher, says the resistance does not necessarily arise from potential participants:

When we set up [the Centre], one of the things that we wanted to do through the public engagement campaign in that, was to sort of, as we call it, change hearts and minds about participating in research because we felt that there was quite a lot of resistance and actually that some of that resistance was coming not so much from patie... I call them patients but, whatever you call them, patients, but was actually coming from mental health workers, nurses and social workers, other psychiatrists, who actually were quite anti-research and sceptical of research.

(Tony, psychiatric genetic researcher) P24

Tony is a researcher but also a clinician. He makes explicit the fact that one of the remits of his Centre's public engagement programme was to challenge what they saw as the resistance and scepticism emanating from the people surrounding and influencing their potential participants. Andrew agrees and elaborates on what they both see to be a problem unique to mental health compared to other areas within medicine:

I suppose we see what we do as being involved with anti-stigma, yeah, raising the profile of mental health, raising the profile of mental health research particularly, trying to change the culture around research in mental health services, very different culture in mental health than there is in other areas of medicine.

(Andrew, psychiatric genetic researcher) P4

Despite introducing their activities as being about anti-stigma in general, Andrew quickly moves on to talking about raising the profile of mental health *research*. He argues that the culture within mental health services is a problem; the shared beliefs, norms and values of those working within mental health services are not receptive to research. Furthermore, when I asked Tony to elaborate on his perception that there is resistance to research, his answer illuminates that he feels the problem is not so much mental health research generally but biological research specifically:

I think that a number of people favour kind of social and psychological explanations rather than biological explanations and that's a problem, you know, the fact that clinical psychol... people are trained in different ways from different rule books, song books, play books ... and there's a big schism between psychiatry and clinical psychology about the way it's trained and it's also a turf dispute about patients as well I think, the psychologists are after a more central role I think.

(Tony, psychiatric genetic researcher) P24

It is widely recognised that there are disputes about the aetiology of psychiatric conditions and mental distress (Bracken and Thomas 2001; Pilgrim and Rogers 2005; Craddock et al. 2008; Pilgrim and Rogers 2009; Hannigan and Coffey 2011; Bracken et al. 2012; Rose 2019). The field of mental health is particularly fragmented (Hannigan and Coffey 2011) and the singular term 'psychiatry' can be misleading because of the inherent multiplicity of its constituent professionals and

incoherence of their views (Pickersgill 2012). Rose has also called for psychiatrists to be part of a rebalancing such that they “work in equal partnership with other professions and service users”(2019, p. 179).

A number of people in this study referred to these disputes during our discussions. Psychiatric genetic researcher Tony ascribed these disagreements to differences in training and the kind of patients who are referred to psychiatrists; particular symptoms suggest more of a biological or social origin. But Tony sees this not only as a matter of mind-sets, fashioned by training and clinical experience, but as what he calls a “turf dispute” with psychologists using the dispute to bolster their own discipline.

This dispute is not restricted to psychiatrists versus psychologists; Tony talks passionately about the views of fellow psychiatrists as being dismissive of genetic research and he goes on to describe how destructive he feels this disunity, “the waging war between the kind of the biologists and the psycho-socialists”, has been for psychiatric genetic research participation and funding because “we’re not speaking with one voice.”⁷⁴ Tony described representations to the UK government, from these different disciplines and professions, as a “cacophony of noise”. He also described how a strong dislike towards him, as representative of a very biological psychiatry, inhibited his interactions with clinical psychology as a discipline. When I asked how this problem might be resolved, Tony replies:

... it’s about trying to have a voice that ... allowed a voice that has a coherent message to lobby for more funds for better facilities for patients and more funds for research because both research in mental health and treatment are underfunded but as I think I touched on before, that’s partly because we’re very easily split and give very divided views on what’s important to do.

(Tony, psychiatric genetic researcher) P24

⁷⁴ In 2017, *Lancet Psychiatry* published a report, commissioned in conjunction with the World Psychiatric Association, to stimulate change within psychiatry to address some of its future challenges, calling for a renewed contract between psychiatry and society (Bhugra et al. 2017). Rose (2019, p178) claims there is incoherence in the report as a result of internal conflicts about the causation of mental disorders and more specifically about the contributory roles of biological and social factors.

Tony argues that levels of funding, and how it is divided up across research and services, are affected by how unified a field is about its priorities and approaches. He draws comparisons with cancer and heart disease, arguing that mental health's disunity means it is underfunded with an inherently unproductive and divisive competition for resources. This attention to funding opportunities and the impact of disunity on the allocation and distribution of funding may account for some researchers' desire for a more collective ways of working.

These divided approaches are particularly important for research participation because, as described in the next section, the psychiatric genetic researchers need access to potential participants, many of who are supported and guided by mental health service staff, staff that the researchers believe are resistant not only to research but biomedical research in particular.

Powerful resistant gatekeepers of potential research participants

During our discussion, Tony had talked about the stigma of mental illness being a barrier to participation, but he also talks about the stigmatised nature of psychiatric genetic research:

And that's one of the barriers but the other barriers are I think ... come from actually as I think I said last time ... often from other mental health workers feeling that they should be protecting people from research partly, I don't know, they wouldn't ... whether that's some sort of paternalism or whether it's ... I think in many cases it actually reflects an ideological view by mental health workers that they don't necessarily agree with particular types of research. And that biological research and particularly genetic research are regarded with a greater degree of suspicion by, say, people coming from a psychological or social perspective.

(Tony, psychiatric genetic researcher) P24

When I asked Tony what the cause of this suspicion might be, he referred to the troubled past of both psychiatry and genetics, the relationship with commercial drug companies and how attention has become split between pursuing the

biological and social determinants of mental ill health. Expanding on this, Tony's response became very impassioned:

... this is the thing I most disagree with 'is a short step towards eugenic practices', that actually what we're doing here is that we're just going to be writing people off and saying there's nothing we can do for you because you've got this particular profile or, worse still, we'll be aborting people because they might develop a particular disorder.

(Tony, psychiatric genetic researcher) P24

In such a contested field of research, these different perspectives are to be expected; the problem for psychiatric genetic research arises when those disciplines and professions are gatekeepers to potential research participants. In this way, they are then not only gatekeepers but are resistant, powerful gatekeepers who may advise, or preclude, potential participant's decision on whether to participate. Research suggests that, in addition to contextual issues such as lack of time and competing activities, there is gatekeeper bias due to a mismatch between gatekeepers' judgement and potential participants' own perceived capacity or vulnerability (Hughes-Morley et al. 2014; Roberts and Kim 2014; Alexander et al. 2018). Gatekeepers tend to underestimate the importance of research to potential participants and to overestimate vulnerability compared to the participant's perspective (Roberts and Kim 2014), although it is unclear whether this is because of undue paternalism or an appropriate sensitivity to the presence of vulnerability.

Eleanor, who co-ordinates research within the Centre, describes her previous reliance on mental health services for access to participants:

I go and present to MDT⁷⁵ meetings and talk to people about the research that we're doing and try and encourage them to refer participants to us but I guess, when I was a PhD student and in previous roles, I've relied kind of entirely on mental health services to refer participants into my studies ...

(Eleanor, psychiatric genetic researcher) P31

⁷⁵ MDT meetings are multi-disciplinary team meetings designed to improve the quality of care for people within mental health by incorporating perspectives from multiple disciplines, although the effectiveness of these teams has been disputed (see Raine et al. 2014).

This comment of previously relying entirely on mental health services highlights the power that these resistant gatekeepers have had, a resistance that, according to Andrew and Tony, is unique to mental health. According to Tony, these gatekeepers are withholding willing participants who “once you get to them” are appreciative of the value of research. Eleanor confirms this and, from her experience, describes participants as being helpful and trusting and “generally people are quite willing to help and take part.”

As can be seen in the following extract, Andrew agrees with Tony and sees mental health service staff as a barrier to accessing potential participants. In the extract, Andrew frames his perspective by making comparisons with cancer research and talks about how, unlike in mental health, there is a culture within cancer clinics whereby patients expect, and are expected, to be part of a research trial because of what he sees to be a shared belief that research will improve understanding and treatment. Andrew openly laments that mental health is not like cancer in this respect:

Cancer’s the prime example where the third of patients coming through cancer services actively participate in research and it’s an expectation, and a belief, a strong belief in services amongst clinicians, amongst patients, that through research things will get better and it’s been a real ... (heavy long sigh) [...] so one of the remits of [the Centre] is to try and change that culture that exists around research, the very paternalistic culture in mental health services about protecting people ...

(Andrew, psychiatric genetic researcher) P4

This comparison with cancer research is not an unusual rhetorical strategy for psychiatric genetic researchers (Lewis and Bartlett 2015); as a research endeavour, cancer has been seen as a success. Waging war on mental illness, as described in the opening paragraph of Chapter 1, is a direct reference to the war on cancer in which, since the 1970s, metaphors of war galvanised substantial support and funding for cancer research (Sontag 1991; Marshall 2011; Ledford 2014).⁷⁶

⁷⁶ This war metaphor is also problematic and is discussed further in Chapter 7.

It is also clear from this excerpt that Andrew agrees with Tony's belief that mental health services are a barrier to participation. Their view is that people would be more inclined to take part but gatekeepers prevent or discourage this participation because they don't share the same beliefs as them, and others in the Centre, about what underpins these conditions.⁷⁷ Whilst this apparent discouragement to participate might be seen as protecting people from harm, Andrew also views this as being a result of a strong paternalistic culture within mental health services, whereby staff consider themselves to know what's best for the service user without their consultation.

Aside from the need for participants, this problem with gatekeepers might explain why the Centre chose to put great efforts into their public engagement programme, bypassing the gatekeepers and attempting to reach potential participants directly.

To sum up so far, psychiatric genetic research participation is seen as vital but the psychiatric genetic researchers in this group have perceived a resistance from gatekeepers within mental health services. They attribute this to a culture of resistance to research and antipathy towards their biological positioning within conflicting views about the aetiology of mental illness, thus creating a barrier to recruiting participants. Psychiatric genetic researchers regard public disputes between psychiatrists and psychologists, but also within different factions of psychiatry, as divisive and disruptive, making a coherent approach to understanding and treating mental illness a challenging task. Consequently, this has repercussions for research recruitment and, as I will demonstrate in the next section, the researchers have risen to this challenge in a number of strategic ways.

⁷⁷ From the perspective of mental health service staff, there is also another aspect here that is to do with duty of care: mental health care staff may view participation in research as being an unnecessary risk to their clients or a burden to their own heavy and under-resourced workload when there is no obvious immediate benefit to that individual (Hughes-Morley et al. 2014; Loades et al. 2019).

5.4 Strategic collective working, giving back and getting the job done

Andrew considers the desire for a collective vision to be idealistic. He acknowledges there are problems with collective ways of working and, during our discussions, often talked about how things *should* be rather than how they are:

I do feel that this is ... and this is the idealistic thing, ideally it should be people with lived experience, clinicians and academics coming together to solve a tractable problem ... and this is why I've put that there is that ... I'm very much in the ... this is going to be bloody difficult and it's going to take a long time and it's early doors

(Andrew, psychiatric genetic researcher) P4

Andrew describes this process of “coming together” as being at a very early stage, protracted, and extremely difficult. The problem itself, i.e. that of a better understanding of psychiatric conditions and how to address and mitigate the distress arising from them, is clearly considered to be something that is possible to deal with given time. According to Andrew, the difficulties arise not from the problem itself but from the social relations between the various people involved. And yet, many of these difficulties arguably persist because of the prevailing prioritisation of biomedical research and biomedical approaches to psychiatry and understanding mental illness. Rose (2019, p. 197) calls for a new psychiatry in which there is a coming together to radically change how psychiatry goes about gaining this knowledge and understanding, a change in which biological research is embedded within a foundation of social research, calling to “relocate these disorders in their social context.”

Andrew also talks about how the research hinges on participation as an act of giving with no expectation of immediate benefit to individuals:

I recognise that actually without the participation of people, without building, people giving their consent and, you know, giving ... there's something in there saying about it's something that they give without any individual immediate benefit, without that the research is nothing ...

(Andrew, psychiatric genetic researcher) P4

This demonstrates how crucial the participants are seen to be to the research and how central the idea of 'giving' is. Arguably, research scientists benefit greatly from the research in terms of careers, salary, publications and prestige, but both Andrew and Eleanor argued that participants do benefit. Eleanor described what she considers to be the motivation behind people taking part: to make things better for their own families in the future, despite not being paid and the unpleasantness of donating blood, and that they "like the opportunity to be able to tell their story and often do get quite a lot out of it."

Validation of the illness experience is important, especially when services are underfunded and participants are limited in the time they are given to discuss their personal mental health history in depth. Andrew highlighted this was an advantage for participants but he also recognised the power of the 'patient' voice. In talking about public engagement and encouraging people to take part in psychiatric genetic research, Andrew gives primacy to the voice of those with lived experience of psychiatric conditions over the research scientists:

And yeah I'm a very strong believer that that voice of people with experience of the condition and experience of the research is much more important to hear and much more effective to hear than dry academics talking about science.

(Andrew, psychiatric genetic researcher) P4

This belief in the relative importance of those with lived experience is partly on the basis of what is most "effective" in terms of inspiring other potential participants. Those with lived experience, and in particular those who can also endorse the participation process, are seen as having much more leverage than those with scientific knowledge.

Similarly, Tony also talks in a distinctly instrumental way when describing how greater public disclosure and discourse about mental ill health provides a mechanism for people to acknowledge such problems in their own families, thereby raising support for research and its funding:

... if we can get people to start talking and being upfront about it and ... which is happening, that will drive the funding because people will be able to acknowledge that these are problems that they have or their families have and feel more personally connected with it.

(Tony, psychiatric genetic researcher) P24

Tony argues that when people feel a greater connection to a problem, they are more likely to want to do something about it. Andrew similarly demonstrates the desire for a more research-enthusiastic society:

... the other thing that comes into that one is the need to not just get participation but to feed back, to keep in touch with people, to let them know about progress and the research and I think that's been something that we've felt is really important as well so that we produce newsletters and let people know about the work that's been done and I guess the idea with that is that you enthuse them and they're hopefully gonna spread the word and tell other people about it ...

(Andrew, psychiatric genetic researcher) P4

Andrew describes how the Centre's efforts to keep in touch with their participants are not just about feeding back, so that people are aware of the progress being made as a result of their participation, but is also about encouraging further participation. So, this motivation for feeding back is entangled with the desire to "enthuse people" so that they "spread the word" about the research which, in turn, would encourage other people to take part.

These strategic instrumental gestures are embedded within gestures towards giving back something of value to people's lives:

... equally, we're a centre looking to improve the lives of people with mental health problems and obviously we can do that through scientific research but we can also do it more immediately through raising awareness and giving things back like information and having a website with lots of information on it and we deliver psycho-education and things like that. So, yeah, it's all part of that really.

(Eleanor, psychiatric genetic researcher) P31

From Eleanor's perspective, such acts of giving-back serve as signals to participants that this is not just about achieving the scientific research of psychiatric genetics but is part of a broader remit to improve lives for those with mental health problems. However, as we will see, researchers and participants may not have similar views of what 'improving life' means, which may complicate this offer of 'giving back'.

When discussing the Centre's success with public engagement activities for recruiting participants, Eleanor talked about how they have developed, with advice from people with lived experience, a branding that is geared towards making the Centre and field team approachable, friendly and non-threatening:

... our literature and things, rather than being really boring and academic looking, we spend a lot of time and effort kind of having a good sort of brand and attractive pictures and we get the opinions of people with lived experience on our materials so I think we've created a good sort of brand for want of a better word that makes us look quite approachable.

(Eleanor, psychiatric genetic researcher) P31

Sharing stories of participants' lives and experience of participating in the research, both online and off, also helps to create the impression of a community of participants.

Constructing community: seeking social mechanisms to increase participation

STS work on 'communities of promise' has proposed the existence and shaping of 'imagined communities' surrounding science and technology (Anderson 1983; Brown 2003; Martin et al. 2008). According to these theories, such communities are spread across time, space and disciplines in which individual hopes and the promises of science are brought together as a community, via the imagination, through which relations are stabilised. People in this community are invested in the development of some *intangible* future whereby the work of hope, in the past and present, serves to create tangible structures and networks of belief systems upon which promise becomes collective rather than individual. And yet, it is important to

tease apart what it means to be a community and what that provides, or purports to provide, over and above a collective of individuals.

Steve, the experienced social worker we heard from earlier, provides an example of the kind of view that highlights differences between collectives and communities. When asked about the various Q-sort statements related to coming together, having a united commitment and being part of working in a collective way, Steve responded through considering how our needs are met beyond that of the individual and talked instead of community:

... we're all interrelated and interlinked to somebody in some way for our basic needs and our general wellbeing. It's kind of like, it's alright to have all your individual aspirations and wants and likes and dislikes but it's all interrelated with how you are as a community...

(Steve, social worker) P16

Steve emphasises the primacy of community and communal living such that he considers the desires and “aspirations” of the individual as being subordinate to meeting basic needs and wellbeing, achieved through the relational connections of larger groups such as that of a community. From Steve’s perspective, individuals thrive within communities.⁷⁸

According to Etzioni (1996; 2000), authentic good communities involve an affect-laden criss-cross of relationships that reinforce each other and become networked and interlinked. This particular notion of community is something the Centre attempted to foster in building their cohort of research participants. Eleanor says:

So, in [the Centre] we've had lots of discussions about kind of making people feel more involved and making it feel more like a community. And we've had lots of discussions about what to call ourselves [...] and pitched the idea [to their PPI⁷⁹ group] of calling ourselves a community and I think most of them had taken part in the research and they

⁷⁸ I would argue that Steve’s view reflects that of neo-communitarianism which Etzioni has put forward as a balance between providing opportunities for individuals to pursue their own interests whilst enhancing their ability to contribute to the production of community level outputs (Hoedemaekers 2007; Etzioni 2009, 2014).

⁷⁹ PPI is patient and public involvement.

were like 'it's not a community, you can't call it that because it's definitely not a community'. So, even though we sort of try to make people feel part of something by sending regular newsletters and tweeting and Instagram and Facebook, having a website with lots of blogs, we really do try and engage people and make them feel part of something, I think that's a very difficult thing to achieve and I don't think we have achieved it and I don't think the majority of our participants, possibly with the exception of our research champions, feel like they're part of it really, even though we'd like them to, if that makes sense.

(Eleanor, psychiatric genetic researcher) P31

According to Eleanor, the PPI group strongly disagreed with the idea of naming the cohort of participants a community and many participants, for whatever reason, have not taken up the researchers' attempts to create a community feeling. Eleanor affirmed this saying: "Yeah, they didn't feel that it was a community in the slightest so ... they felt like they were people on a mailing list essentially." When I asked why the Centre wanted to foster this sense of community, Eleanor replied:

I think, again, because they've given of their time and, you know, we want to stay in touch with them, we want to follow them up over time so we want to keep them engaged because we send out follow up questionnaires and things so we'd like to retain them as part of the cohort, for them to potentially take part in other bits of the research in the future. And, yeah, just because they have taken part and they have contributed to it and it would be nice if they saw our findings as kind of something we've all achieved together really.

(Eleanor, psychiatric genetic researcher) P31

What can be interpreted from Eleanor's response is that there are dual motivations for attempting to foster a sense of community. One is emotional, a desire for a joint sense of achievement; the other is very practical and strategic and concerns participant retention for further research. The PPI group's rejection and Eleanor's comments above suggest the instrumental nature of this desire for community but also call into question participants' view of its authenticity. Indeed, participants have been found to attend to symbolic cues of reasonable practice when they make judgements about whether to 'cooperate' with research (Dixon-Woods and Tarrant 2009). The possible appropriation of 'community' also reflects existing critiques of the discourses of partnership, community involvement, and active citizenship, seen

as a means to galvanise the provision of tissue samples (Tutton 2007; Woolley et al. 2016) and capture the public (Raman and Mohr 2014).

That these activities are entangled is further reflected in the Centre's public engagement events. According to Eleanor, public engagement events that are explicitly stated to be about mental health are not well attended.

We do get the same handful of people basically and we have sort of found that if we don't make it an event about mental health specifically, more people tend to come but if you put 'this is an event about mental health', they don't really come, they don't, whereas if you make it sort of more general and just a nice thing to do, people tend to come more then.

(Eleanor, psychiatric genetic researcher) P31

Eleanor observes that if an event is branded as a mental health event then they get fewer numbers of people attending. Strategically, they have learnt to downplay the mental health elements of their events, making them more enjoyable for people to attend but also to increase the number of people attending. Therefore, these are less about providing information or addressing issues to do with mental health and more about offering a communal experience to existing participants or increasing opportunities to recruit participants, thus demonstrating again the entanglement between giving back and accomplishing science, this time through creating community.

A group of people that Eleanor felt the Centre had succeeded in making feel part of a community were their research champions. Similar to an advocate, who publicly supports a particular cause or policy, a champion supports the cause more vigorously. At the Centre, research champions are people who have already taken part in psychiatric genetic research and have been approached by the Centre to share their story and experience of participation in order to encourage others to take part. They attend public engagement events, possibly giving public talks. Below, Eleanor comments on the value of research champions and how the Centre works with them to encourage others:

And we also rely quite heavily on our research champions, they're people with lived experience who have taken part in our research and are willing to tell their stories and encourage other people to take part as well. So, us working with them to encourage other people to take part, I think, is kind of part of the recipe for why [the Centre] has been successful in recruiting that number of people.

(Eleanor, psychiatric genetic researcher) P31

Again, working with champions to publicly share their story and experience of participating in the research demonstrates another effective social mechanism that leverages increased recruitment. For example, Debbie, who has a diagnosis of bipolar disorder, has taken part in psychiatric genetic research but has also become slightly more involved by becoming an advocate for the research as a research champion. In comparing how she felt by just participating versus being approached to be more involved, Debbie describes how she then felt part of something bigger and when asked if she felt part of a collective, she described this feeling using the language of community instead:

I feel that it's sort of like a community in a sense but yeah I'm not sure. I guess I felt like I ... doing just the participation in the research that, that I was just sort of a participant and that I contributed but that was kind of it, that was my first feeling and I was glad that I'd done it and hopefully it has a good impact but I sort of link ... this is a little bit ... with the idea of like having an ownership of the research, kind of a thing, which is like ... that's not something that it felt like for me, so I didn't feel like I was an integral part of it but just kind of one sort of cog in it I guess, you know, so ... but in a sense, since then being a research champion and things, yeah, I feel sort of, I guess more part of a community in that sense, part of a wider sort of a campaign ...

(Debbie, research champion) P36

Debbie talks about being a cog and not feeling an integral part of the research nor having a sense of ownership over the research; this made her feel that her contribution was limited when she was only providing a blood sample and personal history. By being asked to become more involved as a research champion, she felt she was contributing in a wider sense and has begun to feel part of a community of people although her response is very hesitant. This is most likely because she had only recently become a research champion but it could also reflect her uncertainty in the status of community in this context. Although limited, the change in feelings can be viewed as the direct result of having been asked to be a research champion

and has brought about an active feeling of being part of something bigger, thus making the approach a potential social mechanism to effect greater participation amongst others. This suggests that becoming a research champion has the potential to produce some sort of transformative change, not only in recruitment rates but also in what it means to be a participant, or conversely, in what it does not mean to be a participant. Hearing from both Debbie and Eleanor, I'd argue that being a research champion might provide a sense of community but being a participant does not.

So, we see how the goal of having a collective and a united commitment is a feature of those in this group but that, for the psychiatric genetic researchers, there is the added motivation of fostering a sense of community to enthuse existing participants to "spread the word" and encourage others to take part. What we see in this group is that the use of research champions provides a social mechanism for engineering a feeling or perception of community.

In the final section, I introduce comments made by researchers in this group that are relevant for the wider discussion on participation as a responsible thing to do (statement 4) and as a moral obligation (statement 17). It is important to note that the positioning of these statements were not found to be a feature of the 'socially engaged strategists', at least not something that typified them as a group or distinguished them from other groups (See statements 4 and 17 in Figure 5 and their absence from Table 2). However, as we will see in subsequent chapters, these statements were significant for distinguishing other groups and the following discussion provides invaluable insights that will help in drawing some of those later findings together more robustly.

5.5 Responsibility, obligation and bypassing informed consent: a side note

As discussed in Chapter 1, there have been calls for research participation to be compulsory or viewed as a moral obligation on the grounds that prioritising

autonomy hinders research unnecessarily (Harris 2005; Schaefer et al. 2009; Rhodes 2010). The majority of people in this 'socially engaged strategists' group agreed that participation is a responsible thing to do but disagreed, often very strongly, that participation should be a moral obligation. However, when talking to the psychiatric genetic researchers about these particular statements, a tension became evident concerning how far to pitch participation beyond it being a responsible thing to do and towards it being a moral obligation.

I think it's down to the individual, no-one should feel obliged to take part in research, it's down to them but if I had a mental health problem, I would feel responsible to take part in the research but no-one should feel obliged.

(Eleanor, psychiatric genetic researcher) P31

Eleanor attempts to consider how she would feel if she had a mental health problem. She provides a typical response of the majority of people in this study, highlighting a distinct moral separation between participation as a responsible thing to do and the more negatively viewed proposition of being made to feel obliged. This concurs with previous findings that people in the UK see research participation as a good thing but not morally required (Dixon-Woods and Tarrant 2009; Schaefer et al. 2009).

But there's a certain point at which research participation *relies* on that feeling of it being a responsible thing to do and, despite its negative connotation, in tipping into a sense of obligation. Andrew describes this tension as follows:

There's a tension isn't there, there's a tension between ... in upping that obligation factor and putting that ... but actually trying to get people enthused and excited and being part of something that you feel is really potentially important and will bring benefit ... and there is a tension between that, how far does that go into putting an obligation on somebody.

(Andrew, psychiatric genetic researcher) P4

Andrew's main concern is about the tension between generating feelings of belonging, enthusiasm and excitement compared to the negative impact that might occur from "upping" that sense of obligation to take part. Andrew is concerned

about going too far in the push towards making people feel obligated but alternative strategies of recruitment potentially evade these moral dilemmas.

I guess that's the other thing about this whole debate about whether ... being able to do research on samples and with electronically collected data that's anonymised, that doesn't involve consent, gets into that as well doesn't it because then ... that removes that element of ... we try our best to make it as free for people to make that decision but people make those decisions within a power relationship with their teams and their clinicians and their ... so maybe that would be an argument to say that this is really important work that needs to be done but actually we should do it in a way that doesn't involve putting people in that position where they have to make that call, I don't know.

(Andrew, psychiatric genetic researcher) P4

Tony confirmed Andrew's view and spoke very passionately about recruitment and retention problems for schizophrenia research:

A lot of the work we do is collaborative because that's the only way that you can get the size samples that you need for these large genetic studies. We've actually ... the other way we've done it ... is we've recruited people anonymously through the blood test that you have to ... have to be on clozapine so we can obtain their blood without consent because it's anonymous you see.

(Tony, psychiatric genetic researcher) P24

Whilst this strategy contravenes a long history of the use of informed consent, it is proposed on the grounds of alleviating any sense of personal blame on the part of the individual if he/she decides not to take part. Hoedemaekers and colleagues (2006) have argued for reducing control over personal data and samples, for particular kinds of genomic research on conditions that seriously impair autonomous and social functioning. As discussed in Chapter 1, debates about when obligation or reducing control might be acceptable involve assessing the balance of public good versus individual risk, but also treating consent as an on-going contextual process rather than a single event, recognising the blurred boundaries between clinical practice and research, and ensuring a duty of care towards participants throughout the research (Coleman et al. 2003; Walley 2006; Ponder et al. 2008; Ursin and Solberg 2008; Townsend and Cox 2013)]. According to Kerr (2003), this should include a governing process that does not rely solely on research

organisations' judgement of whether and how their research contributes to the public good.

5.6 Conclusion

Arribas-Ayllon and colleagues (2019, p. 181) have previously described psychiatric genetic research participation as social engineering based around hope, involving "instrumental visions" aimed at gatekeepers in order to gain access to potential participants. Whilst imagined futures based on hope were a feature for this style of thinking, findings from this chapter suggest researchers' attempts at more short-term social mechanisms to effect recruitment. Researchers sought to construct 'community' and a sense of belonging for their participants, using research champions as a social mechanism to engineer a feeling or perception of community. In the context of psychiatric genetic research with its troubled history, disciplinary conflicts and perceived resistance from within mental health services, creating a regime of hope with gatekeepers was arguably too challenging; bypassing the gatekeepers altogether proposed a more effective strategy.

Consequently, researchers focused their sights on more tangible offerings, providing training, information, enjoyable public engagement events, and a sense of community, both online and off. I argue this desire to give something back of perceived value to those with mental health problems is entangled with the need to achieve recruitment to research. There are three pieces of evidence for this: (1) that researchers recognise that participation and public discourse provides an opportunity for participants to validate and express their illness experience while also acknowledging it as an effective form of leverage to advocate for further participation and funding; (2) that desires to "feed back" and share a sense of achievement in the progress of the research also serves to enthuse participants to encourage others to take part and (3) that creating the impression of a community and trying to provide a communal enjoyable experience for participants was also an

attempt to retain their on-going engagement and contribution to the cohort of research participants.

Framing 'participant' as community member demonstrates how psychiatric genetic researchers have attempted to socially intervene in what it means to be a participant. Following Brown (2003) and Arribas-Ayllon and colleagues (2019), I argue that psychiatric genetic researchers offer hope of better therapies in the future in exchange for research participation. However, when this hope begins to falter, because of delays in the potential for therapeutic outcomes, I further argue that alternative strategies become necessary. Similar to the provision of information and training, the provision of enjoyable events and a sense of community can be seen as a similar form of exchange. As such, researchers see these public offerings as potentially filling the gap left by waning hope and providing an opportunity to bypass powerful gatekeepers to potential participants.

The following chapter, drawing more heavily on the accounts of existing research participants who strongly support psychiatric genetic research, demonstrates the rejection of a community experience in favour of what they see as a more perfunctory collective activity involving responsible effective action towards helping others, located in scientific research participation.

Chapter 6: The Untroubled Progress-Seekers

6.1 Introduction

This group see participation as part of a collective scientific process involving researchers and those with psychiatric conditions but reject the social bonding that might be expected from the idea of belonging to a community. What we can learn from these ‘untroubled progress-seekers’ is that, despite being very supportive of psychiatric genetic research, attempts to foster a sense of community are likely to be seen as irrelevant, ineffective or inauthentic for this group of people. However, trust in the research, and a strong sense of participation as an active and responsible way to help others, provides evidence to suggest there is some basis for a solidarity-based view of participation from people with this style of thought.

I present the analysis of qualitative data from 13 people identified as ‘untroubled progress-seekers’. Four were female and nine were male, spanning a wide age range and, of these, two were psychiatric genetic researchers and two were mental health professionals. Over half of this group have a mental health diagnosis, many of who have taken part in psychiatric genetic research. In this chapter, we hear from a range of people from within the group. Russell has participated in psychiatric genetic research and is a research champion and Jane has repeatedly taken part in genetic research, including for psychiatric conditions. Ellie and Megan take part in online discussions about mental health whereas Philip is heavily involved in mental health activities as part of public engagement and public health; all three have also taken part in psychiatric genetic research. Lawrence and David are both researchers within the Centre and Oliver is a mental health professional.

The key statements that characterise and distinguish this group are shown in Table 3 and tend to relate to the scientific, rather than socio-ethical, aspects of psychiatric genetic research participation. In section two, I show how people with this style of thought see scientific research participation as an effective action compared to other ways of being involved in mental health, have greater expectations of potential participants and are likely to suggest more extreme methods to increase

participation. This group agrees more strongly than other groups that participation is a responsible thing to do to help others. In section three, I argue that whilst the group generally claim obligation is too much of an infringement on people's autonomy, they do not consider framing participation as a responsible thing to do to go far enough. These views reflect, as shown in section four, their strong support for psychiatric genetic research, their belief and trust in science, its procedures and its governance. Consequently, as illustrated in section five, participation is seen as part of a practical collective process for achieving research outcomes rather than an opportunity to be part of a collective *experience*.

Table 3: Estimated position of statement agreement/disagreement and distinguishing statements for group 1 ‘Untroubled Progress-Seekers’

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
4	is a responsible thing to do to improve the understanding of psychiatric conditions	5	1	0	0	***	Distinguishes gp 1
41	means being part of a realistic hope of treating mental illness	5	1	0	2		
Other statements (those ranked higher in group 1 than in all other groups)							
22	means accepting the biomedical model of mental illness	4	-3	0	-3	6*	Distinguishes gp 1
44	means someone is really listening and trying to understand psychiatric conditions	4	1	-2	-1	*	Distinguishes gp 1
30	needs government and funders to focus more attention and money on this kind of mental health research	4	2	-2	0		
6	means challenging the diagnostic criteria of the past	3	1	0	1	*	
28	is likely to stimulate discussions within families about psychiatric conditions and their heritability	3	0	2	2		
19	is no different to taking part in research about other health conditions	1	-1	-2	-4	6*	Distinguishes gp 1
Other statements (those ranked lower in group 1 than in all other groups)							
32	needs to overcome mental health specific barriers that hinder people from taking part in research	0	4	1	3		
45	means people overcoming a distrust of research(ers)	-1	0	1	2		
38	will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems	-4	-2	3	-3		
Statements ranked at -5							
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		
36	is promoting an idealised vision of scientifically perfected human beings	-5	-3	2	0	*	Distinguishes gp 1

6.2 Participation as a means of effective action

Analysis of the individual Q-sort accounts from people in this group suggests they view psychiatric genetic research participation very positively compared to other ways of being involved in mental health. Many people with experience of mental ill health in this group were involved in mental health activities in some way and had taken part in psychiatric genetic research. They view participation in research as an effective form of practical action towards understanding and treating psychiatric conditions; they want action and see scientific research as a route to progress.

Russell, for example, has a diagnosis of bipolar disorder, has taken part in psychiatric genetic research and is a research champion. He's given public talks about his experiences of taking part in the research and shared his experience of dealing with both his diagnosis and his condition. He's on social media and is aware of the various campaigns that aim to increase the discourse surrounding mental health. Despite being motivated to take part in research and share this experience at various mental health events, Russell described the reasons for his limited input into most online activities related to mental health as being his cynicism about who's actually listening and the desire for practical effective action:

So, I guess the short answer is no, I don't sort of take part in a lot of that kind of stuff, like bipolar day and international this day and that day. I don't think it's, I don't know, I never know what good it does, that sort of ... yeah, I don't know ... that sort of 'let's break the stigma' and ... it's weird, I guess it's what you believe works. I think this sort of thing is useful, like actual research I mean.

(Russell, research champion) P35

Russell is selective over how he participates in activities related to tackling mental health problems. He wants to see action but he wants to be involved in things that he feels "works" and are "useful", arguing he's uncertain whether anyone is really paying attention to the various postings distributed on the Internet. Russell sees research as a more useful endeavour compared to awareness-raising for mental health; he is cynical about the value of social media and the various mental health related campaigns because he thinks the Internet is overloaded with information.

He says: “Yeah I think there's so much, like there are so many ‘international day of’ that there’s kind of like a fatigue in the general population.”

Russell feels that, despite the need for the general population to be paying more attention to the issues within mental ill health, posting comments on social media does not seem to be that effective. In comparing mental health related activities with taking part in psychiatric genetic research, Russell goes on to discuss the need for his struggles to be heard. However, this is not a desire for people to hear about what his struggles are as such but a need for those struggles to be taken seriously and, significantly, to be acted upon.

It's probably couched in slightly emotional terms for me because I think it's important for me to know that someone *is* listening without wanting to sound too wishy-washy about it but I guess something concrete is being done, this is proof that something concrete is being done by people who want to do something about psychiatric conditions and understanding them better so yeah, that's why probably.

(Russell, research champion) P35

What can be understood from Russell’s comments is a sense that he views such online campaigns and discourse as being superficial in terms of definite and positive action whereas he sees research as more substantial. Russell’s personal struggles with his condition mean that he needs to know that there are activities taking place that go beyond words, and that there are people seeking understanding in order to take action, rather than simply for awareness-raising about mental health.

Russell is not alone in this view. Philip is a prolific mental health advocate and has similar feelings towards the kind of mental health campaigns and activities that he feels are not action-oriented. When asked about mental health campaigns, Philip said:

I think a lot of them just pay lip service to err ..., I don't think they have any real gravitas really. You know, the conversation never moves on. It's like, stop raising awareness! I've not seen a conversation yet, they're very awareness raising ... it used to anger me, now it embarrasses me.

(Philip, mental health advocate) P1

When asked why it made him embarrassed, Philip responded “Come on guys, we’re better than this.”

Philip has a diagnosis of bipolar disorder and has learnt to live with his condition over many years. He has been heavily involved in various mental health related activities, both through work and because of his personal experience. Philip pointed to a number of the statements that he felt reflected both inaction and the kind of sentiment that enabled people to have an excuse not to be more involved; he commented on one specific statement that summed up his visible frustration:

... it’s almost an excuse not to do anything, you know, it’s not a fact, it’s not an action ‘is an empowering and positive [thing] that helps the individual’ is an emotional state not ... it doesn’t ... it doesn’t *achieve* anything.

(Philip, mental health advocate) P1

Philip makes clear that, in his opinion, the positive feelings gained from taking part in psychiatric genetic research is a poor substitute for research outcomes; he wants action in the form of practical scientific outcomes. He is also not tolerant of the idea that people may participate for their own emotional benefit, viewing this as an “excuse not to do anything.”

... and I find statements like that ... and I brand them as hippies because it’s almost enough for them, it’s the *minimum* that you need to know to feel that you’re doing something ...

(Philip, mental health advocate) P1

Philip’s comments reflect his strong activist-like mentality but also the practical unsentimental nature of his activities, something that came across throughout our discussions. His comments also suggest that he questions whether people are incurring similar ‘costs’ in terms of the effort they are putting in; his desire for action resonates with Prainsack and Buyx’s (2017, pp. 41-45) conceptualisation of solidarity as a practice, which they insist should involve some external expression rather than only a feeling.

Jane also has a diagnosis of bipolar disorder and has been on medication for many years. She is a strong believer in genetics as an explanation for her family history of mental illness and has taken part in a number of genetic studies that originated from her desire to find out more because of her child's symptoms. Jane describes the need for people to incur inconveniences in order for science to progress and talks about how science would be affected if people did not participate in research:

Yeah, yeah, where would science be without people doing these things you know, I mean you're not going to move forward ... they go on about animals being tested and they hate animals being tested, what else are they going to test if they don't test animals, you know? I mean they haven't got to squirt things in your eye, they just take some blood.

(Jane, mental health support group user) P9

Jane highlights the dependence of science on people's willingness to participate and to donate blood, she describes the donation of blood as being unproblematic, limiting her justification to the physical process of blood donation itself and making comparisons with objections against animal testing. This view of psychiatric genetic research as relatively unproblematic is a theme that I will return to in section four but, for now, we see from these extracts that incurring costs to help others is important to this group and genetic research is seen as an effective route to progress.

David, a psychiatric genetic researcher, also favours a scientific results-based kind of action. His own research depends on a large number of participants and he believes participation is a good decision, so much so that he advocates for all newborn babies to have DNA samples taken for the purposes of research:

I mean, my personal view, I think everyone should have their DNA taken at birth and put in for some of these studies, these medical studies, to get the maximum amount of data that we possibly can and link that to health records throughout life and I reckon within the next 50 years probably cure most of these conditions if that was the case.

(David, psychiatric genetic researcher) P25

Optimistically, David considers that the routine gathering of DNA en masse with subsequent linkage to health records is an approach that will provide cures for the

majority of psychiatric conditions, such is his belief in the value of genetic data for understanding and treating these conditions. David is keen to maximise the potential amount of data available for the purposes of research, proposing an alternative approach to secure more DNA samples. Whilst talking to David, his comments suggested a desire to take control of, and improve on, the current participation rates by circumventing the need to *persuade* people into taking part. David had said that he does not want people to feel pressured to take part but he quickly moved onto talking about this in terms of maximising the number of participants by making DNA donation standard practice unless people choose to opt out:

I think it should be like the organ donation consent set up now so it's an opt out system, so that if you don't want your data to be included in the study then you can opt out potentially but, as a default, everyone's data should be included.

(David, psychiatric genetic researcher) P25

David's comments demonstrate his desire to change the current system of recruitment for psychiatric genetic research to secure as much data as possible, to take control of the collection of data, and to pre-empt the need to attract participants and what that entails. Such desire sits amongst ideas of presumed consent and its success relies on people being aware that this is standard practice and the majority of people being in favour. However, work in the 'sociology of ignorance' reminds us that, in practice, presumed consent is an aggressive strategic social mechanism that relies on the ignorance of people in order to secure research samples (McGoey 2012; Hoeyer et al. 2015). As discussed in Chapter 1, controversial initiatives such as care.data and deCODE highlight some suspicion of presumed consent. Potential participants may well agree with some of the assumptions embedded within a presumed consent proposal, given the high level of support for genomic research and its possibilities. However, proposals for research governance that foster openness and transparency, and that are founded on dignity and respect for potential participants, are preferable for maintaining mutual respect and reciprocity between individuals and research organisations (Prainsack and Buyx 2013). From this perspective, having a framework in which potential

participants give individual consent to be governed would be preferable to presumed consent.

As these examples highlight, participation is viewed by this group as a practical demonstrable and effective action towards tackling psychiatric conditions, more useful than simply a feeling or less tangible form of support. They are very confident and optimistic about possible future advances resulting from psychiatric genetic research and analysis suggests people in this group would advocate more extreme methods to increase participation.

In the following section, I demonstrate that a number of people in this group feel very strongly about taking part in psychiatric genetic research despite not always explicitly stating that people should feel morally obliged.

6.3 Participation as a responsible thing to do but not quite a moral obligation

Everyone allocated to the 'untroubled progress-seekers' agreed with the statement that psychiatric genetic research participation 'is a responsible thing to do' and, as a group, agreed with the statement much more strongly than any of the other groups. Q-sort analysis demonstrated that this statement significantly distinguished the group from all other groups and qualitative data highlighted three aspects of their accounts related to this statement:

- Why wouldn't you help?
- Help rather than complaining
- Help others in need

For example, Russell has a strong belief in science as a way forward for understanding and treating psychiatric conditions, including his own condition of bipolar disorder. He has participated in psychiatric genetic research and advocates for others to take part but was quite dismissive when discussing the idea of it being

a responsible thing to do. He has previously been asked at public events about why people should participate, to which he has responded: “if you can help then why wouldn’t you?” The question of whether it is a responsible thing to do, for Russell at least, is replaced simply by the possibility to be helpful for the benefit of others and he turns the question around to ask why someone *wouldn’t* help. This reflects some of the long-standing calls to balance the autonomy of individuals with the need for increased research participation, asking why the individual’s right to refuse should override collective benefits (Chadwick and Berg 2001; Hoedemaekers et al. 2007; Mulvihill et al. 2017).

Philip and his parents have all taken part in psychiatric genetic research, something they agreed to do shortly after Philip was initially diagnosed with bipolar disorder. Philip agrees that participation is a responsible thing to do; he also does not tolerate inaction if people are complaining about their situation:

You know, I do believe that, if you have a condition, rather than sit on the side-lines and complain about the lack of help, that what in one small way can you contribute to that and I think it is the responsible thing to do rather than just sit and piss and moan about it.

(Philip, mental health advocate) P1

Whilst we find that research champion Russell regards the question of whether participation is a responsible thing to do as irrelevant, because participation is unquestionably seen as simply a way to help, Philip argues that if you are not prepared to help in some way then you relinquish the right to complain about your situation. When I asked Mary, who has a diagnosis of depression and attends a mental health support group, about why she’d agreed that participation in psychiatric genetic research was a responsible thing to do, she talked not only of herself but of how it might help other people in a similar situation:

I think it is, to help other people ... as well. I think it’s because, like with my conditions, I work for mental health but I didn’t recognise it in myself. I didn’t know enough to realise that it was happening to me.

(Mary, mental health support group user) P14

Mary felt that, despite supporting people with mental health problems in the course of her work, her own lack of insight and understanding meant she was unaware that she was becoming mentally unwell so she feels that participation is a responsible way to improve understanding, to ultimately help people who may also lack that insight.

Overall, analysis of the accounts reflecting this style of thought suggests there is a group of people, some of whom are classed as having severe mental illness, who are highly motivated to take part in psychiatric genetic research. They very strongly agree it is a responsible thing to do and are prepared, but importantly are able, to contribute more to help others, to give up time to participate and maybe even advocate for the research. Despite their condition, those categorised with severe mental illness in this group had the capacity to participate because their circumstances and support from other people enabled that to happen; other people may not have that level of capacity but nevertheless could provide data of great value to the research or may be in great need of the outcomes of that research. Russell, Philip and Mary's positions provide examples of the bigger question of who does have capacity to participate, and what might participation look like if we begin to ask, as Russell does, why should people not participate if they can, rather than ask why they should.

In the UK, research suggests the prevailing view is that participation is seen as a good thing but not morally required (Dixon-Woods and Tarrant 2009; Schaefer et al. 2009). In this study, this group agreed more strongly than other groups that participation was a responsible thing to do but gave a similar *placing*, compared to other groups, of the statement about whether it should be a moral obligation. The group, as a whole, disagreed with this latter statement. However, discussion of the statement provided greater insight. When asked about whether people should be morally obliged to take part, psychiatric genetic researchers Lawrence and David disagreed but reaffirmed that it is a responsible thing to do and a good choice for people to make. David's research relies on large numbers of participants. He agrees

participation should be a process of voluntary informed choice that people are happy to undertake without being made to do it:

So I disagreed with that one because I don't think people should be compelled to take part in research. I think it should be voluntary choice based upon information that people are provided with but I think it's a good choice for people to make if they're happy to go ahead.

(David, psychiatric genetic researcher) P25

Russell, who earlier argued if you can take part then why wouldn't you, also felt that people shouldn't be made to feel bad about not taking part, whatever their reason. Ellie and Megan, both with a diagnosis of anxiety and depression, also share this view. They make a distinction between obligation and what people want to do voluntarily and how that might change people's sense of control over the decision making process. Megan says: "If you volunteer then you've chosen that, it's in your control whereas if you feel obligated to do it then the decision is taken away from you almost."

Megan reflects on the possible repercussions of being made to feel obligated, arguing this is little different to no control at all. Philip, despite having previously been critical of those who complain about their situation but take no action to contribute in some way, warns against taking away people's right not to participate:

Because it *is* a responsible thing to do but you're not judging people for whether they do it or not whereas, by saying it's a moral obligation, you're actually saying you need to do it.

(Philip, mental health advocate) P1

Philip's comment indicates he sees a marked difference between whether participation is framed as a responsible or morally obligated choice; according to Philip, moving to obligation would result in people's actions being judged. Indeed, respecting an individual's decision on whether to take part and their right to withdraw *without reason* was a key ethical consideration when initiating informed consent procedures for clinical and medical research (Faden and Beauchamp 1986; Emanuel et al. 2000). As the examples above show, the group view the idea of a moral obligation as a very negative proposition.

The comments by Philip and David, however, highlight the complexity of the debate about responsible versus obligated choices. Philip criticises those who complain about their situation without contributing “in some small way” but also claims you shouldn’t judge people for not taking part while David says people shouldn’t be compelled to take part in research but advocates the routine donation of DNA in newborn babies. Interestingly, by asking people to make a distinction between what is responsible and what should be an obligation, the boundary between these two positions becomes increasingly less clear and what is of concern emerges.

This complexity arises because of the prevailing normative and liberal view of autonomy as the ideal standard, and obligation as representing some infringement of civil rights; in this study at least, most of my participants tended to reject obligation almost as an uncritical reflex. Unresolved debates persist about whether research participation could be viewed as a moral obligation (e.g. see Rennie 2011; Stjernschantz Forsberg et al. 2014; Yarborough 2017). According to these debates, biomedical and health research are generally considered valuable producers of knowledge for the public good but not all research may be judged important enough to warrant imposing an obligation on the grounds that current regulation fails to prevent wasteful, questionable, problematic research or that the resultant public goods may not have equitable access. In summary, whether the research system is currently worthy of this obligation is still under scrutiny, however, there are calls to shift the focus from assessing consent to assessing the public good of the research.

Although people with this style of thought generally disagreed with the statement that people should be morally obliged to take part in research, that does not mean such sentiments do not exist. For example, Jane has taken part in a number of psychiatric genetic studies and I asked her about her placing of the two statements. She had agreed with the statement that psychiatric genetic research is a responsible thing to do to improve the understanding of psychiatric conditions but had been unsure about the statement that it should be a moral obligation for the benefit of the greater good. However, when I asked her about it, she replied quietly and

nervously, “I think they should be obligated”, demonstrating a hesitancy to reveal her view. At this point, Jane appeared uncomfortable and shifted around nervously in her chair. Jane proceeded to account for her view that participation should be a moral obligation on the grounds that it is not much of a hardship for people to give up the time needed to take part and donate blood:

So, I think it *should* be an obligation of people’s time to donate two hours [out of] a week. What’s that? That’s nothing really is it, you know, and it could make such a difference and they could find out so much more on any illness, you know.

(Jane, mental health support group user) P9

Despite placing the statement regarding moral obligation in the unsure region, it seems this was more due to her hesitancy over revealing how strongly she feels about it. Once the discussion is under way, Jane is very clear about her position and argues that: “by giving that little bit back you could change everything for people in the future even if it’s medication, even if it’s just therapy, anything.”

Jane talks about “giving that little bit back” signifying her view that people with mental illness should give something in return although, at this point, it is unclear what Jane feels they have received in the first place. Jane talks about “taking responsibility for the things we have to do”, taking action “instead of moaning”; she believes psychiatric genetic research is the way to improve things in the future. When I asked her what she meant by the phrase “giving back”, Jane proposed that mental health treatment should be given in exchange for taking part in psychiatric genetic research:

I think that everybody who is treated for mental health should be given an application form to take part in genetic research. When they’re seen by a psychiatrist or seen by a GP, maybe not a GP, but the psychiatrist, they should be given an application form to take part in genetic research.

(Jane, mental health support group user) P9

Jane’s discussion of these two statements suggests she feels participation is a responsible thing to do and should be a moral obligation in order to advance science, sees participation and the research as an uncomplicated direct route to knowledge, no great hardship and takes up minimal time. Jane feels very strongly

that people with mental health problems should take action by giving something back and should participate in genetic research in exchange for seeing a psychiatrist, arguing that genetic research is “definitely the way to go.”

The explicit proposal that participation in research should be done in exchange for NHS services has emerged in recent years and strategic moves towards framing research participation as a duty or opportunity to give back to the NHS are, some scholars argue, attempts to create a research enthusiastic society (Adams and McKeivitt 2015; Wienroth et al. 2018; Wienroth et al. 2019). In a study of participants in the 100,000 Genomes project, Ryan and colleagues concluded that “there was a strong sense of duty related to people’s participation, of ‘giving back’ to the NHS” (2020, p. 35).

When I put this proposal to Russell, he felt quite strongly that this was not the sentiment with which the NHS was set up and says:

I don't think that holds true to the precepts that the NHS was set up with [...] it's not that sort of contract. I think good health is something that is, I don't know, I don't know what the word is ... that you can expect, I don't want to use the word right, that it's a human right...

(Russell, research champion) P35

Russell’s nostalgic view of the NHS does not adequately represent its foundational principles. Described as a national treasure⁸⁰ (West 2013), the UK’s NHS has been resilient to many organisational and political changes but has maintained its free-at-the-point-of-use service since its inception in 1948 (Klein 2013a, b; Gilbert et al. 2014). However, the provision of services is very much a contract, albeit a socio-political one: UK government have a duty to provide a comprehensive health service, funded from taxation of its ‘ordinary’ residents who are each entitled to use it (The National Health Service Act 1946; NHS Wales Act 2006 c.42) . UK residents, who earn enough to pay tax, have a duty to pay tax to a government from which they receive services such as the NHS (Klein 2013a).

⁸⁰ A national treasure is an artifact, institution or public figure that is emblematic of a nation’s cultural heritage or identity.

Stephen Timmons and Paraskevas Vezyridis (2017) have claimed that UK residents, like Russell, continue to see free access to the NHS as a fundamental right but that the changing attitude of service users as consumers may be too strong for the NHS. The 'contract' was not envisaged as being one between the state and individual citizens *without* these same tax-paying citizens accepting that part of the arrangement was an ethics of care towards those unable to pay tax, rather than a consumer-mentality contract of an individual receiving a service. Given that the relationship between the NHS and its service users has changed, the relationship between NHS and research, including what it means to be a research participant, is changing too (Adams and McKeivitt 2015; Wienroth et al. 2019). Drawing on the work of historian François Ewald, Cooper (2008) argues that welfare states invoke obligations rather than responsibilities and the state's commitment to protect life invokes an implicit contract in which individuals give their life to the nation through contributing to a biological economy. Dramatic changes in the globalised biological economy involve power relations that complicate the communal solidarity inherent within donations of blood samples (Waldby and Mitchel 2006).

Whilst the UK population's nostalgia for the NHS facilitates a compliance with donating blood as a gift without expectation of anything in return, it also potentially evades any opportunity to push participation beyond the idea of it simply being a good or responsible thing to do. Obligation invokes ideas of a binding agreement and/or an exchange. Russell argues that people should receive services from the NHS without an obligation to give something in return, that the relationship between the NHS and its users is "not that sort of contract." However, despite his expectation that people would take part, Russell draws the line at the idea of health care in exchange for research data.

So far, we see that people in this group perceive great value in psychiatric genetic research. They consider participation to be proactive and very strongly agree it is a responsible thing to do, a researcher even proposing circumventing the current process and taking blood at birth in order to secure more data for research. It appears there are differences of opinion over how far this responsibility should go,

the majority disagreed it should be an obligation but some commented that people should do something rather than complain or explicitly stated that people should be obligated. I argue that, for this style of thought, there is a big difference between responsibility and obligation. Being obligated was too far for most people in this group but participation as a responsible thing to do was not at all far enough.⁸¹ This is reflected in the disparity between the two statement placements and emphasis on how it is a good thing to do despite disagreeing with making participation an obligation, obligation very much going against an embedded view from many years of prioritising individual autonomy.

At the start of this section, I discussed how Russell had argued that if you can help then why wouldn't you participate in psychiatric genetic research. This highlighted his view of participation as a relatively unproblematic process, something that is typical of people in this group as evidenced in the following section.

6.4 Psychiatric genetic research is no different to other health research and participation is unproblematic

One result from analysing data in this group is that, compared to the other groups, participation in psychiatric genetic research is viewed as relatively unproblematic, whether that is the initial decision to take part, the collection and storage of data, through to thoughts about possible research applications. Based on their accounts from the Q-sort activity, many people in this group demonstrate a strong belief in the value of genetic research and tend to dismiss potential socio-ethical and politically charged problems quite uncritically. I argue that it is their belief in science, and in genetics as a key factor in the causation of mental illness, which drives the view of participation as unproblematic. Unsurprisingly, research has shown that those with a greater belief in genetics as a cause of illness, and in the utility of genetic research to prevent illness, are more likely to agree to the

⁸¹ The positioning of the statement about moral obligation was possibly affected by an unwillingness to openly express their opinion, qualitative data expressing something slightly different to that provided by the Q-sorts.

donation and storage of blood samples (Wang et al. 2001). The majority of people in this group were unconcerned about the security of the data and samples, trusting in the ethical framework they perceived to exist because the research takes place within a respected institution and because the information sheet they were given states it to be secure.

This supports suggestions that information sheets extend beyond the exchange of technical information (Hoeyer 2003; Dixon-Woods et al. 2007) and serve more as signifiers of a process that enables trust to develop (Carter et al. 2015) rather than to provide ethical accountability. Indeed, research has shown that information sheets are generally not read, not readable, or not understood (Cox 2002; Hoeyer 2003; Sharp 2004).

Q-sort analysis showed that people in this group are less likely to agree that participation needs to overcome mental health specific barriers to participating in research. For example, psychiatric genetic researcher David regards the research as “exactly the same, no different to research into diabetes or anything else really” and research champion Russell says “it’s just a health condition, it’s like research on any other genetically influenced illness. We know that, science says that so and I believe in science (chuckles).”

Russell jokingly makes the statement “I believe in science” and whilst this is said in a joking manner, the rest of his comments back up that he is very trusting of science and its potential for understanding and treating mental illness. Russell claims there is “almost always a genetic component to mental illness” and researcher David agrees with this and states: “there’s tonnes of evidence that mental health risk is largely genetic”. Fellow researcher Lawrence, whilst not so assertive of this view, situates genetics as the probable cause for why mental ill health tends to run in families “so there’s probably something genetic going on and maybe that’s part of the clue to trying to understand more about it and to get better treatments.”

Patrick, psychiatric nurse practitioner and trainer, sees genetics as the “bedrock” for our sense of self, “built on because of our experience” and Jane, support group user, draws on her own family experiences and how she makes sense of her illness to conclude that unless it is genetic there is no way of understanding how the prevalence of mental illness in her family has come about. She cites the lack of trauma in family members as a reason to argue for the primacy of genetics. Similarly, Ellie also reflects on her family history of mental illness and uses this to formulate her belief that genetics plays a key role in mental illness because “it’s too much of a coincidence”, focusing on genetics without really acknowledging the role of the shared family.

Consequently, some in this group quickly dismissed the statements about eugenics and the possibility that psychiatric genetic research participation might promote a vision of scientifically perfected human beings, although others tried to articulate why they disagreed so much with these statements. For example, when I asked Russell about what he thinks about the criticism that psychiatric genetic research participation is promoting an idealised vision of scientifically perfected human beings, he considered both the explicit and implicit way in which the research is represented:

I don’t think that’s the ... it’s certainly not the stated and I don’t think it’s the implied motivation for genetic research into mental health. So, I don’t think it promotes a sort of a master race kind of theory. Like, we’re not trying to wipe out mental illness, it would be a nice by-product but I think it’s unrealistic to think that would ever happen anyway.
(Russell, research champion) P35

Russell dismisses the idea that the research promotes some sort of eugenic motivation whilst at the same time admitting that wiping out mental illness would be desirable. He points to the possibility of “some crazy deep sort of wildly paranoid vision” as the source of this proposition and is adamant that psychiatric genetic research is neither motivated by nor promotes a vision of scientifically perfected human beings.

Like Russell, Ellie dismisses the proposition and believes that a “sci-fi type of fear” and lack of understanding is what drives people’s beliefs about psychiatric genetic research: “you say genetics and they just automatically think of like playing god rather than using it to help people.”

Ellie refers to people’s concerns that psychiatric genetics might be associated with eradication or manipulation in a way that has a negative outcome, with someone being in superior control of that process and “playing god”. She defends psychiatric genetic research as an endeavour to help people, criticises the idea that it might be misconstrued, and dismisses the idea that it might become misused as a way of manipulating the population.

Researcher David also dismissed the idea that it might promote a vision of scientifically perfected human beings, foregrounding the research as helpful whilst also regarding it as unproblematic. When asked about whether participation would ultimately lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems, David replied:

So, I think these sorts of studies will ... the main utility initially over the next few years will be to be able to identify people at an early stage who are at high risk of developing some of these conditions so you can monitor symptoms and intervene clinically at a much earlier stage to get better treatment outcomes so I think genetic testing will probably disproportionately benefit people with mental health conditions compared to other health conditions.

(David, psychiatric genetic researcher) P25

David’s view generally focuses on only the medical advantages of genetic testing rather than any social or ethical consequences. Russell, on the other hand, considers social and ethical consequences but frames this possibility as part of the paranoia and negative thinking associated with his psychiatric condition. He very hesitantly admits that he wonders whether there are people, powerful people, who might want to consider genetic testing as a way to remove sections of society.

I'm perfectly willing to accept that it is in part due to my diagnosis, that I have questions around that sort of thing in that I tend to sort of cynical pessimistic thinking sometimes [...] but I don't think it's one hundred percent beyond the bounds of possibility to think that some of the more sort of subtle powerful sections of society would like things like that to happen...

(Russell, research champion) P35

Russell took a long time to articulate his view about this particular statement and it is possible he felt uncomfortable at expressing his concerns. He draws on changes in society, "the way things are going", that suggest he feels there is less tolerance by those in power, power that is not particularly visible or obvious but power that is, nevertheless, prevalent and slightly concerning. Ultimately, Russell disagrees participation will facilitate research that leads to genetic testing that disadvantages those with mental illness. However, he is slightly uncertain and refers to shifting societal attitudes as the root of his uncertainty, admitting that "somewhere deep inside me there is a question mark" but, on balance, Russell does not seem too concerned.

Philip, who advocates for mental health, is also not particularly concerned, saying: "if you open the debate on genetics in this country, I just think common sense or human rights would win." Oliver, a mental health practitioner agrees, referring to the disability act and how the UK has changed over time to improve on how people with additional needs and vulnerable people are treated. He argues that: "a maturing society will be looking to make sure that people aren't disadvantaged and that information is safeguarded."

Researcher David is also extremely confident in the enforcement of ethical procedures. He is very confident that ethical constraints would protect people from being disadvantaged and feels that, from his position as a researcher, psychiatric genetic research is no different to any other kind of research and participation is a straightforward decision:

Yeah, I mean I think the ethical constraints that are in place at the moment prevent that sort of thing happening, certainly in the UK, and in the western world.

(David, psychiatric genetic researcher) P25

Despite having some differences of opinion over the extent to which people should feel obligated to take part in psychiatric genetic research, what binds this style of thought together is the idea that participation is relatively unproblematic and *is* a responsible thing to do, that action is being taken, “something concrete” is being done, and the belief that progress can be made through science and especially through genetics. As will be argued in the next section, this practical focus on the progress of mental health research contributes to why people in this group view participation primarily as an opportunity to contribute towards realistic research outcomes rather than simply being part of something, bound by their experience of mental ill health.

6.5 Being part of a realistic hope

In this section, I foreground people’s accounts related to participation in terms of *being part of* a realistic hope because it both clarified and connected with the features that characterise this style of thought. In general, people in this group view genetics as a realistic approach to treating mental illness in the future through gaining a greater understanding of causation and risk. For example, Lawrence is a senior psychiatric genetic researcher and sees genetics as imperfect but the “best tool” there is. On this basis, he argues that measuring genetic information provides the most realistic way to gain understanding on the risk of mental illness. This highlights Lawrence’s reasoning for giving primacy to genetics: he views psychological or environmental information as “harder” to measure than genetic information, thus he sees it as a pragmatic approach. Indeed, in general, this group view the utility of psychiatric genetic research outcomes as a realistic goal and some see the emergence of psychiatric genetic therapies as inevitable, either as an improvement on current therapies or as part of a “constellation of approaches” as suggested by Oliver, a psychiatric nurse practitioner and trainer.

In terms of those who have participated in psychiatric genetic research, the following extracts demonstrate how *being part of* the research is, for those with this style of thought, also predicated on this assumed pragmatism.

Jane, who has a diagnosis of bipolar disorder, has participated in a number of psychiatric genetic studies and was motivated initially by the desire to see if her illness was likely to have been passed onto her child; this motivation developed into a broader desire in which she says: “you’re actually being part of something that’s actually looking into doing something about mental health.” She talked about the benefits of being able to see ongoing research that is tangible and visible “because you have a newsletter as well, you can actually see the results of some of the tests that they’ve done, if you read it (laughs).” Despite Jane admitting that she doesn’t read the research newsletters, she views them enough that she feels reassured that more participants are coming forward and it is enough for her to see that progress is being made and that she is a part of that.

As mentioned in Chapter 2, Paul Rabinow (1996) had suggested, following the Human Genome Project, that genetic risk markers for disease might prompt people to think of themselves as a particular kind of person such that new social groups would gather on the basis of genetic risk; Rabinow named this ‘biosociality’. Social research of gatherings at large scale conferences concerning a particular genetic syndrome, 22q11 deletion syndrome, suggest that even though this genetic marker brings people together, and can do so despite them being geographically dispersed, this particular kind of sociality is bound and maintained through social acts. It is, argue Rebecca Dimond and her colleagues, “the shared emotional experience of being together that consolidates and renews the connection between members” (Dimond et al. 2015, p. 2). One question is therefore whether public engagement for psychiatric genetic research are not just about raising awareness of the research and the opportunity to take part in the research but also about attempting to develop, bind and retain this biosociality. Facilitating suitable mechanisms and

spaces that enable individuals to become a collective group of participants is important (Martin 2012) but what if that 'becoming' is not desirable, or rather, not desired in the manner in which it may be assumed, such as the offering of 'community' as described in Chapter 5?

Significantly, Jane's account primarily relates to the way taking part impacts on research progress and how, by participating, she is able to see her, and others, contribution to that. From talking to Jane, however, there is little sense that taking part is motivated by a desire for a collective experience with other participants:

... because it's a wider collective you get more chance of taking part in other research as well, you get passed onto different people and you get more chance of doing other research.

(Jane, mental health support group user) P9

Talking to Jane suggests she doesn't really see the collective nature of participation to be important in terms of, for example, the support or sense of belonging from being in a collective, possibly because she already has a strong supportive network at the mental health organisation she attends. The extract above demonstrates that Jane likes the collective aspect because of the improved access to taking part in other research studies; she also talked about how she sees participation as a collective voice, as having greater strength but she also described how this encourages her to complete the research. From this we see that Jane sees her participation as a practical achievement, predicated on its value for research.

Russell also likes that he is part of something that he feels is impacting on treatments and diagnosis; he bases this on what he has read about the research:

I think every day, from what I've been reading, advances are made off the back of that research in terms of treatment and diagnosis for mental health and ... so I think it is ... I think there are good reasons for it being realistic and taking part in it means being part of it.

(Russell, research champion) P35

Russell uses what he reads about the research to validate his view that it is a realistic way to improve diagnosis and treatment of psychiatric conditions. He likes that he is part of that process and when I asked about whether he sees his participation as an individualistic activity or part of something greater he wasn't at all sure but tentatively described it as "part of something with other people, moving in the same direction." Russell reflects on his uncertainty and refers back to the statement that participation 'means belonging to a cause' and he talks about the role of the recruiters:

... actually looking back on it when I said I wasn't sure about being part of a greater cause, I guess what the recruiters are doing is kind of helping you to feel like you are part of something, so that you'll feel engaged and committed so I think they're doing quite a good job.

(Russell, research champion) P35

Russell describes the way in which psychiatric genetic research recruiters help the research champions advocate the research to other potential participants by encouraging their own feelings of being part of something. In this way, the recruiters are themselves social mechanisms for guiding and supporting participation in psychiatric genetic research. As we see in the following extract, Russell goes on to describe how the recruiters attempt to foster a sense of belonging and working together so that the research champions do not regret the extra input they have agreed to, input that extends beyond the simple act of participating as an individual. When I asked Russell what he meant by the recruiters "doing a good job", he replied:

Keeping everybody on board and going in the same direction and feeling like they belong I suppose, like they've made the right decision ... that it wasn't ... because I think some of these things that I've gone to, I've said yes to when I've been feeling quite up and then when the day comes, I've regressed to a lower level of mood and I think, in part, it's up to them, the recruiters, sort of communication and almost geeing up that has made me go, even when I don't want to, I think.

(Russell, research champion) P35

What this demonstrates is that there can be some considerable work involved in encouraging existing participants to attract further people to consider participating. If we think about this 'work' from the perspective of science and technology

studies, it resonates with analyses of institutional discourses that suggest recruitment practices have appropriated the discourses of partnership, community involvement, and active citizenship in order to galvanise the provision of tissue samples (Tutton 2007; Woolley et al. 2016). Russell describes how the mood changes of his psychiatric condition affect his motivation to persevere and deliver on the commitment he gave to helping with recruitment. It is the recruiters and how they communicate with him that helps him to stay committed, rather than this commitment arising from his personal desire to belong to some sort of collective or community of people. Philip, on the other hand, makes it perfectly clear that he does not want to be part of a community of people:

... 'means having a sense of belonging to a cause', it's like ... urghh ... you know, from my take on the world, it's true but like oh, I don't want to hang out with those people.
(Philip, mental health advocate) P1

Although Philip talked during our Q-sort discussion about people he knows who love being in a group and who need the idea of belonging to a cause, he explicitly states that he is not one of "those people." He goes on to criticise the assumption that this is what everyone wants:

... and I think too much of psychiatry or campaigns about mental health is that we're all in this together, you know, trying to group us together as if we'd all feel happier and you're going, well actually, that is the *antithesis* of what I want.
(Philip, mental health advocate) P1

Philip strongly rejects the proposition that "we're all in this together" and makes it clear that this coming together, the idea of a community of people, is not what he wants at all. This sentiment concurs with sociological ideas that question the normative value of community. Reviewing the literature on community and its many definitions, Etzioni (2000, p. 189) writes that "no *a priori* assumption is made here that communities are necessarily socially desirable". Etzioni evaluates the normative assumptions that tend to be made about community, one of which is that social bonding is inherently a good thing, and argues that these bonds have their limits after which they become damaging, thus requiring a balance between communal bonds and individual autonomy. Philip does not want or need these

bonds; he resents attempts by mental health related organisations to group people together on the assumption that this is desirable, and defends his autonomous approach and desires. Furthermore, what Philip argues for is transparency and plain speaking and, in the following extract, he invokes the language of a sales pitch to make his point:

Come to me and go, listen, we're doing genetic research, we need research subjects, the fact that you're here means you might be suitable, will you do it. So, don't try to sell me on the 'we're all in this together, do you want to be part of something', just put the facts up is we need people with mental illness to give us their blood.

(Philip, mental health advocate) P1

What this tells us is that Philip is not for sale, so to speak, on some idea of solidarity or a collective. Philip claims that it's unnecessary to appeal to him on the basis of being part of something. Combining this with his rejection of the idea of belonging to a cause, because he doesn't want to "hang out with those people", also suggests that he does not want to take part in the research in exchange for an emotional feeling of belonging; this is not something he wants or needs.

Noticeably, he also cuts out the language of research *participants* and refers to them as research subjects instead. This reference is in opposition to the historical shift in the late 1990s when research subjects in the UK were renamed as research participants (Boynton 1998; Chalmers 1999; Jackson 1999). Originally intended as a way to acknowledge the important role of research subjects and as a move to promote greater involvement in the research process, this shift was later criticised as a form of institutional power seeking to use the rhetoric of participation in order to increase the number of research subjects (Corrigan and Tutton 2006).

Philip's use of the term research subjects, together with his call for a direct approach to recruiting participants, suggests a preference for transparency but also that he is critical of attempts to frame participation as anything other than acquiring the necessary human resources for research. Alongside other sociological analyses of participatory discourses (Irwin 2006; Tutton 2007), Philip's comment is a

further example whereby the actions of research institutions are interpreted as rhetorical flourishes to galvanise the provision of tissue samples and data.

The analysis suggests that participation, for this group, is a practical part of a process to achieve research outcomes rather than as a means to be part of a community. Therefore, despite the possibility that social groups may gather around genetic risk, some people do not desire or need this.

6.6 Conclusion

People with this style of thought see psychiatric genetic research participation as an effective demonstrable action compared to other ways of being involved in mental health; they desire action and progress and see scientific research as a possible route to this. Their view that participation means being part of a realistic hope of treating mental illness is driven, I argue, by their trust in science and their view of participation in psychiatric genetic research as a practical achievement that is not particularly ethically or politically charged. Analysis suggests that participation, for this group, is a practical collective activity rather than a shared collective experience, with little desire for feelings of community but a very strong sense that it is a responsible thing to do to help others that is potentially, though not overtly, shifting towards obligation. Combining these results with relevant academic literature suggests that describing participation on the basis of *solidarity* between group members may be more appropriate to people in this group.

According to Gunson (2009, p. 246), mere membership of a group is not sufficient for solidarity, solidarity must be expressed through action and it is this action that distinguishes solidarity from individual psychological states such as empathy. Solidarity in the context of research participation involves contributing to research at the individual level to help others with whom the individual recognises sameness plus involves recruitment systems that work collectively at a social level to ensure

shared costs in order to benefit others (Prainsack and Buyx 2011), trusting in the organisation to uphold the shared values of the collective (Prainsack and Buyx 2013). People in this group display sentiments that resonate with the concept of solidarity, their desire for practical action and progress, trust in the research organisation, and a strong desire towards helping others.

The analysis also suggests that, whilst the group adhere to the idea of collective action, they reject what they see as the social bonding that might be expected from the idea of belonging to a community. Consequently, despite being very supportive of psychiatric genetic research, attempts by research organisations to foster a sense of community are likely to be seen as irrelevant, ineffective or inauthentic for people with this style of thought.

In the next chapter, we hear from a group of people who take a more critical stance on psychiatric genetic research and participation.

Chapter 7: The Concerned Critics

7.1 Introduction

In this chapter, I present the analysis of qualitative data from six people identified as ‘concerned critics’, people who are reticent about the value of participation and resentful of the status and prioritisation of psychiatric genetic research, arguing that its speculative promise is at the expense of broader needs for understanding and treating mental ill health. Of the people in this group, spanning a wide age range, five were female and one was male, and four had a mental health diagnosis. Within this style of thought we hear primarily from Charlie, Alex, Elizabeth and Sarah who are all involved in mental health research; there is also input from Harriet and Annie, two service users.⁸² One person in the group had taken part in psychiatric genetic research, although now regrets it, whereas two others had been approached and decided not to take part. The key statements that characterise and distinguish this group are shown in Table 4 and we see there are a lot more statements that distinguish the ‘concerned critics’ from the other groups.

In section two, I demonstrate the reluctance of the ‘concerned critics’ towards psychiatric genetic research. This style of thought perceives that psychiatric genetics, as a field of knowledge production, has given little consideration to the potential negative social impacts of its research. People in this group also have concerns about the lengthy timescale of psychiatric genetic research, arguing it represents a disconcerting and distant endpoint that does not address the needs and suffering of people with psychiatric conditions now. Analysis of the accounts of these ‘concerned critics’ about what participation means, suggests a perspective that psychiatric genetic research is trying to unravel the causes of conditions that are too complex and hinges on the use of diagnoses that are inherently too

⁸² Annie was rather shy and, although happy to articulate her reasoning for the placement of her statements, her responses were limited so most of her input comes from the placement of statements.

subjective and multifunctional. At their most critical, as discussed in section three, these various concerns manifest themselves as a resentment of the funding that goes into this kind of research, support that has resulted from its elevated status and prioritisation at the expense of social research. These 'concerned critics' are also critical of how researchers represent psychiatric genetic research. In section four, I discuss how people in this group critique the approaches taken to encourage participation and how they object to attempts to portray the participation process as being part of a community or collective.

There are two core arguments in the chapter:

(1) the way that psychiatric genetic research is represented, within a broader approach to mental ill health, is important to this group's view of participation, demonstrating a sensibility towards authenticity and arguing there is a "right way" to inspire participation

(2) there is a disconnect between psychiatric genetic researchers and potential participants, particularly in terms of disparities in the costs and benefits of participation, that would need to be reconciled if there were changes in what it means to be a participant.

These arguments highlight that a framework based on solidarity may address some of these concerns about representation by making the process and promise of psychiatric genetic research more explicit, and by paying detailed attention to the costs and benefits involved.

Table 4: Estimated position of statement agreement/disagreement and distinguishing statements for group 3 'Concerned Critics' (part 1 of 2)

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
15	doesn't address the things needed to deal with psychiatric conditions now	-2	-1	5	-2	6*	Distinguishes gp 3
24	needs greater public debate about the implications of future technologies from this kind of research	0	0	5	3	**	Distinguishes gp 3
Other statements (those ranked higher in group 3 than in all other groups)							
39	is based on a fragmented and incomplete account of someone's psychiatric condition	-2	-2	4	2	**	Distinguishes gp 3
18	is only focussed on extracting scientific data from human resources	-3	-4	3	0	*	Distinguishes gp 3
38	will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems	-4	-2	3	-3	6*	Distinguishes gp 3
21	challenges the belief that people are the instigators of their psychiatric condition	2	0	3	1		
10	is a generous act for the future benefit of others	1	2	3	-1		
37	is a short step towards eugenic practices for improving the mental health of society	-4	-4	2	-3	***	Distinguishes gp 3
16	means giving up time for no personal gain	-2	-2	2	-4	6*	Distinguishes gp 3
36	is promoting an idealised vision of scientifically perfected human beings	-5	-3	2	0		
20	takes advantage of the altruistic intention of potential participants	-1	-1	1	-2	**	Distinguishes gp 3
1	isn't going to help because these conditions are too complex	-4	-5	0	-5	6*	Distinguishes gp 3
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		

Table 4: Estimated position of statement agreement/disagreement and distinguishing statements for group 3 ‘Concerned Critics’ (part 2 of 2)

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Other statements (those ranked lower in group 3 than in all other groups)							
43	needs a united commitment from both researchers and those with psychiatric conditions	3	5	1	2		
6	means challenging the diagnostic criteria of the past	3	1	0	1		
41	means being part of a realistic hope of treating mental illness	5	1	0	2	**	Distinguishes gp 3
2	demonstrates the need for a more scientific approach to mental health	1	2	-1	0		
13	needs to inspire volunteers so that research can move forwards	0	3	-1	4		
8	is vital for developing new treatments and overcoming the shortcomings of current therapies	2	5	-1	2	***	Distinguishes gp 3
31	needs public resources to shift from addressing mental distress to that of severe mental illness	-1	-1	-2	-1		
44	means someone is really listening and trying to understand psychiatric conditions	4	1	-2	-1		
30	needs government and funders to focus more attention and money on this kind of mental health research	4	2	-2	0		
11	means being part of a collective working towards a better future	1	4	-2	1	*	Distinguishes gp 3
12	means having a sense of belonging to a cause	0	0	-3	0	*	Distinguishes gp 3
14	means coming together to wage war on mental illness	-2	1	-3	-1	*	Distinguishes gp 3
42	incorporates knowledge from people who are experts in their own condition	-1	0	-4	-3		
7	means having better access to diagnosis, care and treatments	3	-2	-4	5	***	Distinguishes gp 3
40	provides a sense of ownership over the research	-1	0	-4	-1	**	Distinguishes gp 3
Statements ranked at -5							
17	should be a moral obligation for the benefit of the greater good	-3	-4	-5	1		
33	is the only way we're going to make things better for people in generations to come	-2	-2	-5	-2	6*	Distinguishes gp 3

7.2 Being reluctant and being realistic

In talking about their concerns for the future, key participants who loaded⁸³ highly and also typified this group on the basis of comments about distinguishing statements, made reference to influential kinds of people positioned outside of psychiatric genetic research. These are people within society as a whole who exercise their right to individual choice, people within commercial organisations who might choose to take advantage of the knowledge gained, and people who would be involved in regulating activities emerging from such knowledge generation. In what follows, we hear mostly from mental health researchers who make up the majority of the group but, first of all, we hear from Harriet who is a service user with a diagnosis of bipolar disorder.

Harriet, a service user, considers psychiatric genetic research to have great potential to provide understanding and possible therapeutic outcomes. Having been approached by psychiatric genetic researchers, Harriet decided not to become a participant, mainly because of concerns about the confidentiality of her information. It is important to note that Harriet's diagnosis was fairly recent and she was still coming to terms with its personal ramifications. She expressed concerns about whether the implications of psychiatric genetic research outcomes have been thought through, drawing on some of the statements to justify her reluctance:

Despite the fact that it's got a huge potential, it's also got limitations and risk and we need to fully discuss these before we decide that this is the only way or that we want government and funders to focus their attention on this kind of research.

(Harriet, service user) P26

What's significant here is Harriet's use of the word "we": we need; we decide; we want, reflecting a democratic view of how mental health research agendas might be developed. Charlie, who is involved in mental health research and has been

⁸³ Recall that the loadings, given in Table 1, provide a measure of how much an individual's Q-sort is associated with each possible group (where group is referred to as a factor within the statistical analysis).

following the progress of psychiatric genetic research for some time, sees the position within more of a 'them and us' scenario. He asks:

... you find out all this genetics ... the information from genetics, what do you do with it? You know, and that's still the worrying thing I think, in the back of my head is, what will they do with it?

(Charlie, mental health researcher) P28

Here, the "you" could be taken as a societal 'you', distinguishable from the "they" associated with social actors both within and immediately surrounding psychiatric genetic research. In doing so, Charlie highlights the role of all individuals to decide what kind of society is desirable in terms of possible interventions for psychiatric conditions but changing the language from "you" to "they" implies a sense of a lack of control for some over those decisions. This subtle but important change in choice of language within this extract also highlights the feeling that some people have more agency than others.

When discussing the statement that participation is promoting some idealistic vision of scientifically perfected human beings, Harriet clearly disagrees but she does not preclude such a vision occurring in the future and she also implies this would involve social actors external to psychiatric genetic research. She says: "... so I think at the moment psychiatric genetic research is not promoting a vision like that but it could in the future be used to do that, but not now." Similarly, Alex, a mental health researcher who has also been following psychiatric genetic research with interest, envisages "other people" who might exploit the knowledge:

I don't think their intention initially started off down a eugenics ... killing babies in the womb and genetic manipulation ... but I do think the knowledge they will gain *will* lead to that. So, I don't think ... their intention isn't that but other people might use the results and the information.

(Alex, mental health researcher) P22

Here, there is a clear demarcation between the research scientists who generate knowledge and those who might translate that knowledge into clinical and non-clinical applications, such as commercial companies or technology-hungry clinics. The integrity of the motivations of psychiatric genetic researchers appears to

remain intact, however: “their intention isn’t that but other people might use the results and the information.” Psychiatric genetic research, like most publicly funded academic scientific research in the UK, sits within the public’s belief of a disinterested science in which commercial pressures and morally dubious applications are beyond the scope of this founding research. Studies suggest potential research participants outside of the research process tend to trust the publicly funded status of genomic research (Ryan et al. 2020, p. 35), often on the assumption of some sort of oversight processes (Lipworth et al. 2011). Results from a recent public attitude survey across England, Wales and Scotland showed that people, on average, trust scientists to make decisions independently of public involvement, and think scientists working within universities should set priorities for health related research rather than scientists within commercial organisations (Steen et al. 2019). However, trust in participant-researcher relationships is also dynamic, “built and easily broken, characterised by reciprocity and negotiation” (McDonald and Cox 2009, p. 35).

From what Alex says there is also a sense that she thinks there will be applications that go well beyond the researchers’ original remit, but also an insinuation that their original remit is changing. Of course, psychiatric genetics’ publics are multiple (Lewis and Bartlett 2015) and researchers need to adapt how they represent future expectations of the research according to the public audience; a tension exists therefore between psychiatric genetic researchers as ethical scientists, cost-effective producers of knowledge, caring clinicians, translational technologists, and perhaps even bio-economy entrepreneurs. To secure funding, psychiatric genetic researchers need to pitch the research in a way that demonstrates its applications, some of which links to commercial opportunities, and potential participants may perceive an alternative future that does not align with their own imaginings. Such a tension has important consequences for collective working across researchers, participants, patients, funders and policy-makers.

Within Alex’s account, she refers to pregnancy terminations and genetic manipulation as inevitable. Yet again, as in the discussion with Charlie, there is a

sense of a lack of control over how the knowledge gained might be exploited, possibly in ways that have not been fully anticipated and considered, which Alex sees as the route towards eugenic practices. Sarah, another researcher within mental health, raises concerns about the possible eradication of some psychiatric conditions and also refers to a broad societal “you”:

I would like to think that there'll be safeguards in place that stop that kind of research and gene editing and all the genetic manipulation that is now seen as being a much more realistic prospect for other conditions, not necessarily for mental health 'cause it's ... they just don't understand it enough to be in a position where they might start applying it for many many years to come but I do worry sometimes about the kind of message that it gives of, well, maybe you might want to eradicate ... try to eradicate some of these conditions, that worries me a bit.

(Sarah, mental health researcher) P10

Here, Sarah describes her hope that there will be ethical bodies and regulations established to protect what she sees as misuse of the knowledge gained but the realisation of this hope is tentative, as indicated by the phrase “I would like to think ” and very quickly followed up with “but I do worry.” Indeed, throughout these extracts, and the discussions that took place, there is a strong sense of different groups of social actors, some of whom are perceived as having more power than others. Elizabeth is another mental health researcher and she agrees with these concerns by Charlie, Alex and Sarah:

I am worried that people might just be written off like, 'oh it's one of these types', do you know what I mean, 'it's this type of person' or nothing ever comes of it, you know, no point in counselling for them because they're never gonna get better. Yeah, I think that's what worries me...

(Elizabeth, mental health researcher) P20

These concerns that elements of society might apply the research to uses that could radically disadvantage or eliminate parts of the population were not universal across all of the diagnostic categories discussed. When probed a little further, it became evident that chronic schizophrenia might be considered a special case for which gene editing or in-utero genetic testing and subsequent termination might be justifiable, for this group, if there was found to be a high risk of a genetic predisposition. This was justified by drawing upon knowledge of people with chronic schizophrenia who sometimes had very poor quality of life, a justification

consolidated by the view that this poor quality of life is exacerbated by the current climate of persistent and serious underfunding of struggling mental health services:

I'm not going to have children so these are hypothetical questions but, yeah, schizophrenia I would seriously think about. I'm being honest there. Depression, I think there's less of a ... erm ... yeah ... I feel bad about saying that but that's why I'm worried about ... this knowledge is going to give people that choice and I'm worried that those people are going to be killed, you know, or they're not going to be born so I am worried about that even though, myself, I would seriously consider it ... I am very worried.

(Alex, mental health researcher) P22

Alex worries about the impact of in-utero genomic screening that might become available for schizophrenia in the future, on “giving people that choice.” In 2018, schizophrenia was added to the list of conditions within the 100,000 Genomes Project⁸⁴ for which DNA samples could be screened for genetic risk variants, such as copy number variants (CNV's) in the case of schizophrenia (Curtis et al. 2019). Although added to the list, it was excluded from the NHS National Genomic Test Directory meaning that such tests are not available until further research is carried out. Such genomic technologies produce uncertain information, moral dilemmas, and the potential for societal inequities; unproblematic benefits from this kind of well-intentioned information to permit parental autonomous decision-making cannot be assumed (Werner-Lin et al. 2019). Furthermore, sufficient public debate to discuss the value and moral implications of these technologies cannot be assumed to have taken place before introduction into the clinic, given evidence suggests this has not taken place for other conditions (Vassy 2005; Werner-Lin et al. 2019; Thomas et al. 2020).

Like Alex, mental health researchers Elizabeth and Sarah also said they would consider termination for high risk of chronic schizophrenia and, despite Elizabeth already expressing concerns about people being “written off”, schizophrenia does seem to be seen as a special case. Fundamental to the drive towards therapeutic

⁸⁴ The UK's 100,000 Genomes Project launched in 2012 and is sequencing 100,000 genomes of NHS patients, with a view to developing routine genomic testing in NHS clinical practice. Coupled with this clinical vision, the data will be made available to research, making it the first research-clinical hybrid on this scale within the NHS (Genomics_England 2020).

genomic advances is the underlying question of what does society consider to be disabling to the experience of living and in need of therapeutic intervention, including termination. Disability activism has sought to disentangle what is phenotypically intrinsic to the impairment of a disabled person and what is due to social expectations of what it is to be able-bodied (Shakespeare 1998; Scully 2008). Adding the inadequate and underfunded status of mental health services into this debate means that such 'choices' also become political; choosing to continue with a pregnancy that involves impairment and/or disability also depends on the available support (Kerr and Shakespeare 2002). From these perspectives, making assumptions about what is autonomous parental 'choice' demands we be aware of when prioritising genetic interventions is actually "choosing to tackle a socially based difficulty through biological means" (Scully 2008, p. 800). Greater explication is needed of the therapeutic role of biomedicine to address impairment to mental health, paying closer attention to how impairment is defined and differentiated from the disabling forces of societal expectations and poor social support.

The concerns expressed by people in this group bring to the fore a sense of a lack of societally agreed control over how the knowledge from psychiatric genetic research will be applied within society. There is also evidence of a moral tension within personal choices about pregnancy termination that is inseparable from the context and adequacy of mental health services. When talking about gene editing as a future prospect for alleviating serious mental illness, Elizabeth says:

I mean I think it'll be great if it worked out that they could just fiddle with people's genes and take away the most horrendous mental illnesses, that would be great, you know, nobody wants to have schizophrenia in inverted commas or, you know, psychosis or nobody wants to spend their life self-harming because they hate themselves so much.

(Elizabeth, mental health researcher) P20

However, both Elizabeth and Sarah question whether such gene editing applications of psychiatric genetic research are even a realistic proposition because of the complexity of psychiatric conditions. Sarah says she would like to see "the eradication of distress and suffering and people being in a position where they feel

like taking their own lives is the only way out” and argues that “surely the majority of people would want to eradicate that” but, in conclusion, she says “maybe I’m trying to be realistic and say ... it just feels like such a complex thing that you’re never going to eradicate it anyway.”

As the last extracts from Elizabeth and Sarah demonstrate, the complexity of mental health makes them question whether they need to be too concerned about technological applications such as gene editing and, as we see in the next section, this is because they question whether it is realistic to think that psychiatric genetic research will overcome the complexity of psychiatric conditions.

Too complex and being critical of data credibility

People in this study who aligned with the ‘concerned critics’ style of thought were predominantly mental health researchers with an insight into the research process. They were critical of the credibility of the data and particularly of the diagnostic categories being used for the phenotype. At various points, each of them made reference to the “subjective” nature of diagnosis, the problem of locum psychiatrists “with all their differing views and opinions and diagnoses” (Charlie), the hierarchy of diagnoses whereby “if you have a psychosis, you’re taken a lot more seriously than people with a mood disorder or something else” (Alex), and the opinion that “diagnosis has probably been utilised for lots of different reasons, for, like, access to care and treatment, and that the criteria have been stretched” (Sarah). Here, we see an awareness of the socio-political dimension of diagnosis in which the people in this group recognise the interplay between social relations, expertise, health and social care.

Rose (2019, p. 183) argues that diagnostic expansionism, whereby the “ordinary vicissitudes of life are transformed into psychiatric categories”, has marked out and shaped a territory for psychiatry to occupy. That this expansionism has overstated the prevalence of mental illness has also meant that modern psychiatry, Horwitz (2017) claims, has become diagnostic psychiatry, in which diagnostic criteria have

become detached from social context, and he calls for sociologically informed criteria in defining what are genuine disorders. According to Horwitz (ibid.), similar to other health conditions, genuine disorder for mental illness needs to stake some prerequisite of natural dysfunction before confounding this disorder with culturally undesirable behaviours. And yet, as other sociological work has shown, these boundaries are 'fuzzy', grey areas that are heavily mediated, originating from multiple social actors, and are regularly shifting erected boundaries between the normal and abnormal (Callard 2014; Pickersgill 2014; Lane 2019). As Rosenberg (2006, p. 407) states: "Bureaucratic rigidities and stakeholder conflicts structure and intensify such boundary conflicts, as do the interests and activism of an interested lay public."

In discussing whether psychiatric genetic research is no different to taking part in research about other health conditions, Sarah goes on to say:

I just feel that to say "it's no different" ignores the reliance that there is on something that is so subjectively described and accounted for [...] (sighs) ... it's that black boxing thing again of, once all that's been said, taken as being true, representative ... and there might be allsorts of reasons for saying the things that get said, not being judgemental about it just going back again to the fact that it's not an objective process [...] Even if you just looked at the genetic component, all of the complexity that's embedded within that ... well, you're trying to marry that up with a very subjective account of that condition and linking that [...] But, I guess, I still feel like it's a good way forward but then I also have my doubts as well (laughs) ... maybe it's that, you know, I *hope* that that's how it's gonna be.

(Sarah, mental health researcher) P10

Sarah's comments demonstrate scepticism, typical of this group, about using these subjective diagnostic categories as the foundation for the research. Whilst they hope for some useful therapeutic outcomes, the 'concerned critics' saw these hopes as idealistic, raising concerns about both the phenotypic data and being able to disentangle the complex relationship between genetic variants, psycho-social factors, and socio-political influences on the diagnostic classifications. For example, Alex talks about how long-term psychiatric genetic research projects will encounter problems because the approach is constrained by being "wedded" to diagnoses that

are not fixed entities. Alex says: “I have grave concerns about the credibility of the data based on the fact that, most people in services, their diagnosis changes.”

Diagnosis is central to medical practice but also yields great power within society (Jutel 2009). As a form of classification, diagnostic categories are constituted in medical, sociological and political ways although socio-political influences arguably affect the boundaries of some conditions more than others (Pickersgill 2013). These boundaries are put to work within the organisation of illness, in determining necessity for treatment, valorising some points of view and silencing others, but also shaping personhood through claims, or disclaims, to a medically legitimated diagnosis (Bowker and Star 1999). Within psychiatry, diagnostic classifications provided a way for psychiatrists to assert some dominance over other non-medical mental health professions, attempting to bring more credibility to the discipline through demonstrable scientific research on diagnostic categories (Brown 1990; Pickersgill 2012). Fierce debates about the utility and validity of these categories persist, whilst also raising important questions about what ‘work’ they do within social life as much as they do in medicine (Pickersgill 2014).

Rose argues that the “whole apparatus of psychiatric research has become predicated on diagnostic categories” in contrast to the idea of a spectrum of mental health (Rose 2019, p. 76). This is a problem because these categories have functioned in multiple ways: as a pathological identifier; a form of socio-political legitimisation for alternative purposes such as accessing employment sick leave, benefits and health care; and authenticating narratives of suffering or exemption of responsibilities (Parsons 1951; Zola 1972; Conrad 1992; Jutel 2009). The Research Domain Criteria (RDoC) project attempts to alleviate the problem of reliance on a categorical system of describing pathology and seeks to improve psychiatric research in the future (Casey et al. 2013; Cuthbert and Insel 2013; Pickersgill 2014), but the neurobiological emphasis of RDoC and its implied changes to clinical psychiatric practice, not necessarily welcomed by clinicians, poses challenges for the scientific practice of psychiatric research (Pickersgill 2019b). Taken together, we

see that the politics of psychiatric conditions are as complex as the biology. As Elizabeth says below, this could take many years to have an impact:

I think it will help, I just think it will take a long time to work out the links between the genes and trauma and childhood experience and thinking styles and all of that, I just think it will take about another hundred years to work out but I think it will so.

(Elizabeth, mental health researcher) P20

Based on the above extracts and the positioning of the Q statements of the 'concerned critics', fears about whether there has been sufficient consideration of societal and commercial uses of the knowledge to be gained from psychiatric genetic research are at the forefront of their minds. What is also demonstrated is that these fears are not easily demarcated from their hopes that this research will contribute towards alleviating suffering; this group does not reject psychiatric genetic research outright. However, they regard ill-considered applications of this research as inevitable or highly likely whilst, at the same time, questioning whether its data is credible enough to make such outcomes a realistic endeavour.

Sociological interest in these hopes and fears for psychiatric genetics is well-trodden territory and so far psychiatric genetic research has managed to sustain its support and practices (Arribas-Ayllon et al. 2010; Lewis and Bartlett 2015; Arribas-Ayllon et al. 2019). However, as shown in the following extracts, the 'concerned critics' display a growing resentment because they feel psychiatric genetic research maintains this support at the expense of other kinds of mental health research.

7.3 Being resentful

For people with this style of thought, patience is wearing thin regarding the balance of funding between psychiatric genetic research, other mental health research, and mental health care and support. As a result, they demonstrate a growing resentment of the status and prioritisation of psychiatric genetic research.

A maybe or an if

Charlie reflects back on a time when [the Centre] was first established with the help of a large funding grant:

I'm trying to remember when [the Centre] launched and I still agree with what I said then. I said: what [the Centre] is doing will be great in 40 years time when everything's all come through the ... you know, it's got to go through various aspects of research ... they start off with the theory ... the theoretical and the genetics and then we'll go onto clinical and then we'll go on and go on. I said: well, what about the generations in-between.

(Charlie, mental health researcher) P28

Charlie looks forward to a positive outcome for the research but refers to the protracted on-going nature of it, "we'll go on and go on", raising concerns about what happens in the meantime. Alex agrees, considers the extensive funding as insulting to those who are struggling with their mental health in the present time, and claims there has been little thought about how the findings from the research might actually benefit people with an existing psychiatric condition. Alex also suggests that potential research applications of psychiatric genetic research are geared towards in-utero manipulation or termination:

So, ploughing millions and millions into this genetic research without really a clear idea of how it's going to improve people's lives *after* they've been born ... I think it's an insult to the millions of people living with really disabling mental health conditions now.

(Alex, mental health researcher) P22

Here, we begin to see how these 'concerned critics' make reference to past promise, present struggles, and future visions of psychiatric genetic research. Alex feels that heavy financial support has been provided with a view to developing interventions to prevent psychiatric conditions in the future instead of supporting people with psychiatric conditions in the present. Alex also demonstrates the power of hope as a driver, and possible distraction, for those participating now:

I think some people really value taking part in psychiatric genetic ... they get an awful lot, you know. As I said, I know some of the [research] champions, they love it, they come to events, they speak passionately about what they do, they *really* believe in it and I hope there is a cure, I hope something ... but I think we can't forget the

devastating way services are at the moment, on pinning it on a maybe or an if in the future, we need to address what's happening in the present as well.

(Alex, mental health researcher) P22

Like Charlie, Alex displays hope that psychiatric genetic research will deliver on its promises of translating research understandings into clinical treatments but the uncertain nature of this, possibly at the expense of current services and other kinds of mental health research, is evident in their accounts and is particularly marked when Alex says “pinning it on a maybe or an if in the future.” Charlie reiterates his understanding of why psychiatric genetic research is valued by the researchers but asks at what cost:

... my worry is there's lots of funding being put into biomedical genetics which is all very well and good and I can understand why they're doing it but patients still have to live in the real world and we're not spending the money to research how to make that happen.

(Charlie, mental health researcher) P28

Charlie's reference to patients still having to live in the “real” world implies he sees funding psychiatric genetic research as not part of that world and at the expense of research on how to help people. Many of the psychiatric genetic researchers I interviewed in this study were aware of the poor state of services, given that a number of them were also clinicians, and their argument was that services and other kinds of mental health research should also be better funded but not at the expense of psychiatric genetic research.

The discussion amongst the ‘concerned critics’ turns to how this kind of research has attained primacy over other kinds of mental health research, the impact of that and how it affects what they feel about psychiatric genetic research participation.

Status and prioritisation

The elevated status and prioritisation of psychiatric genetic research was found to be an emotive topic during discussions with both Charlie and Alex. Charlie claims people see genetics as “sexy” and Alex says: “I'm bitter that other pieces of

research aren't getting as much funding or attention because they don't make headlines," although she qualifies this with "I'm not saying it's not valuable."

Here, Alex draws attention to the newsworthy qualities of psychiatric genetic research, arguing that this is a reason for why it receives more funding than other kinds of mental health research. Indeed, evidence suggests there is an over-representation of biological mental health research in the UK's media (Lewison et al. 2012). Despite their bitterness, Charlie and Alex still see merit in the research itself but, as the extract below shows, Charlie describes their need to "scrape around" for funding:

You know, but we just tend to focus, you know, ... most of the research or research money for mental health goes into genetics, it goes into biomed, not enough goes into the social science, you know, the social aspects, social care and how to live with it. We don't do that, you know, we have to scrape around to find funding for it when it should be a natural aspect of mental health research.

(Charlie, mental health researcher) P28

According to reports by mental health charity and research funder MQ, increases in mental health research funding have been minimal since 2008 (MQ 2015, 2019). In relation to cancer and heart disease, mental health compares very poorly in terms of research spend per affected person, although, as already discussed, the definition of an affected person is likely to be broader in the case of mental health. Information on the distribution of mental health research funding is limited, although we know that 24.5% of mental health research funding is allocated to studying the aetiology of mental health conditions (MQ 2019). Lewis-Fernández and colleagues have called for public debate on the rebalancing of neuroscience, neurobiological, and applied research for mental health in high-income countries (Bhui 2016; Lewis-Fernández et al. 2016). The authors argue that, despite the need for long-term neurobiological approaches, funding for such research often dwarfs that of other more short-term mental health research and does not address the current 'burden of disease'.

Whilst Charlie has previously stated that his objection is not against the research itself as such but the way in which research funding is dispersed and the prioritising of psychiatric genetic research, he draws attention to the prospect that funding will need to continue in order to reap a return on the heavy investment that has already been provided. He says: “it won’t fall by the wayside because there’s been a lot of investment in it and it depends, of course, on the companies and organisations that can profit from it.” However, Charlie argues that we should view funding of this more speculative research as an optional extra if there’s money left after dealing with research that helps to address some of the social factors; he argues for a more balanced approach:

My objection is that it’s sucking all the funding, all this sort of impetus into this one area when the rest of it’s being starved of funding and getting left behind. You know, you’ve got to have a balance somewhere so, yeah, I’m not saying we don’t need genetic research, we do, but we need everything else as well and you have to, you know, spread the funding accordingly.

(Charlie, mental health researcher) P28

In 2017, the United Nations published a special report on mental health with a number of recommendations, urging global changes in how mental health can be achieved and identifying specific obstacles to change (UN_Human_Rights_Council 2017). The authors identified a biased over-reliance on evidence from the biomedical model in mental health policies as a key obstacle, pinpointing a lack of diversification in research funding that is shaped by “powerful actors” and overly influenced by an academic psychiatry that “has mostly confined its research agenda to the biological determinants of mental health” (ibid. p8).

Charlie argues that psychiatric genetic research has been funded in a manner that is incommensurate with the number of people it will help, asking “how much of an impact will that have on the general mental health population?” This is on the grounds that psychiatric genetic research is unlikely to have an impact on a large proportion of the affected population. Similarly, Alex reiterates the value of the research but, again, signifies a growing resentment in light of the limited and narrowly applicable results so far:

They had various others that looked at these wider things and I suppose I'm bitter and angry that ... that's not to say that the research they [] do [isn't] important in [the Centre] but I'm angry at the prioritising of that when nothing has emerged significantly for people with depression or, you know, I just think there are some conditions ...

(Alex, mental health researcher) P22

Alex tailed off at this point, agitated and visibly angry about this prioritisation.

Harriet, a service user with a diagnosis of bipolar disorder, agrees. She says her main concern is "that because genetic research may offer quicker solutions or more tangible solutions that we only focus on this and don't explore other avenues."

Similar to the concerns of Steve, the social worker, who we heard from in Chapter 5, Harriet feels that psychiatric genetic research may limit the way we approach mental health.

So far, we see that people in this group are concerned about future technologies that may be developed by social actors beyond psychiatric genetic research. They acknowledge value in psychiatric genetic research but feel its extensive funding should have considered its uses, abuses and impact more fully. For some with this style of thought, there is a great deal of resentment about the primacy of this kind of research. Either way, we see there are doubts about the credibility of diagnoses that underpin the research and the ability to understand such a complex condition without due consideration to social factors. Whilst everyone in this study considered genetics to be a contributing factor towards the causation of mental illness, the 'concerned critics' generally argued that social factors were of much greater significance and objected to the prioritisation of psychiatric genetic research over other forms of mental health research. In the next section, I present another finding from this group relating to ways of representation and how potential participants are encouraged to take part in psychiatric genetic research.

7.4 Objections to ‘community’ and ‘collective’

As already discussed, the mental health researchers amongst these ‘concerned critics’ understood the requirements of a research project and the need for participants. However, as shown in Table 4, people with this style of thought disagreed with the idea that participation means coming together, being part of a collective, or having a sense of belonging and ownership over the research.

Elizabeth, one of the mental health researchers in this group, says that a united commitment “just means needs more participants”, claiming that appeals on the basis of some collective scientific endeavour are simply stand-ins for a more straightforward appeal to achieve recruitment. Indeed, attempts to use the language of collectives and communities were very strongly objected to by some in the group. For example, Alex says:

So, they’re trying to portray this, it’s a community, we’re a collective, we’re working for the better of the future. But I don’t feel part of it. A collective to me means we all benefit from this. I don’t. How much do they earn in a year, these hot shot professors there, I don’t earn anything like that, I’m getting nothing from it. So, I do not feel part of a collective, sorry.... cause if it was a collective they would have service users guiding the pieces of research, advising them and being at the top of [the Centre] and they don’t, it’s professional heavy, doctors, they do not have people with lived experience at the top or, you know, as part of the core team so, no, it’s not a collective of people like me. [long pause] Yeah, ‘cause they are trying to encourage more people to be part of it ... and it sounds more appealing doesn’t it?

(Alex, mental health researcher) P22

Alex argues that to be a collective, there needs to be some sort of parity in terms of benefits such as salary and status, of “people like me”, thus demonstrating an important feature of what she feels a collective should be. According to Hainz and Strech (2014), individuals should also have a recognised agency within the collective if decision-making is the purpose, thereby distinguishing this from a representative collective for consultation about pre-existing decisions or a loose collection of people brought together by a common purpose.

When Alex says “they’re trying to portray”, this suggests her view that promoting participation as being part of a community or collective is a deliberate and knowing act on behalf of psychiatric genetic researchers to make it “more appealing” so that recruitment to the research increases. When asked about the researchers’ use of public engagement and research champions, Alex and Charlie described this using commercial language. In talking about the research champions, Alex says:

They’re there to ... erm ... sell it; it’s a marketing exercise ... I think they think they’re doing good and that’s not a criticism of them, they genuinely believe that they’re doing the right thing ... I know how research works and they need numbers and they need a lotta numbers to, you know, get the conclusions that they need so I’m a bit sceptical that it’s used ... it is a marketing tool to get people to take part in research and that’s how I view it. [long pause] I don’t know whether that’s a bad thing.

(Alex, mental health researcher) P22

As far as Alex is concerned, she sees the research champions as a marketing tool to increase research participation and whilst she questions its use, she also reflects on whether she should judge it as a negative activity given its context within research. She understands the demands of research and the requirement to have large study sizes in order to make scientific claims but she questions the status of these portrayals. The other researchers in this group agree. Charlie says:

They’ve got a very good website, they’ve got some very good ... they’ve always had a good comms team so that they work with social media ... they’re very slick and very good at what they do so, you know, they’ve got good visibility. But it’s only the genetics, you know, they should be promoting [...] The non-genetic stuff or non-biomedical stuff, you’d struggle to find it on their website ...

(Charlie, mental health researcher) P28

Charlie highlights the “slick” and polished nature of the Centre’s communications with the public but points out that, as a Centre for mental health, it is lacking in promoting non-genetic research. The sub-text of this criticism is that the Centre portrays itself as something other than what it actually does. Sarah, on the other hand, picks up on the difference between just being a participant and being more involved in the research. As a result, she states that she would have no sense of ownership if she were to take part:

I know the process of participating, it's not involved enough to feel like I have some sense of ownership over it, providing data. If I was *involved* in the research in some way, of giving a sort of a perspective in some way that helped them to think through how they were going to design the way they did their research then maybe I would but, in terms of the sort of participation that I know that I'm talking about, I don't think I'd feel a sense of ownership.

(Sarah, mental health researcher) P10

Elizabeth argues that having a sense of ownership requires you to benefit in some way. She says that taking part in psychiatric genetic research might provide "the warm glow of having been helpful" but little else in comparison to the researchers:

I think you might have a nice time, you might like the interviewer or something, I don't know, but you're not gonna ... you're not gonna have any benefit, it's not gonna be good for your career, you're not gonna publish anything, you're not gonna find the cure for something, I don't see how it would ... how you would feel it was yours.

(Elizabeth, mental health researcher) P20

Like Alex, Elizabeth draws attention to the benefits that the researchers gain in terms of career and status, over and above contributing to knowledge. Taken together, these accounts also demonstrate a powerful feeling that techniques of recruitment and representation need to be, in some way, proper and transparent; indeed, using the language of community and collective alienated and angered Alex, suggesting such activities were more a way to capture the public rather than forms of meaningful engagement, involvement or belonging. As Raman and Mohr (2014) note, capturing the public may occasionally work but the legitimacy of its basis will become questioned, especially if the organisation demonstrates little engagement with alternative futures other than a narrow techno-scientific solution.

From my discussions with Sarah, Alex, Charlie and Elizabeth, there was a sense that some aspects of these techniques were inappropriate. When asked about the question of waging war on mental illness, Alex laughed and said "They're trying to market it aren't they? You can see people in suits and capes and stuff. As if." When expanding on her rejection of the proposition of waging war, Alex argues:

But it's not a waging war though is it, it's 10 20 30 years down the line, it's a 30 year war and it's a 30 year war for people living with severe mental health conditions just to exist

so, no, they're not waging war on it and also, coming together, it suggests that ... I didn't see it, I've never met any of the PI's when I've taken part, it's normally the underlings, you know, people on ... the assistants and stuff so, no, I don't feel a sense of coming together and I think this war is a fake war.

(Alex, mental health researcher) P22

Alex highlights the long-term nature of psychiatric genetic research and her disdain with using the 'waging war' metaphor is palpable during the discussion. On discussing this further, it becomes apparent what is meant by a "fake war" when Alex makes a similar point to Charlie by saying "If you really want to fight a war you wouldn't just be doing [genetic research]." Once again, Alex demonstrates that she is not objecting to the research itself, but she feels very strongly about the way in which the research is represented in terms of recruiting participants. She says:

Okay I do think they need to inspire volunteers but they have to inspire in the right way and people have to do it for the right reasons. I don't like the advert saying we need you, come and wage war on mental illness, you know, let's put a stop to it now ... because you're selling a lie. You know, we all know that you need psychological therapies and understanding of (inaudible) and understanding of the social circumstances people live in and grow up in ... (sighs) I don't know.

(Alex, mental health researcher) P22

Having expanded on what she means by a "fake war," Alex implies this is a deliberate oversight by the psychiatric genetic researchers of the contribution that social factors play in the causation of psychiatric conditions. This is seen in the phrase "we all know that you need ...", shortly after which Alex becomes exasperated with the conversation.

Waging war on cancer, in which the cause of the disease is seen as an invading enemy of the body to be excised, has been a successful metaphor for galvanising support and funding for cancer research (Sontag 1991; Marshall 2011; Ledford 2014). Aligning with cancer would therefore be an advantageous strategy for gaining support; psychiatric genetic researchers in this study have made comparisons with cancer research and similar researchers have done this when engaging with public groups (Lewis and Bartlett 2015). However, Susan Sontag

(Sontag 1979, 1991) has highlighted the problematic nature of illness metaphors, arguing they stigmatise those who are ill as well as the illness itself. Furthermore, people with mental illness may well have a very different relationship with their condition compared to cancer patients and, in this study, the idea of waging war on mental illness was often not well received. In addition to Alex's comments above, other people felt it signified a war with the individual or associated it with eradication or eugenics, for example: "I feel like you're going to end up doing something violent or trying to eradicate mental illness in a way that's a bit like short sighted", "that it could go down that [eugenic] kind of a path if you're waging war on it". Other comments by people in this study suggested they may see mental illness as more closely aligned with personhood than in cancer, for example, "could be read as you're going to wage war on a part of me" and "I don't think we should be waging war with anyone ever."

Yet again, we see the difficulties when psychiatric genetic researchers attend to their different publics, and it brings to the fore the possible mismatch in future expectations. A certain kind of talk has power, it persuades and produces, and can direct the course of science and its priorities (Gross 1994), metaphors played a major role within the development of genetics and the status afforded to geneticists (Keller 1995; Kay 2000). However, as Hacking (2000, p. viii) reminds us, the metaphor of war "makes the very existence of real wars seem more natural, more inevitable, more a part of the human condition. It also betrays us into an insensibility toward the very idea of war, so that we are less prone to be aware of how totally disgusting real wars really are."

Explicit in what Alex says about recruitment is the statement that "they have to inspire in the right way" and that adverts to encourage participation are "selling a lie". This draws attention to the idea that there is a right and a wrong way in which to appeal to potential participants, however, again this does assume that how a

research organisation represents itself is aimed at only one public group outside of that organisation.

Charlie talks about how psychiatric genetic researchers need to think more about a process of involvement rather than simple participation:

... genetics research needs to engage with the people and bring them into the discussion about what they're going to research, how they research it and that doesn't happen. So, agree that we need united commitment but it's how do you go about it.

(Charlie, mental health researcher) P28

Like Alex, Charlie has been very critical of the status given to psychiatric genetic research but, also like Alex, he views it as necessary research needing a united commitment but questions the way in which this has been approached. When I asked why he thinks this united commitment doesn't happen, he replied:

People are precious⁸⁵ and there's still a big distrust of researchers, especially around psychiatry 'cause, you know, there's a historical thing within the service user community about psychiatry, you know, you've got the survivors of psychiatry and you've got psychologists now saying that psychiatrists are wrong, it's this us and them bit. They're becoming, for the most part, a bit polarising around psychiatry ... so then, as most of the genetics researchers I know do have a psychiatric background, it goes back to this, it's biomedical and for a lot of service users, it's not, it's nothing to do with biomedical, it's more social. So, you've got to get these two camps together before you can really move forward.

(Charlie, mental health researcher) P28

The discussion has turned towards the problems that come with competing professional perspectives, in addition to any differences of opinion between psychiatric genetic researchers and people with psychiatric conditions. Charlie declares the need to think about "how" these different perspectives might come together, emphasising the existence of "two camps" and demarcating biomedical and non-biomedical thinking about mental ill health. Charlie's points resonate with those made by the 'socially engaged strategists' we heard from in Chapter 5. Compounding these differences of opinion about the aetiology of psychiatric conditions is the controversial nature of psychiatry, the anti-psychiatry movement

⁸⁵ Precious is used here in a derogatory way to signify someone being overly concerned about something of value to them.

of the 1960s and 1970s and the more recent emergence of psychiatric survivor groups (Pilgrim and Rogers 2009). Opponents of the biomedical model, psychiatric diagnostic labels, and the power yielded by psychiatry and its products are encapsulated in survivor movements, resisting interventions based on objective claims to knowledge (Rose 2019, pp. 150-172).

More recent disputes between professional disciplines reflect 'turf wars' over ways of working within UK mental health services, with attempts to reassert the dominance of a biomedical psychiatry along with non-biomedical psychiatrists and clinical psychology fighting back (Kingdon and Young 2007; Craddock et al. 2008; Pilgrim and Rogers 2009; Bracken et al. 2012). In 2013, the British Psychological Society strongly challenged the biomedical model (Awenat et al. 2013) and in 2018 proposed a similarly controversial non-diagnostic framework for understanding mental distress.

These issues make the idea of a collective united commitment between psychiatric genetic researchers, other mental health professionals and service users a challenging proposition. In the above extract, Charlie also discusses the fact that there should be a united commitment but that researchers, in general, are protective of their intellectual property, "precious", and he uses this as an argument for why researchers are not fulfilling this unity. This highlights that, as well as having challenging relationships between service users and professionals, there are barriers to working collectively across professions themselves, especially when there are different worldviews about how to go about research for dealing with psychiatric conditions and disparities in how these approaches are valued and supported.

If we return to the discussion with Alex, disparity is also brought into focus when she talks about the power imbalances between psychiatric genetic researchers and potential participants:

See I feel that this one is putting the onus on the public to say you should be committed to taking part but they don't get anything from it whereas researchers get an awful lot from it, it's their career, so the power imbalance and what everyone gets out of this is so disproportionate that a united commitment is just based on a massive power imbalance
(Alex, mental health researcher) P22

Alex draws attention to the unequal nature of the relationship between researchers and potential participants, arguing the public "don't get anything from it." Sarah adds to this and talks about researchers not being exposed to what it means to live with a psychiatric condition, and how attempts to draw people into a collective group do not recognise these difficulties:

Erm, you know, there's a number of these statements that are about being united, about being part of a collective and I think that ... I'm not sure they appreciate how isolated some people are and how much of a ... how much of a big deal it is for them to just go to something or to go online, you know, there's so many people with mental health problems that are just not connected to the internet, they're not engaged to a large part of society because they're just struggling with getting out the front door. So, yeah, some of these like 'coming together to wage war', some of these issues that are more to do with all being in it together and 'working together for a better future' ... it's not that they [the researchers] overlook the reality of it, it just doesn't ... they're just not exposed to it.

(Sarah, mental health researcher) P10

This attribute of being in touch with real-life problems is something that Charlie described earlier when arguing that patients have to live in the real world. So again, for people with this style of thought, these extracts demonstrate there's a feeling of disconnect between psychiatric genetic researchers and people with psychiatric conditions, despite the fact that some of the researchers are also clinicians. This suggests a united commitment is idealistic but also perceived as presumptuous in light of the imbalance in costs and benefits between researchers and participants. Whilst this highlights a possible disconnect between psychiatric genetic researchers and their potential participants, it also draws to the fore the difficulties inherent in recruiting participants whose lives can be very challenging. This creates a problem for the nature in which a united commitment and collective ways of working might be productively facilitated.

7.5 Conclusion

The 'concerned critics' are supportive of psychiatric genetic research as one approach amongst many but consider its outcomes to be too distant and ill considered. They feel that psychiatric conditions are too complex to have a research agenda they perceive as narrowly focused on genetic research and have concerns about the credibility of the diagnostic criteria upon which the research is founded. They resent the status and prioritisation afforded to this kind of research, arguing its speculative promise is at the expense of funding other forms of mental health research and supporting people with psychiatric conditions now.

People with this style of thought also have concerns about how researchers represent psychiatric genetic research, and strongly reject the use of 'community' and 'collective' to encourage people to take part. These 'concerned critics' understand the need to inspire volunteers to participate but talked about the need for psychiatric genetic researchers to inspire potential participants "in the right way." They wanted researchers to be realistic about the potential of genetics, arguing that waging war on mental illness from the limited perspective of psychiatric genetic research is "selling a lie", given the multifactorial nature of psychiatric conditions along with the timescale and slow progress over which that war would take place.

In this chapter, I have argued that what is important to the 'concerned critics' is both how psychiatric genetic research participation is represented and the disparities in costs and benefits of participation between psychiatric genetic researchers and potential participants. These findings have significance for the solidarity-based framework proposed by Prainsack and Buyx in which seeing sameness with others is a key component. Reconciling these disparities will be important for moving psychiatric genetic research participation towards more collective ways of working in the future. Findings from the 'concerned critics' suggests that any moves towards a more collective approach to justify increased participation would need a more expansive debate about the societal repercussion

of translating the research into clinical applications, and how the knowledge gained could be integrated or co-produced with knowledge from research on social factors.

Chapter 8: The Cautious Obligators

8.1 Introduction

In this chapter, I argue that rather than relying on the altruistic giving of information and tissue samples, there is support amongst the ‘cautious obligators’ for participation to become viewed as more than just a responsible thing to do and be regarded as a moral obligation. I present this style of thought based on the analysis of seven people:⁸⁶ James, Frank and William who are all retired mental health professionals, Evan who is a psychiatric genetic researcher, and Martin, Graham, and Terry who each attend a mental health support group. Within this group, two disclosed a mental health diagnosis and no one had taken part in psychiatric genetic research.

In Chapter 6, I described how the ‘untroubled progress-seekers’ implied that participation should go beyond simply being a responsible thing to do and, whilst not always explicitly stated, was indicative of a shift towards viewing participation as a moral obligation. Similarly, the predominant view of people discussed in this chapter was that participation *should* be a moral obligation. However, what distinguishes this style of thought from the ‘untroubled progress-seekers’ is that participation is not talked about in an unproblematic way. This group *do* talk about psychiatric genetic research as being more concrete, tangible and realistic⁸⁷ but they have greater concerns about the possible misuse of future technologies that may arise from psychiatric genetic research and their view is that this needs greater public debate. Consequently, discussions about collective ways of working centred around bringing psychiatry out of “its entrenched position”, “being more grown up” and having more sophisticated and inclusive debates about the outcomes of

⁸⁶ As noted in Chapter 4, this group of ‘cautious obligators’ was created with greater emphasis on the qualitative data and the crib sheet for the quantitative data was based on only two of the Q-sorts and is, therefore, not included.

⁸⁷ Note that the term realistic is used in a general way to mean something that is practical and achievable rather than referring to an approach involving assumptions of realist ontology about the existence of phenomenon or entities.

psychiatric genetic research such that this kind of research is not seen in isolation from other ways of understanding and treating mental illness. Therefore, the greater agreement that participation should be a moral obligation is contingent on decisions about research applications being collectively and morally debated, and balanced with non-biomedical approaches.

Section two highlights the view, as it is characterised by people in this group, that psychiatric genetic research is a realistic approach to treating mental illness compared to other approaches. However, as discussed in sections three and four, there are particular concerns that call for more sophisticated, collective debate in order to balance the progress of this research with the governance of its potential applications to ensure it meets society's⁸⁸ needs. There is a demand for possible repercussions of the future applications of psychiatric genetic research to be made more explicit, and to consider who gets to control and define the limits of those applications in order to provide moral assurances on how the research can serve the public interest. In light of the continued need for research participants, I discuss in section five how these individuals talk about participation as a moral obligation for the greater good, highlighting what concerns come to the surface when participation moves from being considered a worthwhile responsible thing to do into becoming an obligation.

Based on this analysis, I argue that people with this style of thought would approve of psychiatric genetic research participation that is founded on a system of solidarity similar to that proposed by Prainsack and Buyx (Prainsack and Buyx 2011, 2012, 2013). If individual autonomy is to be relaxed under the sway of obligation then, according to this definition of solidarity, recruitment systems should work collectively at a social level to ensure shared costs. This will then benefit others whilst protecting the individual from harm, but this relies on trust in the organisation to uphold the shared, explicitly stated, values of the collective.

⁸⁸ A distinction is made here between society's needs and individual's needs, emphasising that evaluation of need should extend beyond the needs and rights of individuals.

8.2 Psychiatric genetic research participation: being part of a realistic hope

Similar to the majority of people in this study, these individuals were generally approving of psychiatric genetic research. In particular, they all agreed with the statement that psychiatric genetic research participation ‘means being part of a realistic hope of treating mental illness’, albeit with varying degrees of agreement. During discussion of this statement and other related statements, comparisons were often made between psychiatric genetic research and psychological therapies as well as reflections on the current situation for the treatment of mental illness.

James, a retired psychiatric nurse who specialised in working with patients with a diagnosis of schizophrenia, not only agreed that participation ‘means being part of a realistic hope’ but most strongly agreed with the statement that psychiatric genetic research participation ‘is vital for developing new treatments and overcoming the shortcomings of current therapies’. When I asked James to elaborate, he said:

Well, because there’s so much we don’t know and it’s only research that’s going to get us there, you can’t just leave it like it is. And you know with genetic stuff which is developing itself, you’ve got to be looking at things like this, you know.

(James, retired mental health professional) P15

There are two key phrases in this extract, one is that you “can’t just leave it like it is” and the other is that genetics is “developing itself.” Combining this with his very strong agreement of the statement that research participation ‘is vital for developing new treatments and overcoming the shortcomings of current therapies’, James views psychiatric genetic research as an approach to treatment that is managing to develop whereas other therapies are inadequate and not evolving. James discussed the limitations of psychological therapies, largely due to funding issues, arguing that they are in short supply and underfunded, describing the shortcomings of current therapies as follows:

Well, what have we got, just drug treatments and nothing else [...] I mean if they were to at least discover a gene for schizophrenia or something, you know, there’s a possibility of treatment then isn’t there.

(James, retired mental health professional) P15

What can be understood from this comment is that, by omission, James does not consider psychological therapies as being part of the possibility of treatments. In fact, he implies that the use of drugs as it currently stands is not a sufficient form of treatment either. This can be seen from his comment that “we just have drug treatments” and that a genetic discovery for psychiatric conditions such as schizophrenia would mean “there’s a possibility of treatment then.”

James is now retired but comes from a generation in which the powerful discourse at that time was establishing genetics as the primary agent of life, creating a different biological way of the talking, thinking, and doing of science whilst also embedding itself into the public imagination (Keller 1995; Kay 2000). Lippman (1992) has claimed that this resulted in an increasing geneticisation of disease through which the biological was foregrounded and the social was relegated but other scholars have questioned the empirical validity of geneticisation as something that has resulted in genetic determinism (Hedgecoe 2009b; Arribas-Ayllon 2016). Although research on public perceptions suggests there is less genetic determinism than claimed (Condit 1999; Bates et al. 2002), the individuals I talked to in this study did tend to foreground genetics much more heavily in terms of potential *treatments*, even if it dominated less so in terms of causation. This emphasis may change over time as the UK’s IAPT programme becomes more widely available for severe mental illness.⁸⁹ Although, according to Pickersgill (2019a), IAPT is neither re-centring psychological approaches nor challenging the dominance of biomedical approaches.

James is a retired psychiatric nurse who spent many years looking after people who were severely mentally ill. He ran a rehabilitation unit for long-term schizophrenia patients, over which time there was little change in the available treatments. This may account for his low regard for the use of drugs but particularly for his dismissal

⁸⁹ The UK’s Improving Access to Psychological Therapies (IAPT) initiative for anxiety and depression, introduced in 2008, was later extended to severe mental illness following pilot studies between 2012-2015.

of psychological therapies, viewing schizophrenia as rooted in biological rather than psychological origin. From James's point of view, there has been very little progress in treatment; he then summarised the discussion by proposing that "genetics is the way forward", signifying a very biomedical view of the future as well.

Martin, who is about twenty years younger than James and has regularly attended a mental health support group for many years, talked about treatments for psychiatric conditions as being a "stab in the dark" for psychiatrists and a "shot in the dark" for psychologists. He argued that neither approach is based on a causal understanding, leaving psychiatrists and psychologists with something of a trial and error approach. In the following extract, he compares talking therapies with the possibility of treatments from psychiatric genetic research:

... it might be right for so and so but it won't be right for someone else, you know, and it's sort of hard like, you know, so I don't think they will ever cure mental illness by talking. It helps, it mollifies the condition but until you know the root cause of it, you know, and it's like, you know, with the nurture and the nature, because it could be part of both, how can you treat the both parts, you know, it makes it even harder then. So, that's why I think it's realistic. To me, it's starting on a more solid base.

(Martin, attendee at mental health support group) P11

After comparing what he sees as the trial and error approaches of psychiatrists and psychologists, Martin summarises by saying that psychiatric genetic research is "starting on a more solid base." Also, what Martin is seeking is what he refers to as "the root cause of it" and, similar to James, he envisages a "cure", the elimination of symptoms and restoration of a symptom-free view of health, rather than the amelioration of symptoms. This is important because, as I will discuss in the next chapter, any reconceptualization of what research participation involves may depend on the expectations and beliefs about the research and its applications.

Both Martin and James view psychiatric genetic research as providing the route to a better understanding of the causes of psychiatric conditions that is a "more solid base" on which to develop treatments. Graham also attends a mental health

support group but is much younger than both James and Martin. Whilst he thinks there are many other ways to provide treatment, he also sees psychiatric genetic research as part of a more “concrete” and “tangible” hard sciences approach:

I guess I do believe that there are many other ways to treat mental illness than just psychiatric genetic research participation but I do also believe that scientific research is kind of more concrete, I guess [...] If you take part in this kind of research then you do feel like you’re doing something tangible so therefore realistic, it’s like a realistic hope of treating mental illness [...] but I do think there are other things that are realistic hopes of treating mental illness, like, I think that mindfulness practices and more kind of, like, soft sciences are quite important as well and I do worry about too much focus on hard science to treat mental illness. I think it ties into this whole fear of eugenics and the idea of a scientifically perfected human being.

(Graham, attendee at mental health support group) P2

Crucially, what is significant about Graham’s comment is that he accounts for his concerns about too much emphasis on hard sciences by linking them to his fears about eugenics and ideas of seeking perfection. This implies that Graham considers there are risks associated with an approach based on the hard sciences compared to what he refers to as the soft sciences. As already discussed in earlier chapters, psychiatric genetics has inherited a very troubled history as a result of abuses within both psychiatry and genetics (Propping 2005; Lewis and Bartlett 2015). These fears are important because they represent a negative aspect of an approach Graham is in favour of; addressing these fears would be important to secure his participation.

Analysis in this section has shown that people with this style of thought agree that psychiatric genetic research participation ‘means being part of a realistic hope of treating mental illness’ because they view it as contributing towards providing treatments based on some underlying cause and because the research is developing and moving forward compared to psychological therapies, which are seen as underfunded and less effective. This accounts for why someone with this view would take part, or advocate for others to take part, in this kind of research. This view of psychiatric genetic research as a realistic hope of treating mental illness overlaps with those of the ‘untroubled progress-seekers’. However, whereas that group see the research as unproblematic because of their strong belief and trust in

science and genetics, people in this group share concerns about potential applications with the 'concerned critics'. In the next section, we hear more from Graham about what concerns him regarding psychiatric genetic research.

8.3 Let's Talk About Eugenics

In the last section, Graham's account of his concerns suggested his support for psychiatric genetic research is impeded by his perception that there are risks associated with its potential applications that would need to be controlled. Graham has a keen interest in popular science and describes how the lure of improving human beings could draw the research into old territory:

... it's a very attractive idea that there's such a thing as a perfect human which is exactly the same idea that people had at the beginning of the 20th century, that it was possible to create a perfect human being and I think it's that same really attractive idea that could draw this kind of research down that direction potentially.

(Graham, attendee at mental health support group) P2

Historical reflections on the development of human genetics convincingly argue that it is this desire to gain biological control over the human race that has been a continuous draw for scientists (Kevles 2011; Comfort 2012). According to historian of science, Daniel Kevles, this possibility of control has continued to "tantalise" and "seduce" scientists (Kevles 2011, p. 330), but the risk of abuse has shifted from population level state controlled interventions towards risks driven by the desires of autonomous individuals and the commercialisation of genetic information. Either way, the introduction of genetics into medicine has resulted in a prevailing narrative of gaining knowledge to treat and prevent disease at the molecular level in individuals as part of them exercising their human medical rights (Kevles 2011; Comfort 2012).

Not surprisingly, psychiatric genetic researcher Evan disagrees with Graham's view and frames the research as being about understanding, rather than about seeking to remove human imperfections from society. In doing so, Evan attempts to

decouple the research from potential applications perceived as human enhancement:

... most of the heritability that we've explained of these conditions is common variation and will probably be ... well, it is now hundreds and will probably be thousands of different variants so, you know, it's not feasible that those could be genetically altered or edited but, even if it was, we don't know what the reciprocal effect of doing that would be. So, what people are trying to do in doing this research is understand what causes these conditions; it's not about moving towards some notion of perfection which doesn't exist.

(Evan, psychiatric genetic researcher) P34

According to Nathaniel Comfort, a historian of science and medicine, medical genetics stems from two impulses: the relief of suffering and the lure of human improvement. Comfort warns us against treating the two as separate entities whereby one is lauded as a noble act, making it hard to question, and the other is framed as a stealthy form of harmful social control (Comfort 2012). Political, historical and social scholars warn us that changes in rhetoric about eugenics does not necessarily reflect changes in underlying beliefs and highlight how narratives have developed that enable a distancing of current practices from past atrocities (Nelkin and Lindee 1995; Kerr et al. 1998; Paul 1998; Kerr and Shakespeare 2002; Duster 2003; Koch 2004; Comfort 2012).⁹⁰ Additionally, some scholars argue that the distancing work from the concept of eugenics may, ironically, run the risk of a return to eugenic practices because of the closing down of intellectual reflexive debate (McCabe and McCabe 2011; Arribas-Ayllon 2016; Lombardo 2018).

⁹⁰ Francis Galton published an article in 1865 about the possibility of engineering society, almost 20 years before introducing the term eugenics in 1883 and encouraging the British Sociological Society to promote eugenics as a national endeavour (Renwick 2011). Eugenics emerged as mainstream worldwide ideology, using science for social improvement at a time when the idea of eugenic practices was considered progressive, humanitarian, and highly scientific with great expectations (Koch 2006; Kevles 2011). It was considered an admirable field of study, promoted not just by those on the political right but also by the progressive reformists of the political left and, despite the diminishing use of the term eugenics, eugenic thinking still dominated social reform in a number of countries for decades after the atrocities of Nazi racial cleansing (Koch 2006; Renwick 2018).

By the 1950s and 1960s, medical geneticists were already distancing their own form of eugenic work from 'bad' eugenics, although it wasn't until the 1970s that, in addition to moral concerns about its applications, the term became scientifically disreputable (Paul 1998). Indeed, Evan finds the statement about eugenics extremely offensive:

It equates people doing this research with a movement that was one of the most destructive in the ... in the history of the world and it does that deliberately I think and so that's why I reject it. It's also irresponsible because it shows ... well, for any number of reasons it makes me angry and that, for me, ... they would say that with obviously a fundamental misunderstanding about the research.

(Evan, psychiatric genetic researcher) P34

Evan immediately distances psychiatric genetic research from eugenics in his account of why he finds the association with psychiatric genetic researchers offensive, regarding 'eugenics' as an intentionally derogatory insult. Paul Lombardo, a legal historian, describes resurrecting the term eugenics to use as an insulting weapon within discourse as a fairly recent phenomenon (Lombardo 2011).⁹¹

Despite rejections of this link to eugenics from researchers who view it as originating from an irrational public (Kerr et al. 1998) or ill-informed anti-genetic anti-psychiatry critics (Craddock et al. 1999), such fears persist, as demonstrated by comments made by people in this study. These fears hang over the field because of how the mentally ill were targeted by eugenic thinking, complicating the relationship between psychiatric genetic research and its various publics (Lewis and Bartlett 2015).

⁹¹ Some argue that the underlying eugenic impulse is timeless despite persistent attempts to relegate eugenics to a historical coercive movement (Comfort 2012; Lombardo 2018). Even shortly after the Nazi atrocities, it was the misguided application of eugenics rather than the scientific concept of eugenics that was being criticised (Koch 2006). The accounts of how eugenics initially proliferated around the world serve to remind us that scientific values and scientists' ability to be reflexive are rooted in the context of the time; scientists "did not plan the atrocities but they undoubtedly helped to prepare the intellectual ground" (Propping 2005, p.2)

In the last section, we heard from Martin, a service user, who talked about how psychiatric genetic research was starting on a more solid base and, as such, provided a 'realistic hope of treating mental illness'. However, his therapeutic optimism does not come without its fears and criticisms. Martin talked about how the activities of scientists in the past, along with the possibility of research being misused "if it fell into the wrong hands," are what make him wary of scientists and future applications of psychiatric genetic research. During our discussion, he accounted for these fears using historical examples but, in talking about these concerns, Martin does not disassociate the past from the present and says: "I'm a bit wary of this because of history more than anything and I don't think we're any wiser now." Martin also questions the behaviour of scientists:

This one here 'genetic testing', you never know with that do you? It's like, I mean, scientists haven't got a very good name have they really (laughs), let's be fair. They haven't have they? It's like we'll make the H bomb but we won't use it, things like that [...] I think sometimes you're a bit wary of them, like, are they gonna behave themselves or are they gonna believe their own beliefs and even when it's shown it's wrong, still carry on with their beliefs, like, do you know what I mean. It's like they used to buzz people with electricity didn't they because they thought that was gonna do them good ... yeah, and then someone come along and said oh that's bad so they stopped doing it then and then someone says it's good [...] and it's like depending on who shouts the loudest, sort of, says it's the right thing to do or the wrong thing to do.

(Martin, attendee at mental health support group) P11

Martin portrays scientists as rule-breakers in the name of science, not open to scrutiny or able to take opposing views on board. He also demonstrates a view that science is absolute, that there is a definite right or wrong action to take but that this is not necessarily based on the scientific evidence but on whichever scientist is the most persuasive or, rather, most vocal. Arguably, this is a popularised view both of science and scientists, the mad scientist gone wild. However, recent examples of rogue scientists such as He Jiankui, who shocked the global scientific community by facilitating the birth of genetically edited babies (Cohen 2019), along with calls for scientists to defend the integrity of science and behave appropriately (Agre and Leshner 2010) does little to allay these fears or to demarcate the activities of present scientists from past atrocities. Martin goes on to say that the research will

be abused and that, even if scientists have high ethical standards, they may be blinded by their own “hype”:

It's going to be used by someone innit, someone is gonna not just use it, they're gonna abuse it as well, unfortunately, because that's the nature of mankind innit, you know, and that's one of my things about that is where it's going to lead to. I mean, like everybody ... I suppose a lot of ... whatever science you're in, you might start off with the highest ethics in the world and if you start believing your own hype, you can abuse it then, you know, can't you?

(Martin, attendee at mental health support group) P11

As has been shown in previous chapters, there is a question about where psychiatric genetic research will “lead to” but, importantly, what Martin's extract draws attention to is the question of whether it is possible, except in retrospect, to recognise when research is being abused, or even what counts as abuse. What is also important to consider, is whether this recognition is restricted only to scientists and commercial entrepreneurs. Indeed, thinking back to the discussion about eugenics, there is also risk from a more “homemade eugenics” (Wright 1990, p. 27) in which individuals exercise reproductive freedom, or are potentially lured by the prospect of individual gain within the lucrative commercialisation of genomic information and technology (Kevles 2011).

Martin raises a number of issues, but of particular relevance are the concerns about how this ‘realistic hope of treating mental illness’ might be governed and that scientists themselves are included in those concerns, accused of not being reflexive and just as flawed as people involved in any other human practice. Retired mental health professional Frank agrees that we need to be alert:

‘Will lead to genetic testing that will [disadvantage those with mental health problems compared to those with physical problems] ...’, sorry, I mean I totally disagree with that but that is a danger unless we consider, again, we've talked about as being honest research or ethical research again, we have to just be aware that some people may be around who might manipulate some information.

(Frank, retired mental health professional) P18

Frank had already talked about the need for honest ethical research and says we should be alert to the possibility of the research outcomes being misused or manipulated. However, in talking about these concerns, Frank does not see this as a barrier to the research nor that we should put tight limits on what the research outcomes can be:

So, I mean there are a whole range of issues which ... but unless we're talking about research which is totally abhorrent ... I mean, by and large, we shouldn't be afraid of what the outcomes are and that, for me, is what the public debate is.

(Frank, retired mental health professional) P18

During our discussion, Frank talked about "the true meaning of research" and held the view of research as pushing the boundaries as much as possible, only stopping short at particularly unacceptable kinds of research. In the extract above, Frank draws attention to the need to debate the possible outcomes of the research, arguing that we shouldn't be afraid of what these might be but should openly discuss them instead, something we hear more about in the next section.

Irrespective of whether or not debate takes place in the public domain, researcher Evan anticipates that individuals will drive the demand for research applications in the clinic. Evan predicts, for example, that there will be demand in clinics for the genomic screening of psychiatric conditions. This is particularly the case for schizophrenia because of its severity and because there is evidence that schizophrenia is indicated by large copy number variants (Grozeva et al. 2010; Marshall et al. 2017).⁹² In talking about this imagined demand, Evan anticipates this pre-natal screening will be available within the next ten years:

The only outcome from this which I've thought about quite a bit in respect of the copy number variants that we're detecting is that people have got to have the information in order to make those decisions themselves and that information's got to be given in a way that helps them make the decision, you know, in a balanced way I think. And so it may come, I think it will ... this will come ... there'll come a time in the next ten years where people are arguing for these large effect copy number variants being screened pre-natally and so we need to make sure that we've got that information there.

(Evan, psychiatric genetic researcher) P34

⁹² Copy number variants are variations in the number of copies of a particular region of DNA.

Evan's concern is to ensure individuals will have the information they will need to make an informed balanced decision about how to prepare themselves for a child with a high risk of developing schizophrenia or whether to consider abortion.

Kerr and Shakespeare (2002, p. 164) warn that we should take great care to look out for "subtle and not so subtle" social forces of stigma and discrimination that can impact on people's decisions.⁹³ As already discussed in Chapter 7, how a psychiatric condition is framed and the availability of social care may not necessarily mean the decision is altogether voluntary nor based only on the availability of scientific information; social, political and commercial forces are also important. In other conditions for which genomic testing is already available, the discourse surrounding commercial direct-to-consumer testing is affecting the decisions that people make within regulated clinics (Horton and Lucassen 2019). This is because the commercial hype creates the perception that genomic information is more deterministic than it is. This highlights the impact of commercial activities on this 'informed' decision-making process.

Werner-Lin and colleagues argue that, despite the assumption that provision of information is beneficial to potential parents, the practical consequences of such uncertain and possibly non-actionable genomic information may actually be damaging and far-reaching (2019). Some consequences are the legitimising of pregnancy terminations, the impacts on judgements about disability along with the effects on parenting and help-seeking under the perception of having a vulnerable child. However, as Thomas et al (2020, p. 89) state, there is "a strong need to move debate and discussion beyond the dominant framings of 'informed consent' and 'reproductive autonomy' alone." How these consequences impact on demands for services and distributive justice for support within a constrained health service are all in need of public debate.

⁹³ Note, however, that a review by Parens and Appelbaum (2019) cautioned against generalising findings and summarised there is still a lot to learn about the psychosocial consequences and the impact of sharing genomic information within different contexts.

During this study, a few individuals anticipated that the issues within future debates about genomic testing/screening for psychiatric conditions such as schizophrenia are likely to have already played out in other conditions such as Down syndrome. However, the public debate about early detection genomic screening for Down syndrome has been “muffled” and “contained”, despite the technology already being introduced into the clinic (Thomas et al. 2020, pp. 14-15). The commercially lucrative opportunities associated with genomic technologies means public debate may not keep pace but that does not mean the technique is socially acceptable or driven only by individual demand for information (Vassy 2005). Such observations do not bode well for schizophrenia, which is often seen as the forerunner for socio-ethical debates in other psychiatric conditions.

In talking about the applications of psychiatric genetic research, Evan discusses how this testing and screening needs to be carefully considered in order to *be* ready for the demand but, in the next extract, he distinguishes this from gene editing in which he talks about considering its use only *when we’re* ready:

So, whilst I think they will come to the clinic, I think that’s got to be done in a really measured way for pre-natally and for clinical testing actually. And the other thing is about gene editing, CRISPR⁹⁴ type technologies for these things as well, and again you’ve got to be very careful about it I think and it’s got to be people coming from a background like you’re going through, the bioethicists, as well as the wider public that make those decisions. And actually, a lot of people think that people in ... sitting where we are, want that to happen and actually, the last ... I *do not* want that to happen prematurely because I think it will be damaging for the whole field, I want it to happen in a really measured way and only when we’re ready, yeah.

(Evan, psychiatric genetic researcher) P34

Evan draws attention to his concerns that, as well as the wider public, there should be people with a greater understanding of the socio-ethical issues when making decisions about testing and gene editing. Indeed, David Curtis and colleagues have

⁹⁴ CRISPR-Cas9 is a relatively new gene-editing tool that can precisely target, alter or correct a region of DNA. It has been described as a disruptor technology that has caused “major upheaval in biomedical research” because it is cheap, quick and easy to use (Ledford 2015).

called for more research to better characterise the advantages and disadvantages of such testing, at least from an ethical perspective (Curtis et al. 2019).

Evan deflects researcher responsibility for how knowledge is to be used, a device for maintaining boundaries so as not to contaminate 'good science' (Kerr et al. 1997). In both extracts, Evan talks about psychiatric genetic researchers as responding to demands for genomic testing but distances this from gene editing, arguing there is an ill-conceived view of researchers as accelerants of such technologies/applications. However, this conceals the subtle interplay between current societal needs, scientific research, its technologies, and the need to attract research funding by promoting its future possible applications. Previously, Evan talked about how it was not feasible that gene editing would take place for psychiatric conditions but, whilst this is currently highly unlikely, we must always remember it is based on current knowledge. In considering gene editing, Evan's concerns are not centred round the possibility of it happening at all but around *when* it will happen, making sure it has been debated amongst people with the appropriate and knowledgeable input.

Evan argues that decisions about the applications of psychiatric genetic research are not to be made by the wider public alone, his responses demonstrate he is well aware of the links that people make regarding eugenic practices and the damage this can do to the field. Similarly, as demonstrated by Martin's comments, scientists are also accused of "misbehaving" and being blinded by their own "hype". Calls for open and more sophisticated debate are discussed further in the next section but what is important here is that many of these concerns are about the governance of the research in relation to visions for its future.

What the analysis of the data in this chapter has shown so far is that it is not necessarily that there are different expectations of whether or not the future should include such technologies from psychiatric genetic research but *when* that takes place, who decides how it is used and who benefits. People want to push the

boundaries of the research but want to know that, if found to be necessary, there is a framework in place to avoid a “slippery slope.”⁹⁵ Eugenic thinking is still seen as a barrier, partly because researchers believe this is how they are perceived but also because people have real fears about the governance of psychiatric genetic research applications. This is particularly important when thinking about psychiatric genetic research participation as a solidaristic practice: whether individuals see similarity in others depends on a shared vision of what psychiatric genetic research can and should achieve. This group of individuals argue that such a shared vision can only come about through more sophisticated collective debate.

8.4 Sophisticated collective debate

In Chapter 5, I showed how disciplinary divisions have been particularly problematic for psychiatric genetics. In this chapter we hear from individuals who specifically argue for more sophisticated debate and collective ways of working. Retired mental health professional James talked about his experiences of working with a range of psychiatrists and psychologists over the years, pointing out that these professions have never really got on and still do not because of conflicts in beliefs about the causation and treatment of mental illness, something discussed in greater detail already in Chapter 5. We have also heard from Martin who talks about the profession of psychiatry from his perspective as a user of mental health services. He described psychiatrists as “entrenched” in their views, arguing that it would take “a new generation of psychiatrists” to acknowledge the limitations of psychiatry. In terms of scientific research, Martin’s perspective is that scientists do not work well across different disciplines and that, by working within their own disciplines, important discoveries may be missed; he calls for multidisciplinary ways of working:

⁹⁵ One argument by opponents to germline gene editing generally is based on the concern that familiarity with a recent technology transforms our perception of what’s helpful and safe, resulting in a ‘slippery slope’ towards accepting emerging technologies that were previously rejected (see Pattinson 2000; Feeney 2019; Drabiak 2020)

... because little things, they're gonna come out the blue and they're gonna come from different parts and unless that's all put together and it's all part of a collective, they're gonna be lost and they could be the most important part of the puzzle and that's why I think it's important that the whole scientific community have got to look at mental illness.

(Martin, attendee at mental health support group) P11

When it comes to working relationships, James and Martin both regard relations between the relevant disciplines as problematic and retired mental health professional Frank agrees that this is a problem for debating the issues. In talking about his concerns, Frank described previous debate as being "unsophisticated" and "a bit Neanderthal." He argues that there are challenging decisions to be made in the future and that maintaining disciplinary divisions is not helpful, calling for the need to "be a bit more grown up and work on that." He talked about the need for ethical debate; debate that he feels should exclude commercial pharmaceutical companies:

... this [psychiatric genetic research] has a role somewhere and it needs to be debated and it needs to be debated in a very ethical way and not with, you know, the pharmaceuticals coming in or whoever, you know.

(Frank, retired mental health professional) P18

Mental health service user Graham is not so concerned about the involvement of commercial companies; he accepts that they are likely to be involved but does not expect them to be a considerable problem:

I've read too many articles about pharmaceutical companies taking advantage of research and I think there's always going to be businessmen who will leap at an opportunity to make a lot of money and then make a quick exit. So, I think that is true to an extent but I don't think that it's maybe going to be totally rampant and horrible and stuff [...] It's not, like, because of that I would be against it or anything but I still think it would happen.

(Graham, attendee at mental health support group) P2

Like other individuals in this study, Graham accepts that commercial pharmaceutical companies are likely to be involved and their focus is on making money but this

would not affect his decision about whether or not to participate in psychiatric genetic research. Frank, however, warns there needs to be transparency and honesty about the whole process so that people are able to have an open debate about how the research and its technologies aims to meet people's needs:

... and making sure that, if we go along a certain line, that it is transparent and it's very clear about whether or not it meets people's needs and as long as ... I always used to say as long as you're honest about what this decision is, that's fine because then we can start changing that but quite often people make decisions and they're not very honest about them.

(Frank, retired mental health professional) P18

So far in this chapter, we have heard from a variety of individuals, all male but spanning a wide age range and a mix of psychiatric genetic researcher, mental health professionals and users of mental health support groups. Their concerns reflect potential problems that may arise in terms of debating a shared vision for the future, not only in terms of getting different parties involved in the debate but also questioning who should be involved and what their social and ethical values are. However, the main topic of the conversation that these individuals have in common concerns whether psychiatric genetic research participation should be a moral obligation for the benefit of the greater good.

8.5 Participation as a moral obligation?

When considering the statement regarding participation as a moral obligation, psychiatric genetic researcher Evan talked about different approaches they have for recruiting participants and the ways in which all genetic databases have to balance the effort involved in recruiting participants with the impact of those efforts (or reduced efforts) on data quality. Evan had already talked about the possible bias introduced into databases due to insufficient targeting of potential participants during recruitment, the need to be aware of how recruitment affects those biases, along with the benefits and pitfalls that come with relying on altruism. During our discussion, he talked about ways this can be circumvented. Evan specialises in

genetic research on schizophrenia and, in the following extract, he explains how, as a research organisation, they have sometimes needed to go beyond this reliance on generosity and altruism for recruitment. He talks about one study where they offered a small financial incentive to appeal to particularly informative participants for schizophrenia research:

... if you just rely on acts of generosity then you get white female rich highly educated people, you get bias towards those groups and what we did by paying people was definitely get better representation among young males. Now we've not looked at it formally for those other under-represented groups but we *definitely* got more young males as a result of paying people which is really important cause it ... for schizophrenia, they're the group that you want.

(Evan, psychiatric genetic researcher) P34

Evan's comment demonstrates that, to obtain particularly relevant participants they needed a financial incentive. This highlights that, as a social mechanism, generosity of individuals and the altruism for other people, is insufficient to provide the quantity and specificity of participants required for psychiatric genetic studies. For some people, however, participating in an act of altruism may be a luxury they cannot afford because their time is preoccupied with earning enough money to live; not paying for participation then excludes those who cannot afford to do so. During our discussion, Evan did not just talk about providing payment to secure participants, he had argued for payment on the grounds that it was the right thing to do. So, we see from Evan that, whilst the majority of their studies rely on voluntary participation, there have been attempts to obtain data through providing a financial incentive. Evan also talked about sourcing data from within the NHS and in doing so he relates this to the common good:

It's just ... I think it is a contract for the common good and so the NHS embodies that and I think the data should be part of that as well. So, it is an obligation in that you're entering into that contract. Now, you **can't** hold anyone to it and I don't think you **should** but I think there is ... there should be ... you know, if the strengths of the NHS are going to be exploited by research I think it relies ... and exploit in a good way I mean ... it **relies** on that common contract and so, in that sense, I think there *is* a moral obligation.

(Evan, psychiatric genetic researcher) P34

Evan draws on the idea of a social contract when justifying the moral obligation to participate in research, a contract that is not explicitly stated nor exchanged but is implicitly initiated once you begin to accept services from the NHS. What Evan argues is that this social contract should be extended to allow NHS data to be made available and exploitable by research. This extends the scope of what might be commonly understood to be included within that social contract. In using the words “can’t” and “should”, Evan remarks there is no legal nor moral function that would permit or condone the extreme action of refusing NHS services due to a refusal to participate in research.

However, *assuming* that research participation can be subsumed within (what is often imagined as) the existing solidaristic practice of the NHS is still problematic. According to Prainsack and Buyx (2017), if solidaristic practices are to be durable, the foundation needs to be built from voluntary practices rather than fear of sanctions.⁹⁶ Utilising the NHS in this way, by aligning with the implicit social contract entered into when using NHS services, potentially permits invoking a sense of obligation but one that does so without fear of sanctions. People might feel morally obliged to give data but they *do* know that they can’t be refused healthcare if they don’t. Such a move would be less problematic if this process is explicitly agreed upon and recognised as such.

Evan argues there are missed opportunities because NHS services hold data that would greatly benefit research that, in turn, would benefit the services of the NHS and society as a whole. During our discussion, Evan described himself as a proponent of the NHS, but it was also clear that he is frustrated by the system because of the untapped potential for research. His understanding of the reliance of research on that social contract signifies his desire for research participation,

⁹⁶ This condition of voluntary and informed practice does pose problems in terms of those with chronic symptoms of psychosis, some of whom may not have a strong enough sense of reality for long enough to have the mental capacity to participate voluntarily and yet their data is probably the most valuable for a better understanding of their particular condition. According to Harris (2005) we are obligated to make decisions for those who are unable to make such decisions themselves, especially if it would be beneficial to them.

currently regarded as a responsible and worthwhile thing to do, to cross over into obligation. Or at least he wants to be able to harness the power inherent in the obligations that are associated with the social contract that, in his view, is embedded in people's usage of the NHS.

Retired mental health professional Frank agrees in the idea of obligation but sets limits on how far this obligation can go:

Participation in research should be, I suppose, an obligation, should be part of our world in the sense of it, you know, should be something we feel that we should get involved ... a bit like a civic duty almost ... and that may be pushing things too far ...

(Frank, retired mental health professional) P18

Frank agrees that participation should be a moral obligation but is hesitant to go as far as declaring it as a civic duty, thus making a distinction between different forms of obligation or duty, especially a duty as a citizen's responsibility or a duty enforceable by law.⁹⁷ It is a tension that is evident both amongst the researchers who tread carefully during their appeals for participation and amongst those who are hesitant to declare their view lest it goes against the currently normative stance of respecting the right for individual autonomy.

Graham, on the other hand, is the only one in this group who explicitly disagreed with the idea of participation as a moral obligation, the rest of the group agreed and one was unsure. In the following extract, Graham describes his resistance and argues for the benefit of presenting participation as a responsible choice instead.

... although I do think that taking part in psychiatric genetic research is for the benefit of the greater good, I don't agree with the philosophy of moral obligations and that sounds too extreme for my sensibilities and I think that telling people that they have a moral obligation to do something or not to do something just seems a little bit too fundamental for me and I feel like it could be a slippery slope perhaps to more ... I don't know, forcing people to do things they don't want to do whereas saying it's a

⁹⁷ Note that in the literature discussing whether research participation should be an obligation or duty, these terms are used interchangeably. The distinction between moral and legal duty or obligation will be discussed in Chapter 9.

responsible thing to do to improve the understanding of psychiatric conditions is phrased in a way that puts more focus on the individual's choice.

(Graham, attendee at mental health support group) P2

Graham's objections are largely on the grounds that a moral obligation could pave the way for more extreme forms of governance and not just research governance. Martin, on the other hand, talks about how to get around this tension between responsible action and obligation by thinking about how forced recruitment can be avoided but participation still achieved:

You know what it's like, if you tell someone to do something and they don't want to do it, the worst thing you can do is tell them to do it ... but if you give em a choice, people will do it, oh I'll have a go at that, I'm doing something here that might make a difference or might make a difference to me.

(Martin, attendee at mental health support group) P11

Here, Martin strategises how people can be nudged into participating by giving them a choice but with the expectation that their choice is to agree to participate. This is a strategic nudge-like use of choice, to increase the possibility of participation, rather than a demand for choice on the grounds that this is the right thing to do.⁹⁸ This interpretation is backed up by Martin's subsequent comment that supports a collective view of society and prioritises this over individual autonomy:

And that 'means giving up time for no personal gain', that's rubbish innit because everybody gives up time for something in their life don't they and they don't get any personal gain. I mean if you can't do that, you're not part of the human race are you (laughs).

(Martin, attendee at mental health support group) P11

Martin draws on the idea of what it means to be part of society when criticising the statement that participation 'means giving up time for no personal gain'. Rather

⁹⁸ Nudge theory (Thaler and Sunstein 2009) has been both influential and controversial in UK and US politics, argued to be a way to push people into making (better) decisions without taking away their freedom of choice.

than commenting on whether or not people would personally gain from participating, he criticises the expectation of personal gain in the first place, arguing that to be part of the human race is to incur cost for the benefit of others.

William, one of the retired mental health professionals, describes how benefits and costs to individuals are rarely specific to the individual anyway, arguing that the family and society also benefit from what is good for the individual. When talking about psychiatric genetic research participation, William says:

I think that's kind of ... that's my view anyway, that it *is* for the greater good, it should be for the greater good of society and the individual is part and parcel of that 'cause he's part of the whole isn't he, no man is an island. So, that's my philosophy anyway, should is the word, *should* be a moral obligation.

(William, retired mental health professional) P7

William's view is that the greater good of society takes precedence over the individual because the individual is a social being whose life depends on, is affected by, and affects other people. This reflects a relational view of personhood whereby the individual is shaped by and embedded within various relationships with others. William's view is also in line with communitarian theories that call for a change in how healthcare systems allocate treatments and this would extend to assisting research to benefit the healthcare system on the grounds of it being for the common good.⁹⁹

Terry, an attendee at a mental health support group, agrees that participation in psychiatric genetic research should be a moral obligation but emphasised that this is dependent on the research and its applications being for the greater good. Specifically, Terry's condition of agreement is "if it was in the public sphere",

⁹⁹ Purely communitarian theories have been criticised for their premise that there is a joint understanding of the common good, arguing this is problematic (for summary of these criticisms, see Prainsack and Buyx 2017 pp. 24-29). Historical reviews of the proliferation of eugenic thinking reminds us that there are also dangers of subordinating individual human rights to some *greater* social good, especially when the driving force is largely economic (Kevles 2011).

demonstrating his lack of support for research that is linked to making a financial profit from its activities. Here we see that there are conditions being made if participation is to be proposed as a moral obligation. In doing so, Terry invokes the idea of reciprocity in that something morally correct is assured in return; in this case to keep the research away from profit-making privatised companies. This suggests that, from Terry's perspective, a social mechanism based on moral obligation would not be acceptable without some reciprocal moral assurances.

What this demonstrates is that people may well put conditions on participation, especially if it were to be promoted on the basis of a moral obligation. Indeed, setting conditions and reciprocity have been regarded as very important if moral arguments are to be used to justify the sacrifice of some level of autonomy within biobanks (Hoedemaekers et al. 2007), requiring a strategy whereby organisations are 'giving back' rather than assuming participation to be a 'gift' (Gottweis et al. 2011). If these conditions cannot be met then this lack of reciprocity will mean that participation, currently viewed only as a responsible thing to do, will not cross over into something considered to be an obligation. It is this obligation or duty that is a particular feature of solidarity at the institutional level, according to Prainsack and Buyx's conceptualisation of solidarity (Prainsack and Buyx 2011, 2012, 2013).

So, we see that Terry has attempted to put conditions on psychiatric genetic research participation if it were to be reframed as a moral obligation. Nevertheless, researcher Evan argues that participation is likely to change in the future anyway; Evan predicts that direct appeals to people to participate in psychiatric genetic research will be replaced with anonymised data linkage:

... moving away from this model of people come, are interviewed and then give us a blood sample and go because that, you know, in five years time is not going to be the situation I don't think. I think it will be ... I mean, we've done it already ... we're using samples that are routine blood samples, anonymously, and we're linking that with electronic health record data as a way to gather together large samples that hopefully will still be very well characterised ... but the genetics has obviously got particular issues that it's raising and we're working with some bioethics researchers around some of those issues but that's something else that I think increasingly will come to the fore ... is

a whole different [...] conceptually, participation is different in those different contexts isn't it so I think there's much wider discussions and considerations in those issues.

(Evan, psychiatric genetic researcher) P34

If Evan's prediction is borne out and participation becomes less reliant on attracting participants who give informed consent before their blood and information is taken and used for research, there will be greater reliance upon presumed consent. In order for this approach to function, the governance framework would need to accept that potential harm could come to individuals as a result of their unknowing participation. Alternatively, the risk of potential harm could be made explicit and argued to be a cost incurred as a condition of the kind of solidarity that is already inherent within the existence of the NHS.

Evan suggests that appeals to responsible action, altruism and generosity are not effective enough in acquiring the right quantity and specificity of participants needed for psychiatric genetic research. Alternatively, and if presumed consent or moral obligation are not deemed acceptable on the grounds of infringing individual rights or providing insufficient reciprocity, an alternative approach would require strong safeguards in place that would protect people from harm (Prainsack and Buyx 2013), and also signal they will be protected from harm.

8.6 Conclusion

For the 'cautious obligators', there is some support for participation to be seen as a moral obligation on the basis that this is for the common good, arguing that individuals are part of society and should accept costs and risks to themselves in order to care for others. This societal level view, coupled with the desire to avoid the extremes of regarding participation as a "duty" or something that is enforced, suggests people with this style of thought would be approving of a system based on *solidarity*.

My analysis indicates there might be some support for less emphasis on the prevalent autonomy-based approach to research participation but that any change in practice would require demonstrable reciprocity between all stakeholders along

with mutually agreed goals and multidisciplinary ways of working. Whilst this group are supportive of psychiatric genetic research and agree it is realistic and, in some cases, vital, their concerns about the governance of the research and its applications motivate their call for greater debate in order to have more sophisticated discussions about how these applications might best serve society whilst addressing some of the concerns about future applications.

Prainsack and Buyx (2011, p. 79) claim that their particular conceptualisation of solidarity helps us to make explicit when and how axiomatic practices, i.e. those based on value and worth, “cross over or change into deontic practices,” i.e. those based on duty and obligation. By paying close attention to the concept of solidarity, as defined by Prainsack and Buyx, it is possible to explore the nature of the tension that exists when considering this crossover in the context of psychiatric genetic research participation. Many of the individuals discussed in this chapter agreed with the statement that participation should be a moral obligation for the benefit of the greater good but what the analysis of the qualitative data has shown is that this is not without conditions.

This chapter provides empirical support for bioethical arguments (Hoedemaekers et al. 2007) that conditions of agreement would be necessary if solidarity were to be used as the basis to justify reduced autonomy within psychiatric genetic research participation. In the next chapter, I draw together the various findings from this and previous results chapters to argue that there is an appetite for more solidarity-based practices in the case of psychiatric genetic research participation.

Chapter 9: Discussion

9.1 Introduction

Within this study, I have produced four distinctive styles of thought about psychiatric genetic research participation by analysing both quantitative and qualitative data on what participation means for researchers, mental health professionals and people experiencing psychiatric conditions. I will argue here that there is a need and an appetite for exploring a solidarity-based conceptualisation of psychiatric genetic research participation. My argument is that this participation is changing and, unless the governance of psychiatric genetic research moves towards a framework based on solidarity, what it means to be a participant may instead move closer towards presumed consent, opening up the possibility of social inequalities because of unaddressed concerns about future applications of psychiatric genetic research. My argument to support this is based on four key findings, some of which are unique to a particular style of thought whereas other findings cut across the four styles. I begin with an overview of how the findings fit together to tell a story, which I argue suggests that psychiatric genetic research participation is undergoing change, moving away from appeals for altruistic donations that rely on autonomous informed consent. I then take each of the four findings in turn before addressing how these findings answer the research questions.

9.2 Line of reasoning: Summarising the findings

The findings from this study tell a story of how psychiatric genetic researchers have worked hard to bypass powerful gatekeepers to their potential participants and, in doing so, have attempted to foster a sense of belonging and community to attract and retain participants. These possibly benevolent, but also strategic, attempts at 'giving back' are entangled with the necessary demands of doing science, of

attracting funding, and recruiting human participants. Appealing to a sense of responsibility, one that sometimes verges on calls towards moral obligation creates a tension that has been difficult for researchers to navigate and 'giving back' in some way has been felt necessary in exchange for participation. As evidence in this study shows, supporters and critics alike have rejected this use of the language and spirit of community. A key reason is that potential participants want to work collectively to assist others but do not want a shared collective experience; they do not want to bond with other people through psychiatric genetic research participation. At the same time, the need for specific participants is not being met despite these attempts; according to the psychiatric genetic researchers in this study, public engagement has tended to attract educated middle-class women with depression. Consequently, rather than having to attract volunteers through public engagement, there are moves by researchers towards finding alternative approaches such as anonymised record linkage to routine blood samples taken during NHS treatment.

Some bioethicists and sociologists have argued that participation in research *should* be a duty or moral obligation (Chadwick and Berg 2001; Harris 2005; Rhodes 2010) and, in this study, this is a particular view that exists and cuts across psychiatric genetic researchers, mental health professionals and potential participants. However, the suggestion to subsume consent for research participation to within the pre-existing social contract of the NHS veers towards an element of presumed consent and may not be welcomed by critics, given the troubled history of both psychiatry and genetics (Propping 2005; Lewis and Bartlett 2015). Any moves towards activities involving reduced or unknowing 'consent' will be met with resistance, even though researchers suggest it is becoming a practical necessity; in this study, the 'cautious obligators' raised concerns regarding the outcomes and governance of psychiatric genetic research just as much as the 'concerned critics'.

On the other hand, traditional informed consent is also problematic. It has been described as cumbersome, restrictive, over-regulated and unjustifiable (Schaefer et al. 2009; Koski 2010; Rhodes 2010), a legal tool to manage risk (Prainsack and Buyx

2017) and difficult to achieve in practice, resulting in an empty ethics that “strips the principle of consent away from its social context” (Corrigan 2003, p. 787). Hoeyer (2003, p. 241) describes informed consent as a biopolitical development that, in some situations, gives greater “room to manoeuvre” and utilises a sense of individual responsibility as a way to increase recruitment. Indeed, potential participants are found to rely little on the provision of information within the informed consent process, scholars arguing that the route into participation is more socially negotiated (Cox 2002; Corrigan 2003; Hoeyer 2003; Sharp 2004; Dixon-Woods et al. 2007; Ponder et al. 2008) and that bioethical approaches to thinking about consent are insufficient without empirical sociological evidence (Haines 2002; Hedgecoe 2004).

Within this study, we have heard talk of an unresolved need to address suffering from mental ill health. Potential participants often evaluated the promissory therapeutic nature of psychiatric genetic research in light of any perceived pessimism of alternative imaginaries of treatment. A number of people in this study were very supportive of psychiatric genetic research and there is a perceived fatigue with simply raising awareness and talking about mental health. For these supporters, there is a desire for action in the form of psychiatric genetic research, demonstrating a willingness to give up time and tissue samples to help others. However, critics and supporters alike are concerned that its applications and repercussions have not been fully considered, that more *sophisticated* discussion about this is necessary, and that its development is at the expense of social research into mental health. Consequently, exploring the feasibility of a solidarity based re-conceptualisation of psychiatric genetic research participation should address some of these outstanding issues and concerns, thus meeting the need and appetite for a change in what it means to be a participant, as demonstrated by this study.

9.3 Four findings: entangled reciprocity, a failed community, unresolved concerns, and solidarity

Finding 1: Bypassing powerful gatekeepers and the entanglement of research needs and reciprocity

Psychiatric genetic researchers perceived that problematic social relationships between biomedical psychiatrists and both psychologists and non-biomedical psychiatrists, in particular those working within mental health services, have created a barrier between themselves and their potential participants. Note that this perception of problematic relationships is not unique to research participation; antagonism from psychologists within mental health services had already been observed in clinical practice, the hostility located as originating in more general objections to a biomedical approach to treatment (Craddock et al. 2008). Some psychiatric genetic researchers in this study have described the desire for a collective way of working as idealistic but other data show that this desire is also part of a strategy to recruit and retain participants. Launching a public engagement programme to “change hearts and minds about participating in research”¹⁰⁰ was an attempt to bypass what the researchers perceived as powerful gatekeepers to potential willing participants. Rather than “converting gatekeepers to regimes of hope” as suggested by Arribas-Ayllon and colleagues (2019, p. 181), I argue that the people initiating the public engagement of psychiatric genetic research were attempting to bypass the gatekeepers altogether. Locating a perceived generosity in the decision to participate, attempts were made to create ‘community’ and to give something back to participants in the form of research updates and supportive information about their condition but also to orchestrate a sense of kinship that community can sometimes provide. Consequently, as the data suggests, the tension between the motivation for giving something back and the need to recruit participants creates an entanglement of moral reciprocity and scientific research needs.

¹⁰⁰ This is a quote from the director of the Centre when talking about the motivations for their public engagement programme.

Finding 2: Constructing community is a failed strategy

In this study, the psychiatric genetic researchers' attempt to construct community has failed as a strategy. Researchers confirmed that they feel this community has only emerged amongst the research champions; even those participants who are very supportive of psychiatric genetic research regard the idea of fostering a sense of community as irrelevant, ineffective or inauthentic. This paints a different picture to the presence of a community amongst researchers and participants which has arisen amongst some specific conditions (for example, Dixon-Woods et al. 2008b) or within pre-existing communities (for example, Tutton 2002). Indeed, there is no evidence in this study to support Paul Rabinow's concept of biosociality (1996), the current lack of valid biomarkers being a possible reason for this. Such a concept proposes that genetic risk markers might prompt people to think of themselves as a particular kind of person such that new social groups might gather, but staff within the Centre have had to work hard to try and draw potential participants together, many of whom have rejected this particular form of sociality. Public engagement events run by the Centre did not have a core group of attendees gravitating around some biomedical focus, and the topic of mental health, never mind genetics, was strategically downplayed in order to attract people to events.

Data from across the four groups demonstrates there has been considerable work involved in attracting further participants, through heightening the visibility of research recruitment and through attempts to foster belonging and community. However, the 'concerned critics' in this study, many of whom were mental health researchers who understand the needs of research projects felt that techniques to increase participation needed to be, in some way, proper and transparent and attempts by psychiatric genetic researchers to utilise the language of community alienated and angered some. These feelings resonate with analyses of institutional discourses that suggest recruitment practices have strategically appropriated the discourses of partnership, community involvement, and active citizenship because of public ambivalence towards scientific research (Tutton 2007) and to increase research subjects for scientific research (Woolley et al. 2016). They also resonate with broader critiques about the growing rhetoric of public engagement and

participation amidst strained relations between science and its publics (Irwin 2001, 2006, 2014).

Finding 3: Unresolved concerns and a resistance to the prioritisation of psychiatric genetic research

This study suggests that while there are concerns about the applications of psychiatric genetic research, there is general support for the research itself. For some people, psychiatric genetic research is relatively unproblematic and there is a strong desire for action in the form of scientific progress. The data suggests these supporters perceive a general fatigue with national campaigns geared only towards raising awareness and talking more about mental health. Instead, these supporters locate progress within the results-based action of scientific research. This emphasis on the need for action resonates with Prainsack and Buyx's (2017, pp. 43-48) conceptualisation of solidarity which regards it not as a value or feeling but something that is enacted as an external expression of some action rather than as an internalised sentiment.

Amongst many in this study, there is a perception that psychiatric genetic research is a realistic way forward in the absence of alternative approaches. Such sentiments may reflect a view of big biology coming to the rescue of the 'soft' science of psychology but, over time, assumptions about the limited access to psychological therapies may be challenged following the UK's ambitious national IAPT¹⁰¹ initiative and its extension to include severe mental illness (Jolley et al. 2015). However, IAPT is neither re-centring psychological approaches nor challenging the dominance of biomedical approaches; criticisms of IAPT have highlighted its economic framing of health care, undiscerning overuse and lack of cost-effectiveness (Pickersgill 2019a).

¹⁰¹ The Improving Access to Psychological Therapies (IAPT) initiative for anxiety and depression, introduced in 2008, was later extended to severe mental illness following pilot studies between 2012-2015.

Regardless, psychiatric genetic research is seen as either vital for developing a greater understanding in order to press ahead with translating this knowledge into treatments or, from the perspective of its critics, useful for demonstrating whether genomics actually contributes less to the causation of psychiatric conditions than has been promoted by psychiatric genetic researchers. Either way, there is little resistance to the research itself, the resistance comes from the status and prioritisation given to the research and how applications of the research might be developed without proper consideration of their societal consequences, including concerns about how such developments might be governed. This finding reflects the limited existing research demonstrating general support for psychiatric genetic research (Trippitelli et al. 1998; Jones et al. 2002), albeit with mixed feelings about its moral implications (Illes et al. 2003).

The 'concerned critics' identified in this study argue that the implications of psychiatric genetic research outcomes haven't been thought through. They claim there isn't a clearly articulated idea of how it will improve people's lives and society, and that lengthy extensive funding of costly genetic research on psychiatric conditions is at the expense of social research on mental health. Combined with concerns expressed by other people in this study, fears of possible negative exploitation of the research suggest there are differences of opinion over what is meant by 'improving' society. A number of mental health researchers and people with psychiatric conditions expressed concerns about the possible elimination of genetically susceptible groups within the population. Schizophrenia, for which genomic screening might become a possibility within the next decade, was seen as posing a particularly distressing moral dilemma. Whilst researchers argue that research is needed to allow prospective parents to make informed choices, a number of people in the study raised concerns about a return to eugenic practices, arguing that these 'choices' become compromised when made in the context of chronically underfunded and struggling mental health services.

Finding 4: From responsibility to obligation: a conditional proposition

There is evidence in this study that, for some psychiatric genetic researchers, there is a desire for research participation to cross over from being a responsible worthwhile act into an obligation. Researchers are frustrated and have found strategic ways to improve recruitment to their studies; in this study they talked about how to circumvent the need to persuade people to participate or to avoid putting people in the position where they have to decide about whether or not to take part. There were suggestions of greater use of the anonymous linkage of data already held within the NHS or moving towards an opt-out system of participation so that, by default, everyone contributes data and tissue samples to psychiatric genetic studies.¹⁰² Such moves would inevitably involve an element of presumed consent but scholarship within the “sociology of ignorance” warns us that, in practice, presumed consent is an aggressive strategic social mechanism that relies on the ignorance of people in order to secure research samples (McGoey 2012; Hoeyer et al. 2015). However, studies have demonstrated the willingness of people to support research through participating (Dixon-Woods et al. 2008a; Michie et al. 2011). Other studies find that informed consent is of less concern to participants than bioethics warrants but also warn that it is context-specific and depends on the perceived relationship between researchers and participants (Hoeyer et al. 2005; Lipworth et al. 2011; Gaskell et al. 2013; Kelly et al. 2015).

From the perspective of potential participants in this study, many were supportive of psychiatric genetic research and view participation as a responsible thing to do,

¹⁰² Such opt-out systems are not without their problems. In the U.S., lawsuits in 2009 concerning the use of retained newborn blood samples for research without sufficient parental knowledge sparked fierce ethical debate, the destruction of research samples, and conversion of some opt out systems to become opt in (Carmichael 2011; Cunningham et al. 2015). Also, in 1998, the Icelandic government attempted to rush through a law permitting the private enterprise DeCODE to exploit genetic data from the health service, based on presumption of both consent and the general moral support of the Icelandic people. However, despite being heavily criticised at the time by ethicists across the world, public support in Iceland for the genetic database was later found to have been around 80% (Pálsson and Rabinow 2001). Finally, in the UK, opt out organ donation has now been adopted despite a UK taskforce overwhelmingly rejecting the system in 2008. The taskforce’s claim that the new system would undermine donation as a ‘gift’ was criticised (Rieu 2010) and they were accused of privileging individual autonomy over social morality, and for preserving a system that is at odds with UK society’s plea for altruism (Cronin and Harris 2010).

especially those people with a style of thinking whereby taking part is seen as no different to participating in other kinds of research. Amongst some there is also support for participation to be considered a moral obligation, a response that was either implicitly or explicitly stated. This is at odds with previous research that found that, in UK culture, not participating in research was seen as a culturally acceptable position to take on aspiring to the common good (Haimes and Whong-Barr 2004; Dixon-Woods and Tarrant 2009). This difference may be specific to psychiatric genetic research or has been drawn out by this particular methodology, or is a view that has been evolving in more recent years. Some of the people with psychiatric conditions in this study exhibited impatience with a lack of outcomes for dealing with mental illness, and see research participation as a route to greater understanding and treatment. Such a position may explain the desire for participation to shift towards obligation.

Taken together, such actions and perspectives suggest that not participating in psychiatric genetic research is less acceptable than previous studies report for research participation in other fields. Therefore, I argue there is some support for this position but what is significant is that this support comes not only from researchers but also from some of the potential participants and mental health professionals. This finding lends support for previous bioethical calls for research participation to be a moral obligation or duty (Harris 2005; Rhodes 2010). Ursin and Solberg (2008) have asked when such a view might be considered morally acceptable and whilst this study suggests that such a view might exist or be emerging in the case of psychiatric genetic research, participants are likely to demand that certain conditions be met concerning the governance of research applications if there are any moves towards making research participation more like an obligation or duty. Such demands are likely because of fears about commercial exploitation, rogue scientists, and the lack of a strong governance framework. This finding is important because it highlights what concerns arise when the view of a worthwhile responsible act potentially transitions into obligation. Obviously, a number of people in this study reject the idea of participation as a moral obligation, although it is unclear how much this rejection is due to a normative view that it

would contravene a person's liberty to argue so; further research would be needed to unpick this.

9.4 The argument for solidarity

Taken together, the four styles of thought and these four findings suggest that psychiatric genetic research participation is undergoing change and moving away from appeals for altruistic donations that rely on autonomous informed consent. These different views of participation reflect the difficulties of navigating between the two positions of informed consent and presumed consent, both of which are problematic for research governance and practice, as already discussed. Rather than an informed autonomous choice to be made by the individual, Hoeyer argues that participation should be a moral negotiation between researcher and potential participant (Hoeyer 2003). According to Hoeyer (*ibid*), despite their desire to be asked for consent, the seemingly little interest that participants have in the information proffered to them during recruitment reflects their resistance to the imposed individualistic responsibility. It could be that solidarity is the way forward whereby some individual autonomy regarding participation is relinquished in exchange for demonstrable reciprocity on behalf of research organisations.

Recent sociological and bioethical work on the governance of research biobanks attempts to recognise people's willingness to participate in research and focuses on the concept of solidarity¹⁰³ as an alternative to approaches that prioritise individual autonomy (Prainsack and Buyx 2013), thus providing a framework for researchers, study participants and sponsors to work together (Mulvihill et al. 2017). Such an approach circumvents more extreme reactions to the problem of insufficient participants and balances the needs, rights and responsibilities of researchers and participants alike. Researchers have already been finding ways to bypass informed

¹⁰³ Prainsack and Buyx provide a definition of solidarity that signifies 'manifestations of people's willingness to carry costs (financial, social, emotional, or otherwise) to assist others'. Prainsack, B. and Buyx, A. 2012. Solidarity In Contemporary Bioethics - Towards A New Approach. *Bioethics* 26(7), pp. 343-350.

consent because the public engagement and community strategy hasn't worked in terms of recruiting sufficient numbers of the specific participants they require. Potential participants who are keen advocates of psychiatric genetic research might see little need for informed consent and would be comfortable relaxing it because of their inherent trust in research and researchers. However, for those supporters with greater concerns and especially the critics, there are outstanding issues to discuss about the potential applications of the research and its primacy within alternative forms of research into understanding and treating mental ill health.

Whilst this study lends support for reconceptualising psychiatric genetic research participation on the basis of solidarity, such a move is set against a backdrop of existing attempts to reframe NHS patients as a resource for research. The availability of NHS patients as potential research subjects has been seen as part of the UK government's vision to "align and expand interests in the global life sciences industry and in the development of disease treatments" (Adams and McKeivitt 2015). In this context, and alongside broader moves towards commercialisation of the NHS, participation is assumed to be altruistic but is also being primed such that potential participants from within the NHS are to be made available and framed as having entitlements and benefits as a resource and an asset (Wienroth et al. 2018; Wienroth et al. 2019). Priming NHS patients to anticipate some sort of personal gain beyond NHS services paves the way for framing participation as a contractual exchange rather than as a selfless altruistic 'gift' (Titmuss 1997). However, this reframing to promote the 'enterprising self' (Tutton and Prainsack 2011) creates potential conflicts with the idea of solidarity. Personal gain should not be the main motivation for participating in research if participation is to be enacted in the name of solidarity; direct benefit is permissible as long as this is on an infrequent basis (Prainsack and Buyx 2017).

Hayden (2007) has convincingly proposed that the old terrain of gift versus commodity has shifted during debates about participation such that we have entered a new phase, a phase which I argue is reflected in the findings of this study.

This is a phase in which ideas of benefit sharing and risk taking invite debates about the social morality of scientific research applications. An alternative to the enterprising individualistic self is that participants wish to ‘cooperate’ (Dixon-Woods and Tarrant 2009) in a shared, morally negotiated (Hoeyer 2003) regulated process, rather than have an imposed responsibility that is disconnected from a collective moral decision to proceed with research. I believe this argument is supported by the data from potential participants in this study. This leads me to agree with previous calls for a new ethical perspective based on solidarity (Chadwick and Berg 2001) and with Prainsack and Buyx’s (2017, p. 13) assertion that a solidarity-based governance can overcome the currently “unproductive dichotomy between personal and collective benefit” and transfer our attention to shared societal benefit and shared societal responsibility.

9.5 Addressing the research questions

1) Why people would/wouldn’t take part

Other than the expectation of personal benefit through new therapies, findings from the analysis reflect many of the reasons given in previous studies for why people participate in research.¹⁰⁴ This also includes a sense of biocitizenship and genetic responsibility (Novas and Rose 2000; Rose and Novas 2005), specifically a relational genetic responsibility of someone who is socially embedded and conducts themselves, in terms of their genetics, according to their relation to others (Leefmann et al. 2017). Only one person discussed the possibility that their participation might provide them with access to services such as a second opinion on their diagnosis, most saw participation as a means to possibly help their own families in the distant future but primarily to help others more generally and to help scientific research, without expecting anything in return. This is in line with previous

¹⁰⁴ As a reminder from Chapter 1, these reasons included altruism, reciprocity, the expectation of personal benefit through new therapies, direct feedback of study results, the opportunity of the clinical encounter, monetary compensation, an extension of the clinical setting in which they have already developed a trusting relationship, and trust in the publicly funded status of research (Ponder et al. 2008; Lipworth et al. 2011; Ryan et al. 2020).

research that found that altruism and contributing to the common good is a key reason why people participate in research (Lemke et al. 2010; Lipworth et al. 2011; Locock and Boylan 2016). It also concurs with previous ideas of research participation and tissue sample donation as an altruistic 'gift' (Titmuss 1997).

Following on from this, one reason why people don't take part is that they don't have to; previous research has shown that not participating in research is culturally acceptable in the UK (Dixon-Woods and Tarrant 2009). Contrary to this, I have argued this may not be the case for psychiatric genetic research participation; findings in this study lends support for calls that participation should be at least more than a responsible thing to do, if not a moral obligation. Many people in this study view the cost of participation as a small part of being within a society, working collectively towards a greater understanding of psychiatric conditions. On the other hand, as we have heard in Chapter 5, powerful gatekeepers may block potential participants as a result of objections to biomedical research and its status or out of a duty of care towards the seriously unwell; similarly, this may just be a perception of the psychiatric genetic researchers.

A prominent view amongst people in this study is that psychiatric genetic research participation 'means being part of a *realistic* hope of treating mental illness', judging psychiatric genetic research to be starting on "a more solid base" in comparison to psychological approaches and therapies, or being easier to measure and address than the social determinants of mental ill health. This was a recurrent reason that people agreed with and is likely to be a strong driver amongst potential participants for why they would participate. However, the particular nature of this view diverged across the four styles of thinking about participation. From the Q methodology, people's views broadly distinguished them as untroubled, strategic, cautious or concerned.

The 'untroubled progress-seekers' wanted action and sought this through psychiatric genetic research participation, largely because of their trust in

biomedical science and its institutional processes. However, whilst many individuals were supportive of psychiatric genetic research and agree it is realistic, and in some cases vital, concerns about the governance of the research and its applications motivated a call for greater debate in order to have more *sophisticated* discussions about how these applications might best serve society whilst addressing some of the concerns about future applications. These concerns concur with other sociological studies about research participation in which trust was located within the expectation of some public oversight and higher-level control (Lipworth et al. 2011). Objections by the ‘Concerned Critics’ and others in this study towards the representation of psychiatric genetic research, and attempts to portray collective action as a community, potentially creates distrust and resentment that affects desires to participate.

A number of people in this study accepted that commercial companies would need to be involved in transforming the research into therapeutic applications, and potential participants claimed such involvement would not affect their decision about participation. There was an assumption that commercial exploitation that risked damaging the public good would not be rampant and that sufficient governance would be in place. However, others demonstrated concerns that reflected a feeling of uncertainty and lack of control about this. It should be noted that, whilst potential participants agreed that commercial involvement was necessary in the absence of sufficient public funding, they argued that ethical debates should exclude commercial actors/influences. There was also no suggestion that individuals themselves expected financial gain from participation and this concurs with other studies (Hoeyer and Lynöe 2006; Haddow et al. 2007; Steinsbekk et al. 2013).¹⁰⁵

¹⁰⁵ As summarised by Steinsbekk and colleagues (2013, p. 160), based on analysing focus groups of participants: “Getting paid is not a morally acceptable solution to the challenge of benefit-sharing. It would only make things worse.” There were concerns that getting paid potentially exploits the under-privileged, arguing instead for frameworks and regulation that promote communal benefit sharing. It should be noted, however, that these were all people who had previously taken part in unpaid biobank research; Steinsbekk and

As discussed in Chapters 7 and 8, the shadow of eugenic thinking is still seen as a barrier that complicates the relationship between psychiatric genetic research and its various publics (Lewis and Bartlett 2015), and people in my study were aware of how this affects participation. Researchers argued this is how they are irrationally perceived and attempted to distance themselves from eugenics, as noted in previous research (Kerr et al. 1998; Paul 1998). Potential participants demonstrated their concerns about a lack of control over the governance of introducing new applications from genetic research, drawing on social actors with vested interests outside of psychiatric genetic research. Except for the psychiatric genetic researchers in this study, people also questioned scientists' ability to be reflexive enough of these socio-ethical dangers; people wanted to push the boundaries of research but to know that, if found to be necessary, there is a governance framework in place to control its applications. As Catherine Bliss argues "We may have the best intentions for our science, but without proper policy [,] misuses are almost guaranteed." (2018, p. 222).

These concerns highlight why people would not participate or, at least, would be reticent about taking part in psychiatric genetic research. An unexpected finding that I will now discuss was the absence of collectivity around psychiatric genetic research, despite attempts to facilitate this.

2) Social mechanisms and the social organisation of psychiatric genetic research participation

One finding, important to understanding how the social organisation of psychiatric genetic research participation might affect why people do or do not participate, was the lack of evidence for biosociality. There was no natural mobilising around the idea of genetic susceptibility to psychiatric conditions; even the research champions, who are keen advocates of research participation, were heavily facilitated by the Centre. It is not to say that some features associated with

colleagues had been unable to recruit non-participants who may have given a different view.

biosociality were not present but the description of there being a community as such is not supported by the data, either offline or online. A number of people with psychiatric conditions in the study were fairly active on the internet but this did not incorporate any sense of community mobilising around genetic susceptibility, such as that described by Rose and Novas (2005); much of the sociality was geared towards helping others through a demonstration of empathy concerning the condition itself.

One way to understand this unexpected finding is through the rejection of community. As discussed in Chapter 6, providing suitable mechanisms and spaces to become a collective group, as well as binding and maintaining biosociality through both genetics and the emotional connection that collective social acts can provide, is an important aspect of biosociality and has been demonstrated elsewhere (Callon and Rabearisoa 2003; Rose and Novas 2005; Martin 2012; Dimond et al. 2015). However, this is not universally desirable, or even necessarily so. Whilst the strong supporters of psychiatric genetic research in this study see participation as part of a collective scientific process involving researchers and those with psychiatric conditions, they reject the social bonding that might be expected from the idea of belonging to a community. Participation to them is seen as demonstrating their support for collective activity rather than a shared collective *experience*, with little desire for feelings of community but a very strong sense that it should involve responsibility towards helping others. Participation itself is viewed as an individualistic act that is only social in the sense that it helps others through scientific progress, more aligned to a biocitizenship located within a liberal view of how society works.

The facilitation of community described in this study was done on the incorrect assumption that the participants desired this but those with experience of psychiatric conditions in this study either had an existing community at a mental health support group or talked about not wanting to be aligned with a group on the basis of mental ill health. According to Arribas-Ayllon and colleagues (2019), much of public engagement in psychiatric genetics works to reconfigure access to human

resources through creating imaginaries of hope for the future. Similarly, as this study has shown, this reconfiguration of access has also been attempted through the engineering of social relations, through creating imaginaries of community and collectiveness, as well as attempting to construct community.

From the perspective of the psychiatric genetic researchers, they wanted what it meant to be a participant to mean being part of a community by attempting to conjure up the idea of a network of relationships that “criss-cross and reinforce each other” in some affect-laden way (Etzioni 1996, p. 127 cited in (Etzioni 2000, p. 188)). Facilitating a sense of community may have seemed a desirable and effective exchange for research participation because it is often associated with stronger thicker bonds between people; researchers may well have felt that they were then able to give back something of value to potential participants. However, as Hayden (2007) has argued, the reconfiguration of bioscience as something that can and must give back then constitutes its participants in a particular way as people who have received something from which they benefit. Given the long awaited and as yet undelivered promises of psychiatric genetics as translational research, researchers may feel the need to provide something else of benefit for participants in the interim period but that does not mean such offers are wanted or welcomed.

A review by Lipworth and colleagues (2011) found that some studies demonstrated little evidence of strong bonds amongst research participants and this is reflected in the findings within this study. The authors also found that being part of a disease *community* was influential on the decision to participate but that this relied on being able to trust those community members. Some participants in this study, in particular the ‘Concerned Critics’, pointed out departures from reasonable social practices in the recruitment process such as how the research was represented or the attempts to inappropriately use the language of community. They were very attuned to the authenticity of these practices, calling for a “right way” to attract participants and plain speaking about the need for participants. They also either expected to see or questioned the nature of common future goals, thus demanding a reciprocity in which participants donate to research with the expectation that

research will contribute to the public good. This resonates with arguments in the literature that certain conditions of social engagement need to be respected (Dixon-Woods and Tarrant 2009; Carter et al. 2015), deemed as genuine and not for the purposes of capturing the public (Raman and Mohr 2014).

These strategic attempts by psychiatric genetic researchers sit alongside national initiatives by NIHR (NIHR 2017) which has effectively orchestrated a social intervention into the relationship between society and aspects of science, encouraging people to declare as well as publicly share their appreciation, involvement and sense of belonging in biomedical and health research. In the simplest reading of what such campaigning achieves, these initiatives work to create a research enthusiastic society and reframe participants as an asset (Wienroth et al. 2019). However, through publicly highlighting people's individual responsibility towards contributing to a collective research endeavour, including the use of various social media tactics, I argue that the idea of community has been circumvented. Their slogan "I am research, be part of the solution" points directly towards the individual's role within a collective endeavour. The rejection of community and belonging demonstrated in this study may not be a consequence of such campaigns, many individuals were only vaguely aware of these social media efforts. However, both may reflect the current difficulties of attempting to regain some sense of collective working whilst navigating within the terrain of prevailing individualism in the UK.

This suggests that, even though some conditions may mobilise or create a community and this community may have an influence on people's decision to participate, it does not follow that research participation necessarily creates, enhances or demands such a community. As I have shown, a community experience is not a prerequisite for a collective approach towards assisting others and, given the strong rejection of a facilitated community, may even be a barrier to assembling collective action despite the strong desire to help others.

Returning to the idea of donating blood to genetic research as a 'gift', scholars argue that the powerful image of gifted blood donations, as providing help to those in need, performs rhetorical work in representing the social contract between biomedical researchers and publics and, in particular, potential participants (Tutton 2004; Busby 2006), thus promoting blood donation for genetic research as a national resource. In thinking about such strategies, it is useful to consider Irwin's (2006) work in which he interprets the diversionary rhetorical flourishes during the proliferation of public consultation and involvement in the 1990s and 2000s as reflecting the uneasy relationship between science and society at that time.

Thinking about the social organisation of participation from this perspective, these attempts by psychiatric genetic researchers to give back, and the subsequent rejection, potentially reflects a growing tension: data in this study suggests it is becoming less desirable for participation to be procured altruistically as a 'gift' because this approach is increasingly ineffective. However, alternative appeals to giving that are done out of some form of moral obligation potentially brings to the fore existing concerns and demands that would then need to be addressed.

9.6 Suggestions and implications for the governance of psychiatric genetic research participation

These findings have repercussions for the kind of social relationship that research organisations attempt to develop with potential participants in the future. Previous research has suggested that historical changes in the perception of participants from passive subject to active partners has been an institutional response to public distrust and ambivalence about the value of scientific research (Tutton 2007). Similarly, in this study, strategies to represent participants as active partners or community members have been seen by researchers themselves as idealistic and by potential participants as inauthentic, ineffective or irrelevant.

According to Corrigan (2004), there is a mutability in the perception of the participant, not just historically but throughout the participation process itself, shifting between passive subject, vulnerable victim and empowered autonomous citizen. However, individuals themselves choose to take up or reject an identity according to their own circumstances (Lehoux et al. 2012a, b; Martin 2012), creating different levels and styles of participation (Haines and Whong-Barr 2004). Some potential participants may reject the identity of active partner or citizen if this is perceived as inauthentic or conflicts with their capacity as a patient; they may reject the identity of vulnerable victim and community member on the grounds that they are willing to take up the role of passive subject because of their trust in scientific research as a realistic way forward.

The untroubled desire of some individuals, in this study, to provide information and tissue samples as an altruistic gift without anything in return potentially demonstrates a willing nostalgic compliance due to associating blood donation with the NHS. It is this very nostalgia, however, that Busby (2006) claims has obscured discussion about the governance of UK collections of genetic material. On the other hand, such nostalgia has not been evident when applied to the concept of community which, in a traditional understanding of the word, has been rejected by (potential) participants. What this reaffirms is that participants themselves shape what it means to be a participant, just as much as attempts by scientific research institutions and national campaigns. In doing so, what it means to be a participant entails an evolving to-ing and fro-ing between institutions and potential participants in which institutions attempt to frame participants as particular kinds of people, a framing that participants accept, resist, modify or reject.

The finding in this study that the researchers' misjudged offerings of community have been criticised and rejected should inform the next steps in psychiatric genetic research participation. In their review of sociological studies about tissue donation to biobanks, Lipworth et al (2011) concluded that a more detailed and nuanced sociology of biobanking was needed to determine what issues arise both within different contexts of participation and in relation to participants' sense of social

solidarity. Prainsack and Buyx (2011, 2012, 2013, 2017) have provided a detailed conceptualisation of solidarity and shown how this might be applied to the governance of databases for health and disease research.

Prainsack and Buyx (2017, p. 60) suggest that solidarity “is particularly pertinent to situations where no other ties exist to bind people together” and this resonates with the findings in this study because of both the absence of, and lack of desire for, community. Participants demonstrated some biocitizenship but this is insufficient in light of the outstanding need for specific participants, given its alignment with privileging the ability to exert autonomous rights. However, empty appeals to potential participants on the grounds of solidarity may also face similar problems and care needs to be taken to consider what this solidarity would look like in the case of psychiatric genetic research and what it entails.

Similarly, failure to understand and attend to the broader concerns of potential participants and how that affects the relationship between researchers and participants has been shown to have significant impact on the social licence for research to operate (Carter et al. 2015). Carter and colleague’s analysis of the case study of care.data, described in Chapter 1, demonstrates the important distinction between activities that enable the broader social licence for research to practice and those that simply consolidate a mandate to practice that has been assumed by researchers. As stated by Raman and Mohr (2014, p. 273), seeking a social licence is not the same as creating public acceptance for activities already being undertaken and demands a thicker engagement with alternative futures than only a techno-scientific solution. Therefore, if psychiatric genetic researchers want to move towards having a broader social licence to practice in terms of how participants are recruited, they will need to take a serious and rigorous approach to governance, such as the solidarity framework suggested by Prainsack and Buyx.

Reconceptualising psychiatric genetic research participation on the basis of Prainsack and Buyx’s definition of solidarity may provide a much-needed alternative framework for participation but this requires “enacted commitments to accept

costs to assist others with whom a person or persons recognise similarity in a relevant respect” (2012, p. 43). In other words, a collective arrangement whereby people undertake a demonstrable practical action that incurs some cost such as time, money, human tissue or emotional labour in order to help others through recognition of a similar goal. Agreeing on the meaning of costs and similarity will be particularly challenging for psychiatric genetic research and any proposed solidarity framework in this context would need to consider these factors carefully in a discipline where concerns persist about a return to eugenic practices (Propping 2005).

Solidarity often emerges ‘bottom-up’ based on the worth-based practices of individuals in which their actions are motivated by what they consider to be worthwhile and of value (Prainsack and Buyx 2017). Thinking about recruitment approaches based on Prainsack and Buyx’s conceptualisation of solidarity, the criticisms that have emerged in this study have repercussions for what a sense of sameness means. Any attempts to facilitate solidarity will rely on exploring in greater detail what ‘sameness with others’ represents in the specific context of psychiatric genetic research. Solidarity requires feeling sameness with others in some relevant way but, as has been discussed, there are particular challenges specific to psychiatric genetics. There are different beliefs about the causation of psychiatric conditions and different expectations of what genetic research should and shouldn’t be used for. There are also economic inequalities between paid researchers and those participants whose job opportunities are highly affected by their psychiatric condition as well as power imbalances due to the conflation of the dual role of some researchers as clinicians. Some of the data in this study highlights a possible disconnect between psychiatric genetic researchers and people with psychiatric conditions, suggesting that a collective united commitment under the current relationship is idealistic but may also be seen as presumptuous in light of the imbalance in costs and benefits between researchers and participants.

In a solidaristic framework, both the institutions and the participants would be expected to incur costs to support others. Participants give up their time and tissue

samples and would forego their opportunity to have a financial stake in the process, instead seeking long-term gain through their relationship to others with whom they live as part of a society, not just as an aggregation of individuals. Potential participants in this study have demonstrated their willingness to give up their time and tissue samples, if they are in a position to do so, because of a strong sense of responsibility towards helping others with whom they feel sameness in terms of mental ill health. Although I did not specifically ask the question, they are likely to have little interest in having a financial stake in the research and its applications, given evidence of their strong desire to be part of assisting others and expecting nothing else in return except health benefits for the public good. This concurs with other research in which the proposal of individuals having property rights was inconsistent with the values of solidarity and reciprocity expressed by participants (Dixon-Woods et al. 2008a).

Recognising the differing levels of cost to individuals, those drawing up the framework would need to have explored how a collective responsibility could be established to redress any harm to individuals. Participants may risk negative consequences of participation either because of emotional repercussions or the very small risk of being identified as a result. Something that would need thinking through is whether a specified cost to a participant has differing consequences for different people. Accidental disclosure may have much greater repercussions for someone with a severe condition. Likewise, there are perceived costs versus actual costs and someone with symptoms of paranoia may suffer greater costs because they perceive a greater risk to themselves.

In terms of benefits, Prainsack and Buyx (Prainsack and Buyx 2013, 2017) propose that institutions provide not just information on the aims of the research but who will benefit, what commercial interests/links there are, who they share the data with, and greater transparency such that information is more understandable for the public/participants. Similarly, incurring costs to help others may mean that psychiatric genetic researchers need to play a more active role in supporting the development of social research into mental health, something that critics in this

study would welcome. Researchers in this study have demonstrated a willingness to provide information, education and, at times, payment as well as some sense of collectiveness, arguably with entangled motivations towards recruitment and retention of participants. Indeed, reciprocity has been regarded as particularly important for the organisation of biobanks and requires a strategy whereby organisations are 'giving back' rather than assuming participation to be a 'gift' (Gottweis et al. 2011).

Previous studies have suggested that the relationship between scientific researchers and research participants is changing and propose the need for a reframing of the social contract between science and society (Meslin and Cho 2010) because the current form of consent does not capture the social relationships that exist (Kelly et al. 2015). As already discussed, there has been much debate about the value of informed consent, a process that can permit autonomy but can also be a burden that disrupts relationships, especially if recruitment is embedded within a care situation. Such situations in which participation is entangled with care-giving, such as provided by the NHS, redefine what it means to choose and reconfigure what it means to be a participant but a return to more paternalistic regimes are not favoured either (Corrigan 2003).

With all this in mind, I argue that psychiatric genetic research infrastructures would be better served by reallocating resources and energies into exploring a solidarity-based framework for psychiatric genetic research participation rather than continuing with appeals to altruistic donations involving a system of informed consent. Loosening the requirement for individual informed consent could be replaced with a clearer mission statement based on values and goals (at a level sophisticated enough to address some of the societal concerns raised in this study), evaluating and addressing costs and benefits for all parties, and improving ways to integrate the research with non-biological forms of mental health research. These activities would be over and above the promoted health benefits for the public good and thus we would explore, in the words of Cori Hayden, what it means "if

research is to be reconfigured as something that can, indeed must, give back” and how that changes what it means to be a participant (2007, p. 733).

Chapter 10: Conclusions

This thesis is being written in a time of global catastrophe such that the spread of Coronavirus is testing the limits of appeals to solidarity, whereby a *feeling* of solidarity is insufficient and demonstrative commitments to solidarity are being demanded of individuals. During the pandemic, leaders throughout the world have repeatedly appealed to their nations to work collectively and stated that the risks we take are not our own. In doing so, this highlights that the consequences of our individualism affects the collective society of which we are all part. The current UK Prime Minister Boris Johnson has said: “Never in our history has our collective destiny and collective health depended so completely on our individual behaviour.” The lives of those most vulnerable in society are at stake, but the repercussions of incurring costs and recognising sameness with others is very much coming to the fore. How far are individuals prepared to go to incur costs and burdens to assist others? Psychiatric genetic research participation does not compare with the kind of costs that people are being asked to incur or the magnitude of the life and death consequences of their actions in a pandemic. Nevertheless, it does raise questions about the perceived value of different lives, what kind of society we want in the future and what being a psychiatric genetic research participant will come to mean.

This is the first time that the social organisation of psychiatric genetic research participation in the UK has been studied in detail, providing empirical support for a solidarity-based approach to its governance but also demonstrating how reciprocity between researchers and participants, an important requirement for solidarity, becomes entangled with the needs of doing science. Four distinct styles of thought, broadly categorised as untroubled, strategic, concerned and cautious provide a story of the tensions and entanglement arising within psychiatric genetic research participation. Furthermore, challenges that complicate the relationship between psychiatric genetic researchers and their potential participants are highlighted by disparities between researchers and potential participants in what is meant by the public good, improving society, and the costs and benefits of participation.

Since the late 1990s, there has been a shift in the UK from the use of the term research 'subject' to research 'participant'. Advocacy by the NHS and the *British Medical Journal*, a lack of suitable alternatives, and the adoption of the term led to a prolific increase in its usage. However, as described in Chapter 2, this shift did not reflect substantial change in practice from being a research 'subject' but instead performed rhetorical work to maintain willing recruitment to research studies (Jackson 1999; Corrigan and Tutton 2006; Tutton 2007) and to reimagine research subjects in the eyes of the research community. Furthermore, ethical debates and the civil rights movements of the 1970s and 1980s had created the opportunity for this 'participant' to re-emerge as a particular kind of person, a vulnerable victim whose individual autonomy needed to be respected and privileged over the common good (Campbell and Stark 2015).

Giving primacy to this autonomy creates a tension within recent calls for more collective action to achieve research participation. This is because not taking part in research is viewed as culturally acceptable in the UK (Dixon-Woods and Tarrant 2009; Schaefer et al. 2009). In the specific case of psychiatric genetic research, its various publics are essential. This is not only because it needs support, funding and validation but also because it requires access to large numbers of the public to sustain the necessary human resources within its 'big biology' approach, and the public engagement of psychiatric genetic research works, in part, to facilitate this recruitment (Arribas-Ayllon et al. 2019). Consequently, some form of collective action, mobilising people around the idea of genetic susceptibility to psychiatric conditions, would be particularly beneficial in order to advocate and substantially increase participation.

There has been much sociological thinking about *communities* gathering around genomics and about biosociality, biocitizenship and solidarity in the context of genomics (e.g. (Rabinow 1996; Chadwick and Berg 2001; Rose and Novas 2005; Hacking 2006)). Despite some evidence of biocitizenship existing in this study, defending the right not to participate and demonstrating moral responsibilities

towards society at large, this did not sufficiently account for the data. The usefulness of this concept is also problematic because of its reliance on an individualised practised engagement towards research governance; despite not wanting a collective *experience*, people in this study wanted a collective approach. There was also no evidence to support biosociality; failed attempts by researchers to create 'community' were because existing and potential participants generally viewed psychiatric genetic research participation as an individualistic act that is only social in the sense that it helps others through scientific progress. These attempts, however, reflected the researchers' desire to 'give back' to participants in some way because they see a reliance on the altruistic 'gift' of participation as insufficient for the needs of the research. Furthermore, researchers frustrated at the wasted opportunity for exploiting data within the NHS and aware of the limitations of relying on altruism for attracting participants, despite intensive public engagement programmes, are looking at ways to circumvent current practices in order to fulfil the practical requirements of achieving science. These attempts to move beyond the individual's autonomous decision about whether or not to participate suggests the need to reconsider the relationship between psychiatric genetic researchers and their potential participants.

However, psychiatric genetic research participation does not function simply as an altruistic solution to researching the problem of mental illness. Psychiatric genetic research also progresses in its own right as an interesting field and career within research, it is also socio-political and provides opportunity for business (Rose 2001). Increasingly, along with national campaigns that encourage a research enthusiastic society, it has the potential to reframe participation in the UK as an economic transaction and participants as an asset (Wienroth et al. 2019). DNA has become a commodity from which individual donors to research databases could also prosper and this influence may be at the expense of the public good.

Arguments for a market-driven individual property rights model for being a research participant are not supported by this study though. Based on the work of

Titmuss (1997), Hoeyer (2003) describes the act of donation as something that signifies a person's own reciprocity for what they have received in the past and acts as a signifier for others to do the same. This was demonstrated in this study throughout the discussions about participation, and observed in other empirical studies (see, for example, Dixon-Woods et al. 2008a; Locock and Boylan 2016). Rather than a market-driven individualism, evidence in this study suggests both a need and an appetite for solidarity.

As an alternative to prioritising individual autonomy and informed consent, calls for more solidaristic practices for genomic databases and biobanks have been proposed (Chadwick and Berg 2001; Hoedemaekers et al. 2007; Prainsack and Buyx 2013). Rather than relying on the altruistic giving of information and tissue samples, there is support amongst some in this study to move beyond participation as a responsible thing to do and instead towards a moral obligation. However, the study demonstrates a big divide between the view of participation as responsible and participation as *obligation*, and the people who support obligation do so cautiously and with qualifications. There is a demand for the possible repercussions of future applications of psychiatric genetic research to be made more explicit and to consider who gets to control and define the limits of those applications in order to provide moral assurances on how the research can serve the public interest. On the basis of this conditional support, I argue there is an appetite and need for a reconfigured *solidarity-based* approach to psychiatric genetic research participation in the UK.

Smith (2008) has called for a public psychiatry in which the public and the profession of psychiatry “would both benefit from a ‘conversation’ about practical, moral and political aspects of contemporary mental health” and such a call would no doubt include the future applications of psychiatric genetic research. This study has demonstrated that despite some scientists' attempts to distance science from socio-political and moral values, such aspects are both inevitable and inherent to its practices and accomplishments.

However, similar discussions within other health conditions suggest the need to move beyond the dominant framing of informed consent, warning that public debate has been “muffled” and “contained” despite genomic technologies already being introduced into the clinic (Thomas et al. 2020, pp. 14-15). The commercial value of these genomic technologies risks creating unintended harms unless we ask broader societal questions about the value of genomic information, who is to benefit, to what end and who decides (Curtis et al. 2019; Werner-Lin et al. 2019; Thomas et al. 2020). As Catherine Bliss writes, “No matter what’s in store, we must move beyond relying on expert intentions or awareness to ask the bigger questions” (Bliss 2018, p. 191).

Representatives of the journal *Science* have raised concerns over the last fifteen years of increasing examples of ‘society’ pushing back at science as a result of scientific research encroaching on human values, claiming that a risk-benefit approach to governance is insufficient and calling for scientists to embrace more value-laden debate about science and its technologies (Leshner 2005; Agre and Leshner 2010). This chimes with STS work that attempts “to make scientific research more social” (Raman and Mohr 2014, p. 260), rejecting the idea of science as being value free and producing privileged knowledge that is immune to sociological critique (Rohracher 2015; Jasanoff 2017).

Psychiatric genetic research demands large numbers of participants and a new governance framework for participation would need to work at what Prainsack and Buyx describe as an institutional level of solidarity (Prainsack and Buyx 2012, 2013, 2017). A particular feature of solidarity at the institutional level, according to Prainsack and Buyx’s conceptualisation of solidarity, is participation as an obligation or duty. Whilst this study has demonstrated that people would support a new governance framework, it also demonstrates they may well put conditions on research participation, especially if it were to be promoted on the basis of a moral obligation. Indeed, if the sacrifice of some level of autonomy within biobanks and research databases is to be supported by moral arguments, then setting conditions

is very important (Hoedemaekers et al. 2007). If these conditions cannot be met, this lack of reciprocity will mean that participation, which is currently viewed as a responsible thing to do, will not cross over into something that is considered an obligation.

I argue that what it means to be a participant in psychiatric genetic research is moving towards the need to explore this position as something in which people cooperate in a shared, morally evaluated and negotiated, regulated *solidaristic* practice. Over the last ten years, there has been a to-ing and fro-ing between researchers and potential participants, a pushing and a pushing back. Consequently, the circumstances for a solidaristic practice may now be in the making in which there needs to be a more explicit social contract to improve research participation whilst ensuring shared societal benefit and shared societal responsibility, of both giving and giving back by those involved.

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Appendices

Appendix I: Q statements and Q-sort discussion schedules

Table A1: 48 statements for Q-sort activity
Psychiatric genetic research participation...

No.	Statement
1	isn't going to help because these conditions are too complex
2	demonstrates the need for a more scientific approach to mental health
3	heightens the relevance of genetics for people's everyday experiences of understanding their condition
4	is a responsible thing to do to improve the understanding of psychiatric conditions
5	is pointless because mental illness is not a genetic illness
6	means challenging the diagnostic criteria of the past
7	means having better access to diagnosis, care and treatments
8	is vital for developing new treatments and overcoming the shortcomings of current therapies
9	is an empowering and positive thing that helps the individual
10	is a generous act for the future benefit of others
11	means being part of a collective working towards a better future
12	means having a sense of belonging to a cause
13	needs to inspire volunteers so that research can move forwards
14	means coming together to wage war on mental illness
15	doesn't address the things needed to deal with psychiatric conditions now
16	means giving up time for no personal gain
17	should be a moral obligation for the benefit of the greater good
18	is only focussed on extracting scientific data from human resources
19	is no different to taking part in research about other health conditions
20	takes advantage of the altruistic intention of potential participants
21	challenges the belief that people are the instigators of their psychiatric condition
22	means accepting the biomedical model of mental illness
23	helps psychiatry to recognise its current limitations and uncertainties
24	needs greater public debate about the implications of future technologies from this kind of research
25	means being part of informing and educating people about the causes of psychiatric conditions
26	should be publicly shared to encourage other volunteers
27	is more known about because of the increase in public discussions about mental health
28	is likely to stimulate discussions within families about psychiatric conditions and their heritability
29	gives people more reason to label someone as 'a risk'
30	needs government and funders to focus more attention and money on this kind of mental health research

Table A1 (continued): 48 statements for Q-sort activity
 Psychiatric genetic research participation ...

No.	Statement
31	needs public resources to shift from addressing mental distress to that of severe mental illness
32	needs to overcome mental health specific barriers that hinder people from taking part in research
33	is the only way we're going to make things better for people in generations to come
34	opens up opportunities for commercial pharmaceutical companies to exploit research and individuals
35	does not safeguard personal data from being passed onto unauthorised companies
36	is promoting an idealised vision of scientifically perfected human beings
37	is a short step towards eugenic practices for improving the mental health of society
38	will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems
39	is based on a fragmented and incomplete account of someone's psychiatric condition
40	provides a sense of ownership over the research
41	means being part of a realistic hope of treating mental illness
42	incorporates knowledge from people who are experts in their own condition
43	needs a united commitment from both researchers and those with psychiatric conditions
44	means someone is really listening and trying to understand psychiatric conditions
45	means people overcoming a distrust of research(ers)
46	is a complex decision that depends on many factors
47	provides vast amounts of data that will give us many answers in the future
48	has implications for whole families and not just the individual participant

Pre-sort discussion schedule

Demographics

1. Gender (How would you describe your gender?)
2. Age
3. Do you have any children?
4. Occupation (Are you working at the moment? If so, how would you describe the job? Is this your usual kind of work?)
5. How would you describe your mental health? Do you have a mental health diagnosis? (Gently probe family occurrences of mental ill health/diagnosis during Q-sort discussion if Q-sort goes ahead following question 6).
6. Are you currently, or have you recently, been under the care of a community mental health crisis team?

If the answer to question 6 is yes then the activity cannot go ahead.

7. Please could you describe your experience of mental health services.
8. Please could you describe your relationship to mental health research.
9. Please could you describe your experience of mental health campaigns.
10. Have you ever heard of psychiatric genetic research?
11. Have you ever been approached to take part in psychiatric genetic research?
12. Have you ever taken part in psychiatric genetic research?

Post-sort discussion schedule

As a minimum, the following should be asked

1. Looking at the statements you have placed at the far right (strongly agree), please tell me what these mean to you. Why do you feel strongly about these statements?
2. Looking at the statements you have placed at the far left (strongly disagree), please tell me what these mean to you. Why do you feel strongly about these statements?
3. Are there any other statements that you think particularly capture your views? If so, why and what do they mean to you?
4. Are there any statements that you struggled to place? Can you explain why these items were difficult to place?
5. Are there any statements that you would like to add? If so, please put it into words. Would you agree or disagree with them?
6. Are there any statements that you would omit? If so, please explain why you would omit those statements.
7. Please outline your views on the subject that you feel you haven't been able to put forward already.

Appendix II: Ethics

Research Ethics Committee (REC) and other Regulatory Compliance

The School REC approved the study on 24/10/2017 under reference number SREC/2385.] The committee stipulated that sessions take place within settings whereby another person would be available to assist if individuals became distressed; undertaking sessions on my own at an individuals house was excluded. I ensured that appropriate approvals from participating organisations were in place prior to the commencement of research sessions on the premises.

Data protection and patient confidentiality

The research collected potentially sensitive information on the participant's mental health. Participants were clearly told that they did not need to disclose whether or not they had a mental health diagnosis but could disclose a diagnosis if they had one and were happy to share that information. Codes were used as identifiers instead of names for written notes and for file names of audio/image/video files. All identifiable data (including audio and film recordings) were stored on the Cardiff University computer network. Audio recordings, photographs, and film were transferred and anonymised as soon as was logistically possible after the sessions/interviews; data were then deleted from the recording equipment and camera. Transcripts used pseudonyms in place of any true names mentioned. Consent forms were stored in a locked filing cabinet on secure Cardiff University premises. Data and consent forms will be destroyed according to Cardiff University procedures.

Appendix III

Table A2: Estimated Q-sort scores by statement and group¹⁰⁶

Statement number	Psychiatric genetic research participation...	Group 1	Group 2	Group 3	Group 4
1	isn't going to help because these conditions are too complex	-4	-5	0	-5
2	demonstrates the need for a more scientific approach to mental health	1	2	-1	0
3	heightens the relevance of genetics for people's everyday experiences of understanding their condition	2	1	2	1
4	is a responsible thing to do to improve the understanding of psychiatric conditions	5	1	0	0
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5
6	means challenging the diagnostic criteria of the past	3	1	0	1
7	means having better access to diagnosis, care and treatments	3	-2	-4	5
8	is vital for developing new treatments and overcoming the shortcomings of current therapies	2	5	-1	2
9	is an empowering and positive thing that helps the individual	0	-1	-1	0
10	is a generous act for the future benefit of others	1	2	3	-1
11	means being part of a collective working towards a better future	1	4	-2	1
12	means having a sense of belonging to a cause	0	0	-3	0
13	needs to inspire volunteers so that research can move forwards	0	3	-1	4
14	means coming together to wage war on mental illness	-2	1	-3	-1
15	doesn't address the things needed to deal with psychiatric conditions now	-2	-1	5	-2
16	means giving up time for no personal gain	-2	-2	2	-4
17	should be a moral obligation for the benefit of the greater good	-3	-4	-5	1
18	is only focussed on extracting scientific data from human resources	-3	-4	3	0
19	is no different to taking part in research about other health conditions	1	-1	2	-4
20	takes advantage of the altruistic intention of potential participants	-1	-1	1	-2
21	challenges the belief that people are the instigators of their psychiatric condition	2	0	3	1
22	means accepting the biomedical model of mental illness	4	-3	0	-3
23	helps psychiatry to recognise its current limitations and uncertainties	1	4	4	0
24	needs greater public debate about the implications of future technologies from this kind of research	0	0	5	3
25	means being part of informing and educating people about the causes of psychiatric conditions	1	3	1	1
26	should be publicly shared to encourage other volunteers	0	2	-1	-2
27	is more known about because of the increase in public discussions about mental health	0	2	0	-4
28	is likely to stimulate discussions within families about psychiatric conditions and their heritability	3	0	2	2
29	gives people more reason to label someone as 'a risk'	-3	-3	-3	4
30	needs government and funders to focus more attention and money on this kind of mental health research	4	2	-2	0
31	needs public resources to shift from addressing mental distress to that of severe mental illness	-1	-1	-2	-1
32	needs to overcome mental health specific barriers that hinder people from taking part in research	0	4	1	3
33	is the only way we're going to make things better for people in generations to come	-2	-2	-5	-2
34	opens up opportunities for commercial pharmaceutical companies to exploit research and individuals	-1	-1	4	4
35	does not safeguard personal data from being passed onto unauthorised companies	-3	-3	-1	-1
36	is promoting an idealised vision of scientifically perfected human beings	-5	-3	2	0
37	is a short step towards eugenic practices for improving the mental health of society	-4	-4	2	-3
38	will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems	-4	-2	3	-3
39	is based on a fragmented and incomplete account of someone's psychiatric condition	-2	-2	4	2
40	provides a sense of ownership over the research	-1	0	-4	-1
41	means being part of a realistic hope of treating mental illness	5	1	0	2
42	incorporates knowledge from people who are experts in their own condition	-1	0	-4	-3
43	needs a united commitment from both researchers and those with psychiatric conditions	3	5	1	2
44	means someone is really listening and trying to understand psychiatric conditions	4	1	-2	-1
45	means people overcoming a distrust of research(ers)	-1	0	1	3
46	is a complex decision that depends on many factors	0	3	0	5
47	provides vast amounts of data that will give us many answers in the future	2	3	0	-2
48	has implications for whole families and not just the individual participant	2	0	1	3

¹⁰⁶ The group score estimates are colour coded with increasing shades of green for increasing positively ranked statements and increasing shades of red for increasing negatively ranked statements, zero is yellow.

Table A3: Pairwise Comparisons by Statement Number (Part 1 of 2)

(Key: * p<0.05, ** p<0.01, *** p<0.001, 6* p<0.000001)

Statement number	dist.and.cons	f1_f2	sig_f1_f2	f1_f3	sig_f1_f3	f2_f3	sig_f2_f3	f1_f4	sig_f1_f4	f2_f4	sig_f2_f4	f3_f4	sig_f3_f4
1	Distinguishes f3 only	0.085		-1.684	6*	-1.770	6*	0.593		0.508		2.277	6*
2		-0.077		1.116	***	1.193	***	0.595		0.672		-0.521	
3	Consensus	0.324		0.157		-0.167		0.561		0.237		0.404	
4	Distinguishes f1	0.718	***	1.454	6*	0.737	**	1.180	**	0.463		-0.274	
5		-0.147		-0.966	***	-0.819	**	-0.344		-0.197		0.621	
6		0.480	*	0.961	***	0.480		0.520		0.040		-0.440	
7	Distinguishes all	1.635	6*	2.729	6*	1.094	***	-0.968	**	-2.602	6*	-3.697	6*
8	Distinguishes f2 Distinguishes f3	-0.861	***	0.952	***	1.813	6*	-0.073		0.788	*	-1.025	**
9		0.388		0.808	***	0.419		0.322		-0.066		-0.485	
10	Distinguishes f4 only	-0.268		-0.236		0.033		0.822	*	1.090	**	1.057	**
11	Distinguishes f2 Distinguishes f3	-0.866	***	1.347	6*	2.213	6*	0.381		1.246	***	-0.966	*
12	Distinguishes f3 only	0.121		1.120	***	0.999	***	0.150		0.029		-0.970	*
13		-0.807	***	0.460		1.267	6*	-1.040	**	-0.233		-1.500	***
14	Distinguishes f2 Distinguishes f3	-1.262	6*	0.482	*	1.744	6*	-0.326		0.935	*	-0.808	*
15	Distinguishes f3	-0.645	**	-3.270	6*	-2.625	6*	-0.174		0.471		3.097	6*
16	Distinguishes f3 only	0.059		-1.639	6*	-1.698	6*	0.500		0.441		2.139	6*
17	Distinguishes f1 Distinguishes f4	0.456	*	0.573	*	0.117		-1.716	***	-2.172	6*	-2.288	6*
18	Distinguishes f3 Distinguishes f4	0.323		-2.115	6*	-2.438	6*	-1.345	***	-1.668	***	0.771	*
19	Distinguishes f1 Distinguishes f4	1.135	6*	1.252	6*	0.117		2.299	6*	1.164	**	1.046	**
20	Distinguishes f3 only	-0.144		-0.853	***	-0.709	**	0.159		0.303		1.012	**
21		0.755	***	-0.059		-0.814	**	0.408		-0.347		0.467	
22	Distinguishes f1 Distinguishes f3	2.525	6*	1.282	6*	-1.243	6*	2.420	6*	-0.105		1.139	**
23		-0.732	***	-0.533	*	0.200		0.578		1.311	***	1.111	**
24	Distinguishes f3	0.140		-1.758	6*	-1.898	6*	-0.680		-0.820	*	1.078	**

Table A3: Pairwise Comparisons by Statement Number (Part 2 of 2)

(Key: * p<0.05, ** p<0.01, *** p<0.001, 6* p<0.000001)

Statement number	dist.and.cons	f1_f2	sig_f1_f2	f1_f3	sig_f1_f3	f2_f3	sig_f2_f3	f1_f4	sig_f1_f4	f2_f4	sig_f2_f4	f3_f4	sig_f3_f4
25		-0.193		0.422		0.614	*	0.151		0.344		-0.271	
26	Distinguishes f1 Distinguishes f2	-0.456	*	0.543	*	0.999	***	1.038	**	1.495	***	0.496	
27	Distinguishes f2 Distinguishes f4	-0.604	**	0.015		0.619	*	1.777	6*	2.381	6*	1.762	***
28	Distinguishes f2 only	1.105	6*	0.284		-0.820	**	0.322		-0.783	*	0.038	
29	Distinguishes f4 only	0.163		-0.246		-0.408		-2.368	6*	-2.530	6*	-2.122	6*
30		0.351		1.882	6*	1.530	6*	1.180	**	0.828	*	-0.702	
31	Consensus	-0.073		0.128		0.201		-0.345		-0.272		-0.473	
32		-0.833	***	-0.079		0.754	**	-0.553		0.280		-0.474	
33	Distinguishes f3 only	-0.244		1.631	6*	1.875	6*	-0.256		-0.013		-1.888	***
34	Distinguishes f1 Distinguishes f2	-0.451	*	-2.357	6*	-1.906	6*	-2.490	6*	-2.039	6*	-0.133	
35		-0.098		-1.302	6*	-1.204	***	-1.081	**	-0.983	**	0.221	
36	Distinguishes f1 Distinguishes f2	-0.485	*	-2.634	6*	-2.149	6*	-1.993	6*	-1.508	***	0.641	
37	Distinguishes f3 Distinguishes f4	-0.063		-2.383	6*	-2.321	6*	-0.794	*	-0.731	*	1.590	***
38	Distinguishes f3	-0.623	**	-2.486	6*	-1.863	6*	-0.365		0.258		2.121	6*
39	Distinguishes f3 Distinguishes f4	-0.218		-2.756	6*	-2.539	6*	-1.503	***	-1.286	***	1.253	**
40	Distinguishes f3 only	-0.268		1.405	6*	1.672	6*	0.313		0.580		-1.092	**
41	Distinguishes f3	0.778	***	1.512	6*	0.734	**	0.567		-0.211		-0.946	*
42	Distinguishes f1 Distinguishes f2	-0.588	**	1.099	***	1.688	6*	0.795	*	1.383	***	-0.305	
43	Distinguishes f2	-0.570	**	0.865	***	1.435	6*	0.392		0.962	**	-0.473	
44	Distinguishes f1 Distinguishes f2	0.508	*	1.848	6*	1.340	6*	1.566	***	1.058	**	-0.282	
45		-0.488	*	-0.359		0.129		-1.145	**	-0.657		-0.786	*
46	Distinguishes f2 Distinguishes f4	-0.494	*	0.415		0.908	***	-1.527	***	-1.033	**	-1.942	6*
47	Distinguishes f3 Distinguishes f4	-0.305		0.770	**	1.075	***	1.770	6*	2.075	6*	1.000	*
48	Distinguishes f2 only	0.812	***	0.205		-0.608	*	-0.273		-1.086	**	-0.478	

Table A4: Estimated position of statement agreement/disagreement and distinguishing statements for group 1

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
4	is a responsible thing to do to improve the understanding of psychiatric conditions	5	1	0	0	***	Distinguishes gp 1
41	means being part of a realistic hope of treating mental illness	5	1	0	2		
Other statements (those ranked higher in group 1 than in all other groups)							
22	means accepting the biomedical model of mental illness	4	-3	0	-3	6*	Distinguishes gp 1
44	means someone is really listening and trying to understand psychiatric conditions	4	1	-2	-1	*	Distinguishes gp 1
30	needs government and funders to focus more attention and money on this kind of mental health research	4	2	-2	0		
6	means challenging the diagnostic criteria of the past	3	1	0	1	*	
28	is likely to stimulate discussions within families about psychiatric conditions and their heritability	3	0	2	2		
19	is no different to taking part in research about other health conditions	1	-1	-2	-4	6*	Distinguishes gp 1
Other statements (those ranked lower in group 1 than in all other groups)							
32	needs to overcome mental health specific barriers that hinder people from taking part in research	0	4	1	3		
45	means people overcoming a distrust of research(ers)	-1	0	1	2		
38	will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems	-4	-2	3	-3		
Statements ranked at -5							
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		
36	is promoting an idealised vision of scientifically perfected human beings	-5	-3	2	0	*	Distinguishes gp 1

Table A5: Estimated position of statement agreement/disagreement and distinguishing statements for group 2

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
8	is vital for developing new treatments and overcoming the shortcomings of current therapies	2	5	-1	2	*	Distinguishes gp 2
43	needs a united commitment from both researchers and those with psychiatric conditions	3	5	1	2	**	Distinguishes gp 2
Other statements (those ranked higher in group 2 than in all other groups)							
11	means being part of a collective working towards a better future	1	4	-2	1	***	Distinguishes gp 2
32	needs to overcome mental health specific barriers that hinder people from taking part in research	0	4	1	3		
47	provides vast amounts of data that will give us many answers in the future	2	3	0	-2		
25	means being part of informing and educating people about the causes of psychiatric conditions	1	3	1	1		
26	should be publicly shared to encourage other volunteers	0	2	-1	-2	*	Distinguishes gp 2
27	is more known about because of the increase in public discussions about mental health	0	2	0	-4	**	Distinguishes gp 2
2	demonstrates the need for a more scientific approach to mental health	1	2	-1	0		
14	means coming together to wage war on mental illness	-2	1	-3	-1	*	Distinguishes gp 2
42	incorporates knowledge from people who are experts in their own condition	-1	0	-4	-3	**	Distinguishes gp 2
40	provides a sense of ownership over the research	-1	0	-4	-1		
Other statements (those ranked lower in group 2 than in all other groups)							
21	challenges the belief that people are the instigators of their psychiatric condition	2	0	3	1		
48	has implications for whole families and not just the individual participant	2	0	1	3	*	Distinguishes gp 2
28	is likely to stimulate discussions within families about psychiatric conditions and their heritability	3	0	2	2	*	Distinguishes gp 2
18	is only focussed on extracting scientific data from human resources	-3	-4	3	0		
Statements ranked at -5							
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		
1	isn't going to help because these conditions are too complex	-4	-5	0	-5		

Table A6: Estimated position of statement agreement/disagreement and distinguishing statements for group 3 (part 1 of 2)

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
15	doesn't address the things needed to deal with psychiatric conditions now	-2	-1	5	-2	6*	Distinguishes gp 3
24	needs greater public debate about the implications of future technologies from this kind of research	0	0	5	3	**	Distinguishes gp 3
Other statements (those ranked higher in group 3 than in all other groups)							
39	is based on a fragmented and incomplete account of someone's psychiatric condition	-2	-2	4	2	**	Distinguishes gp 3
18	is only focussed on extracting scientific data from human resources	-3	-4	3	0	*	Distinguishes gp 3
38	will lead to genetic testing that will disadvantage those with mental health problems compared to those with physical problems	-4	-2	3	-3	6*	Distinguishes gp 3
21	challenges the belief that people are the instigators of their psychiatric condition	2	0	3	1		
10	is a generous act for the future benefit of others	1	2	3	-1		
37	is a short step towards eugenic practices for improving the mental health of society	-4	-4	2	-3	***	Distinguishes gp 3
16	means giving up time for no personal gain	-2	-2	2	-4	6*	Distinguishes gp 3
36	is promoting an idealised vision of scientifically perfected human beings	-5	-3	2	0		
20	takes advantage of the altruistic intention of potential participants	-1	-1	1	-2	**	Distinguishes gp 3
1	isn't going to help because these conditions are too complex	-4	-5	0	-5	6*	Distinguishes gp 3
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		

Table A6: Estimated statement positioning and distinguishing statements for group 3 (part 2 of 2)

Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
	Other statements (those ranked lower in group 3 than in all other groups)						
43	needs a united commitment from both researchers and those with psychiatric conditions	3	5	1	2		
6	means challenging the diagnostic criteria of the past	3	1	0	1		
41	means being part of a realistic hope of treating mental illness	5	1	0	2	**	Distinguishes gp 3
2	demonstrates the need for a more scientific approach to mental health	1	2	-1	0		
13	needs to inspire volunteers so that research can move forwards	0	3	-1	4		
8	is vital for developing new treatments and overcoming the shortcomings of current therapies	2	5	-1	2	***	Distinguishes gp 3
31	needs public resources to shift from addressing mental distress to that of severe mental illness	-1	-1	-2	-1		
44	means someone is really listening and trying to understand psychiatric conditions	4	1	-2	-1		
30	needs government and funders to focus more attention and money on this kind of mental health research	4	2	-2	0		
11	means being part of a collective working towards a better future	1	4	-2	1	*	Distinguishes gp 3
12	means having a sense of belonging to a cause	0	0	-3	0	*	Distinguishes gp 3
14	means coming together to wage war on mental illness	-2	1	-3	-1	*	Distinguishes gp 3
42	incorporates knowledge from people who are experts in their own condition	-1	0	-4	-3		
7	means having better access to diagnosis, care and treatments	3	-2	-4	5	***	Distinguishes gp 3
40	provides a sense of ownership over the research	-1	0	-4	-1	**	Distinguishes gp 3
	Statements ranked at -5						
17	should be a moral obligation for the benefit of the greater good	-3	-4	-5	1		
33	is the only way we're going to make things better for people in generations to come	-2	-2	-5	-2	6*	Distinguishes gp 3

Table A7: Estimated position of statement agreement/disagreement and distinguishing statements for group 4

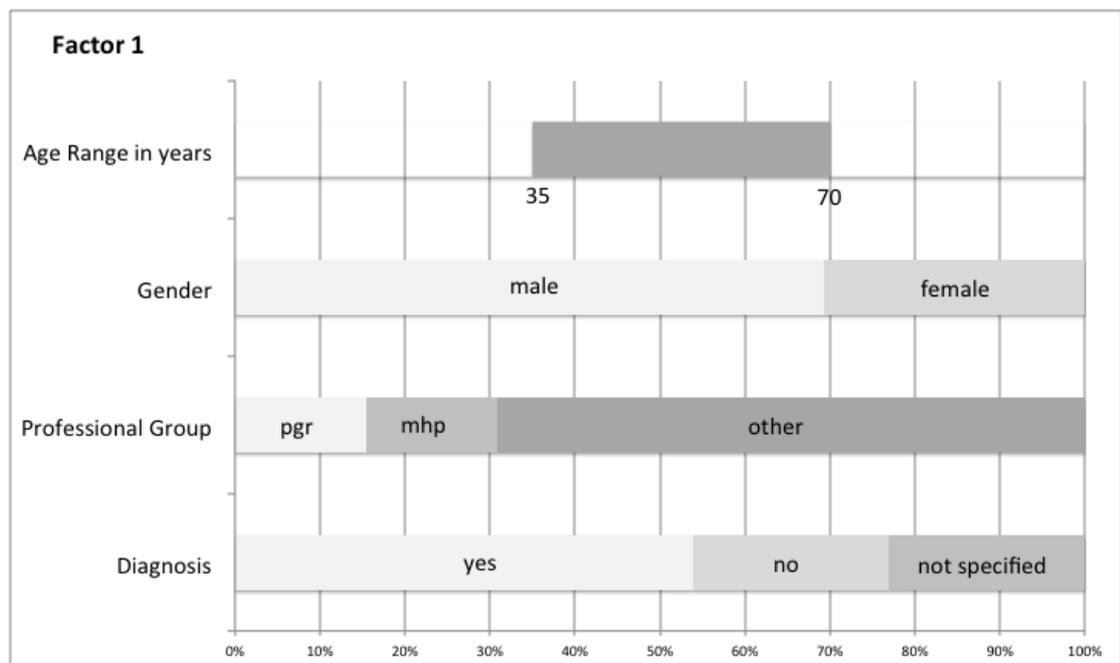
Statement number		Group				Statistically distinguishable from nearest group	Distinguishing statements
		1	2	3	4		
Statements ranked at +5							
7	means having better access to diagnosis, care and treatments	3	-2	-4	5	**	Distinguishes gp 4
46	is a complex decision that depends on many factors	0	3	0	5	**	Distinguishes gp 4
Other statements (those ranked higher in group 4 than in all other groups)							
13	needs to inspire volunteers so that research can move forwards	0	3	-1	4		
29	gives people more reason to label someone as 'a risk'	-3	-3	-3	4	6*	Distinguishes gp 4
45	means people overcoming a distrust of research(ers)	-1	0	1	3		
48	has implications for whole families and not just the individual participant	2	0	1	3		
17	should be a moral obligation for the benefit of the greater good	-3	-4	-5	1	***	Distinguishes gp 4
Other statements (those ranked lower in group 4 than in all other groups)							
23	helps psychiatry to recognise its current limitations and uncertainties	1	4	4	0		
10	is a generous act for the future benefit of others	1	2	3	-1	*	Distinguishes gp 4
20	takes advantage of the altruistic intention of potential participants	-1	-1	1	-2		
26	should be publicly shared to encourage other volunteers	0	2	-1	-2		
47	provides vast amounts of data that will give us many answers in the future	2	3	0	-2	*	Distinguishes gp 4
16	means giving up time for no personal gain	-2	-2	2	-4		
19	is no different to taking part in research about other health conditions	1	-1	-2	-4	**	Distinguishes gp 4
27	is more known about because of the increase in public discussions about mental health	0	2	0	-4	***	Distinguishes gp 4
Statements ranked at -5							
1	isn't going to help because these conditions are too complex	-4	-5	0	-5		
5	is pointless because mental illness is not a genetic illness	-5	-5	-3	-5		

The following pages show some selected demographics for each of the four groups

Group 1: The Untroubled Progress-Seekers

13 participants were significantly associated with this group, four were female and nine were male; the age of participants ranged between 35 and 70 years old. Of the 13 participants, two were psychiatric genetic researchers and two were mental health professionals. Seven had a mental health diagnosis, four did not and two did not disclose a diagnosis. Eight had heard of psychiatric genetic research, five had been approached to take part and five had taken part.

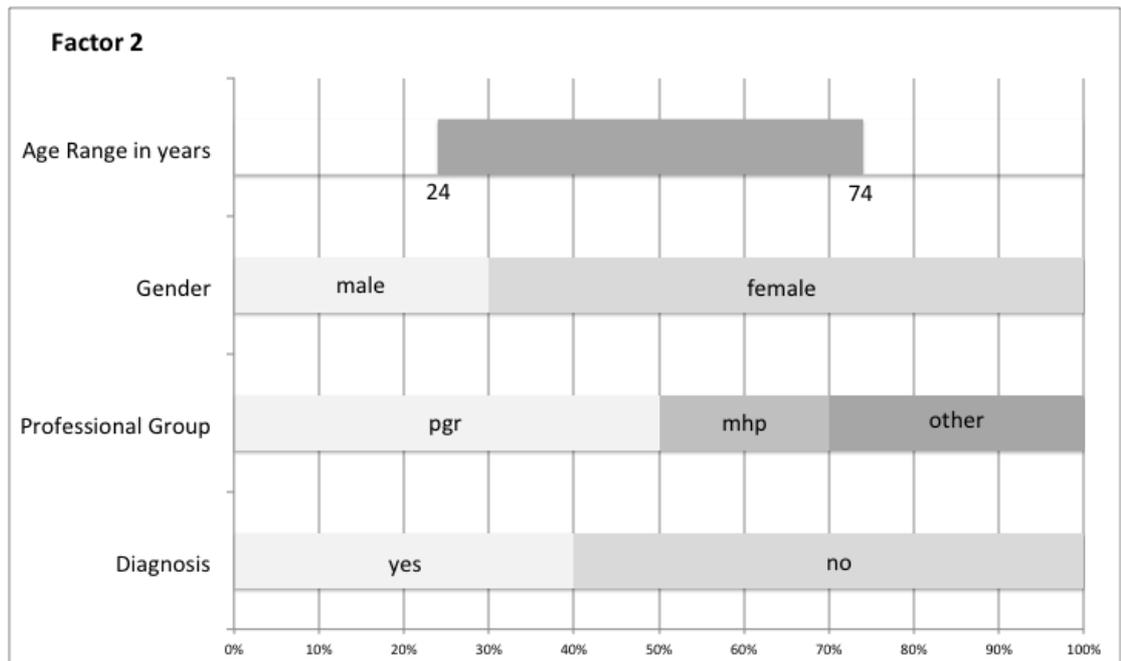
Figure A1: Group 1 demographics



Group 2: The Socially Engaged Strategists

10 participants were significantly associated with this group. They aged between 24 and 74 years old, seven were female and three were male. Of the 10 participants, five were psychiatric genetic researchers and two were mental health professionals. Four had a mental health diagnosis and six did not (or did not disclose a diagnosis). One had been approached and taken part in psychiatric genetic research.

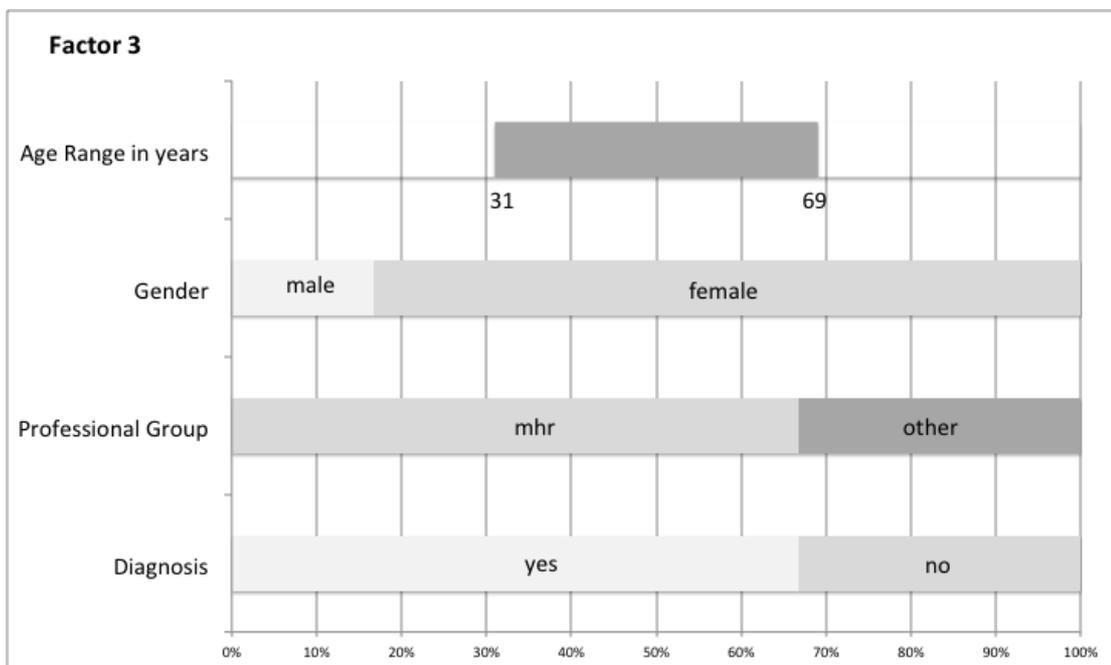
Figure A2: Group 2 demographics



Group 3: The Concerned Critics

Six participants were significantly associated with this group, five were female and one was male; the age of participants within this viewpoint ranged between 31 and 69 years old. There were no psychiatric genetic researchers, four were other kinds of mental health researchers, and there were no mental health professionals. Four had a mental health diagnosis and two did not (or did not disclose a diagnosis). Six had heard of psychiatric genetic research, three had been approached to take part and one had taken part.

Figure A3: Group 3 demographics



Group 4: The Cautious Obligators

All were male, aged between 22 and 69 years old and, of these seven individuals, three were retired mental health professionals and one was a psychiatric genetic researcher. The remaining three people attended a mental health support group. Two people disclosed a mental health diagnosis, none had taken part in psychiatric genetic research and none had been approached to take part.

Figure A4: Group 4 demographics

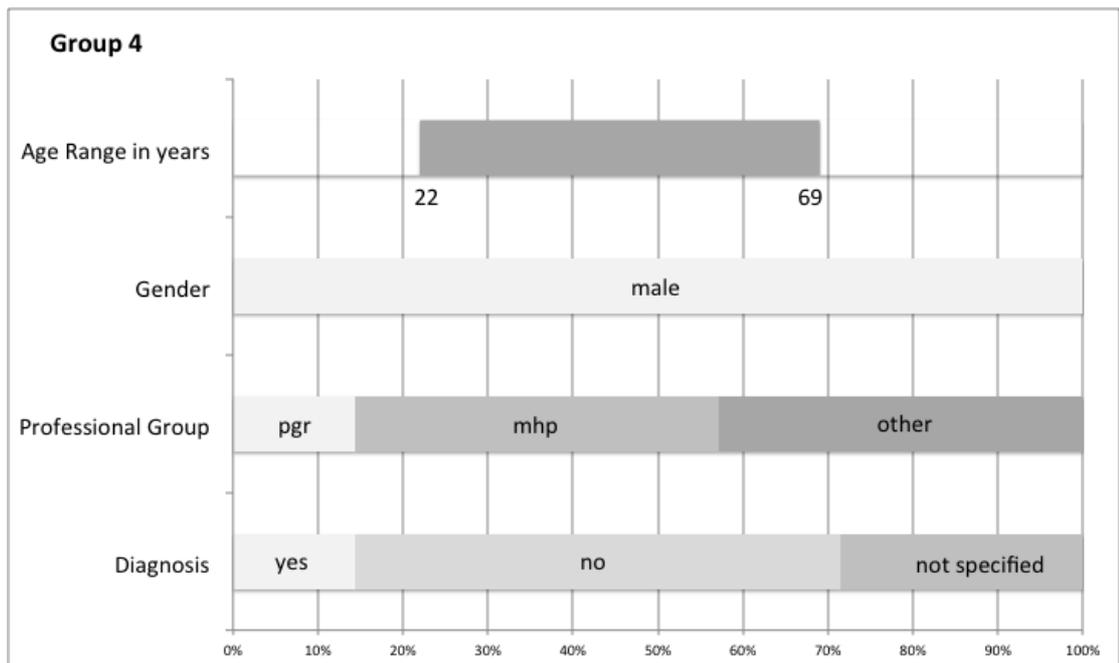


Figure A5: Estimated Q-sort configuration for group 1, (part 1 of 2)
The Untroubled Progress-Seekers

MOST DISAGREE

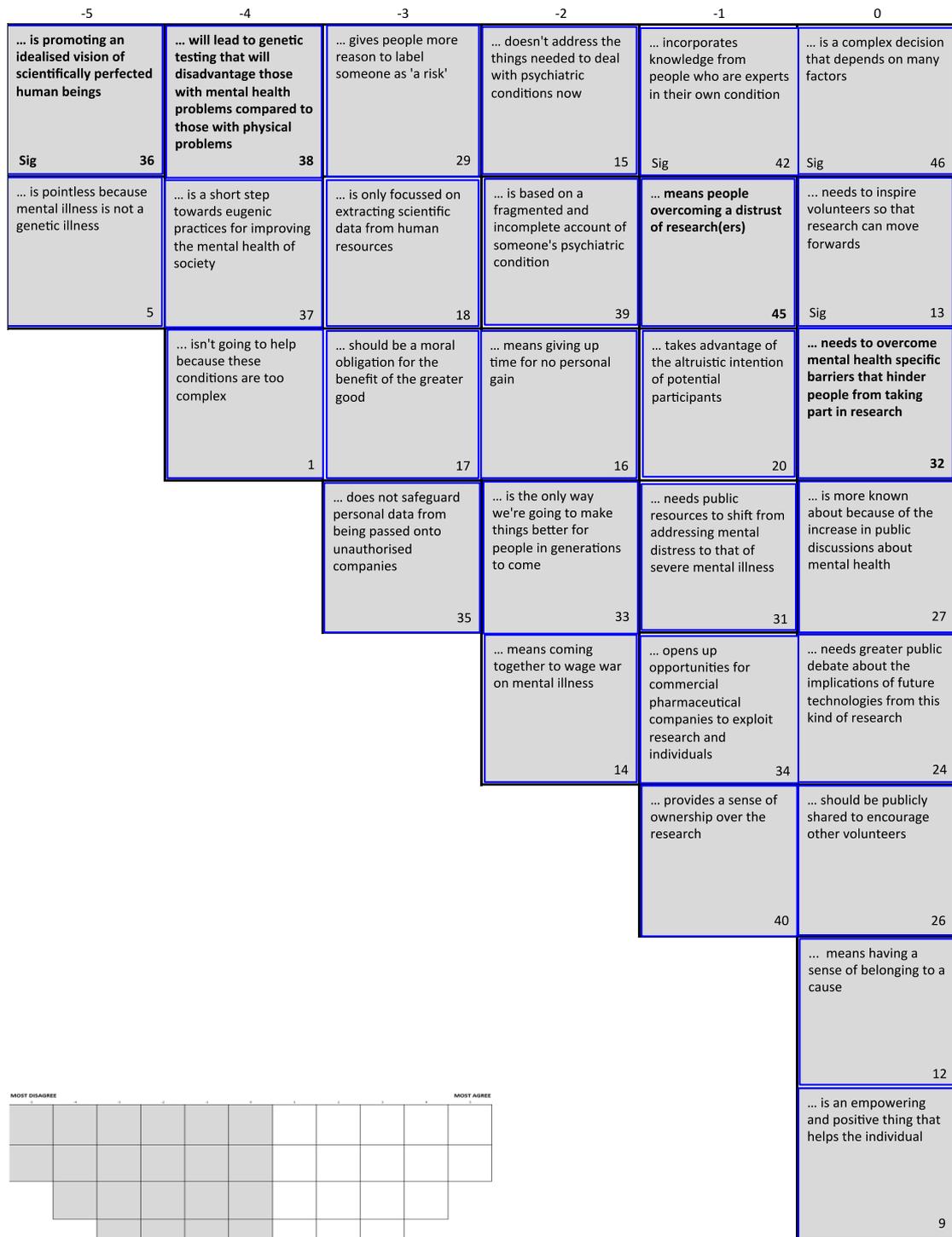


Figure A5: Estimated Q-sort configuration for group 1, (part 2 of 2)
The Untroubled Progress-Seekers

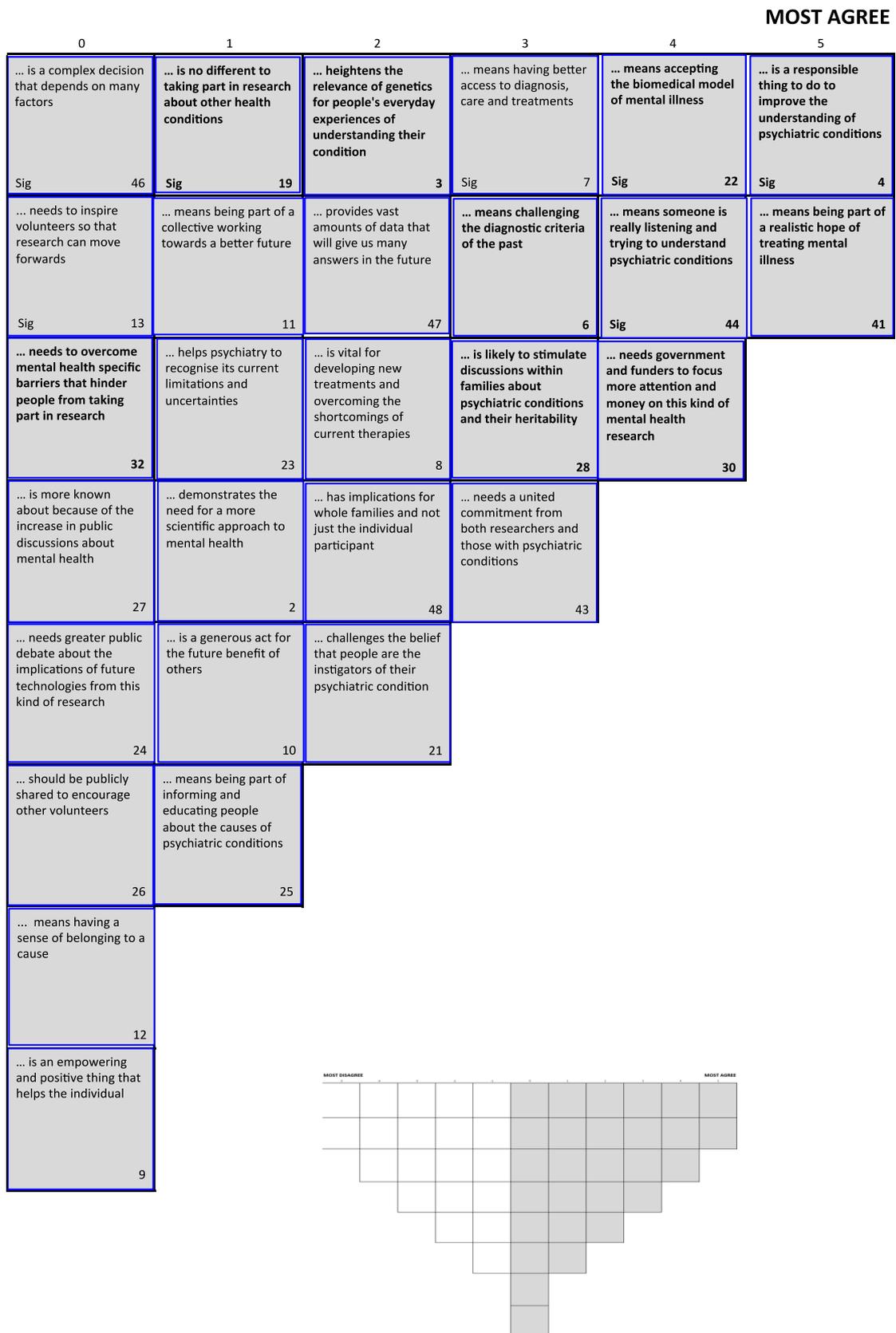


Figure A6: Estimated Q-sort configuration for group 2, (part 1 of 2)
The Socially Engaged Strategists

MOST DISAGREE

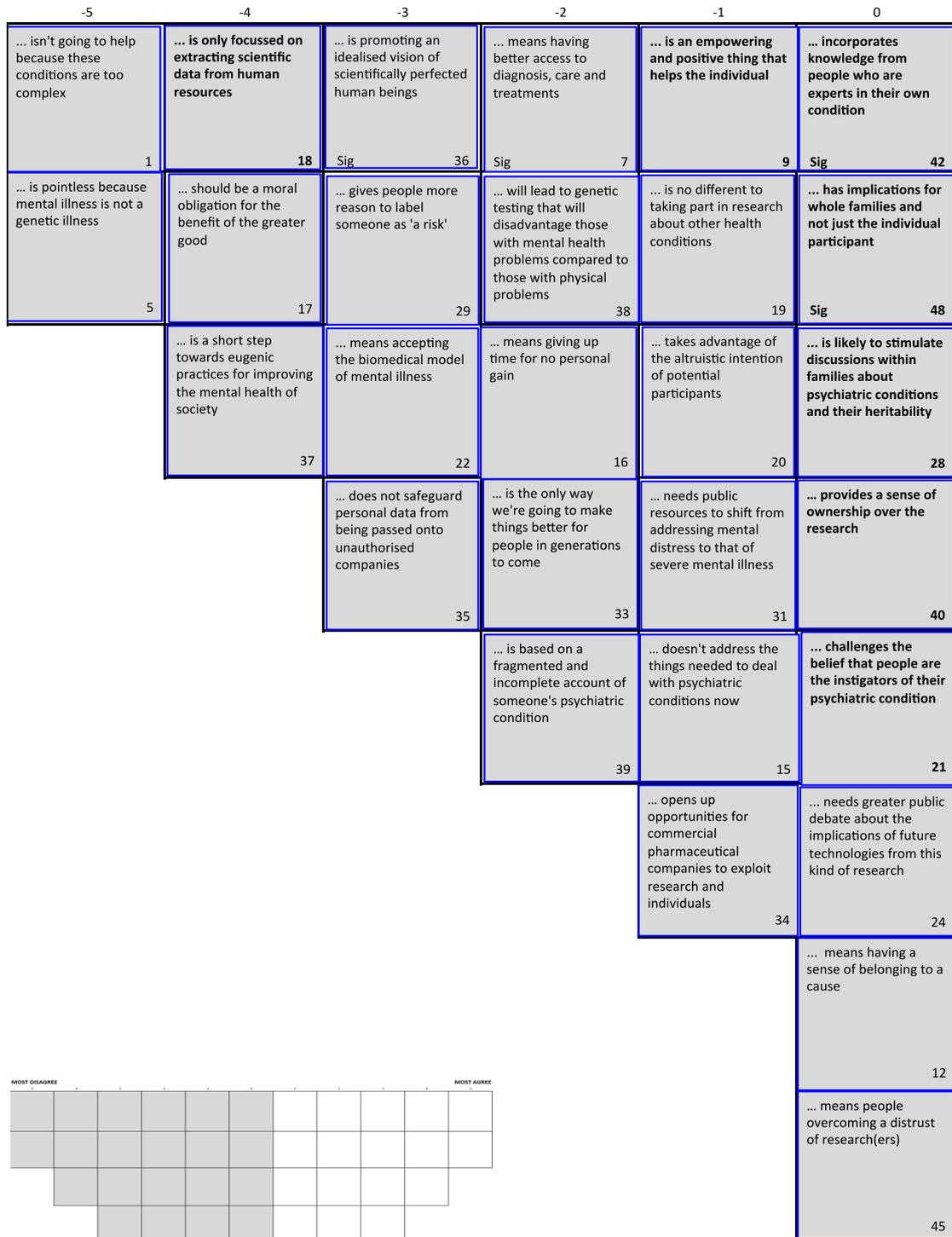


Figure A6: Estimated Q-sort configuration for group 2 (part 2 of 2)

The Socially Engaged Strategists

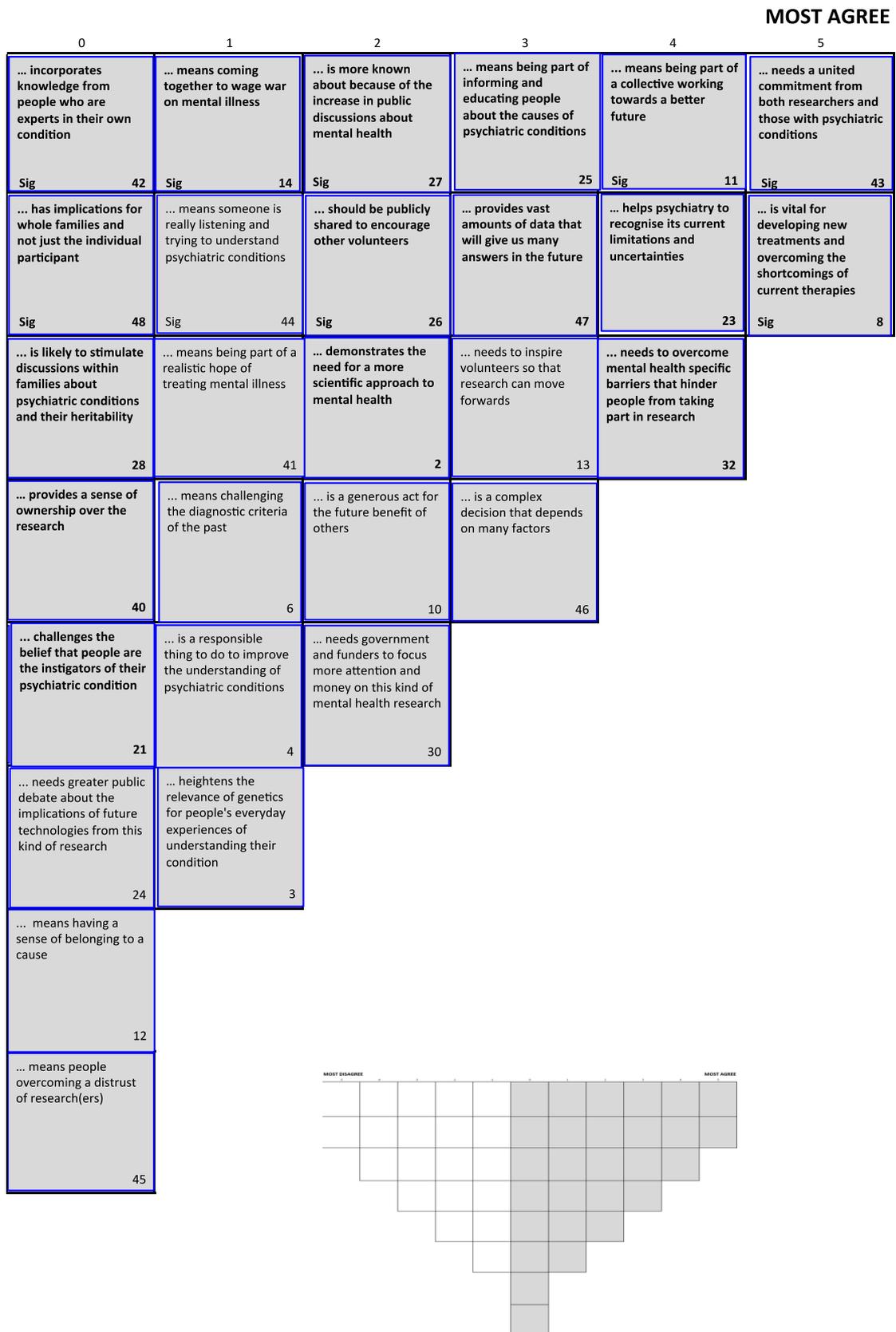


Figure A7: Estimated Q-sort configuration for group 3, (part 1 of 2)
The Concerned Critics

MOST DISAGREE

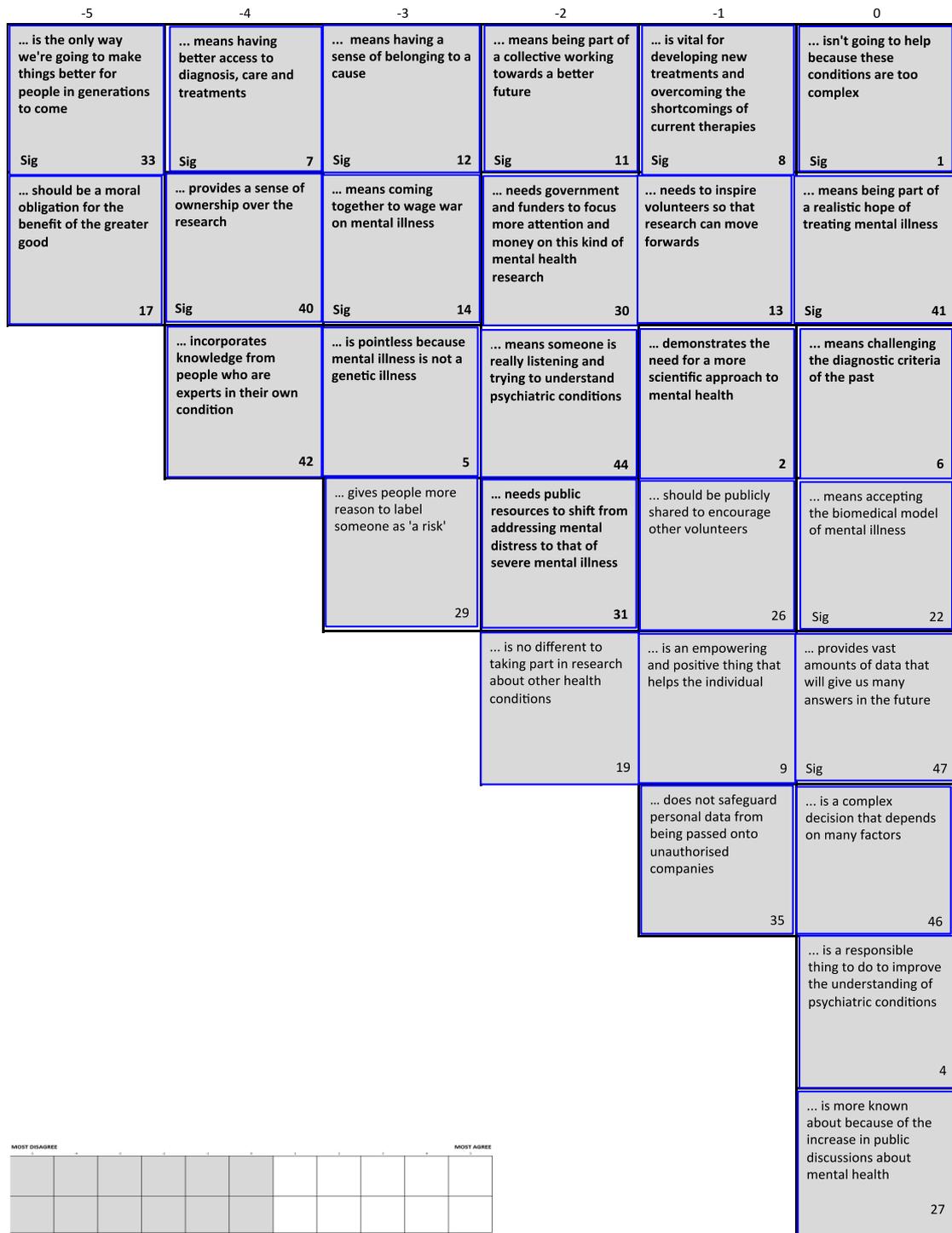


Figure A7: Estimated Q-sort configuration for group 3, (part 2 of 2)
The Concerned Critics

