



**COLLABORATIVE
CENTRE**

- ETHNIC INEQUALITIES
- SEVERE MENTAL ILLNESS
- MULTIPLE DISADVANTAGE

BRIEFING PAPER

The importance of
participatory methods
to research and system
change

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**The importance of participatory methods
to research and system change
The Synergi Collaborative Centre**

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The Synergi Collaborative Centre is a national initiative, to reframe, rethink and transform the realities of ethnic inequalities in severe mental illness and multiple disadvantage. Taking a collaborative approach, the centre aims to use the principles of co-production of knowledge and a creative mix of robust research methods. The centre will work closely with commissioners, policymakers and politicians, as well as public service providers, citizens and those experiencing mental distress, to create and deliver a vision to help eradicate ethnic inequalities in severe mental illness and their fundamental causes.

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INTRODUCTION

The Synergi Collaborative Centre is taking forward a programme of work that aims to reduce ethnic inequalities in severe mental illness in relation to both risk of illness and the provision of care. It will do this by understanding how inequalities relate to experiences of disadvantage, how this develops across the life course and in multiple domains of life, and by using this evidence to work towards developing and applying approaches to reduce them.

These inequalities are longstanding and seemingly intractable. As such, they run the risk of becoming accepted as 'normal'/'natural', difficult or impossible to address. We have argued (Bhui et al., 2018) that the ostensibly intractable nature of these inequalities is primarily a consequence of two issues. First, the underlying drivers of them (historically embedded forms of racism and ethnic inequality) are indeed very difficult to address. Second, is the failure of academic and policy communities to forefront, interrogate and make visible the experiences of service users, namely those with lived experience.

These factors contribute to a fundamental lack of understanding of how inequalities operate and how they might be addressed. This also leads to a lack of compassion about what is at stake for ethnic minority people who experience severe mental illness.

We propose that underpinning this lack of understanding is a relative devaluation of the knowledge held by people with lived experience in comparison with that held by practitioners, policymakers and academics. To address this devaluation and to make progress, it is crucial to have a framework for research and policy work that is fundamentally participatory in nature, allowing a full range of experiences and alternative viewpoints to be brought together in a coherent way.

This is why we are committed to thoroughly embedding participatory approaches into the work of Synergi. In this briefing paper we provide more detail on the rationale for, and our planned approach to, participatory methods, but first we contextualise why there has been a lack of progress in addressing ethnic inequalities in severe mental illness.

WHY DO ETHNIC INEQUALITIES IN SEVERE MENTAL ILLNESS PERSIST?

Ethnic minority people experience an increased risk of receiving a diagnosis of severe, psychosis-related mental illnesses. This increased risk is exceptionally high for Black people (five to six times higher than for White people), but it is also high for other ethnic minority groups (Synergi Collaborative Centre, 2017). It has not changed meaningfully over the past 50 years and persists across generations. In addition, ethnic minority people with a diagnosis of severe mental illness experience higher rates of contact with the police and criminal justice system, less voluntary inpatient care and fewer primary care interventions (Synergi Collaborative Centre, 2017).

These more adverse, less therapeutic pathways into and through care don't reflect increased levels of violence or substance misuse, nor delays in access to first episode services (Halvorsrud et al. in press). Rather, these experiences may well reflect wider issues of disempowerment, lack of trust, social exclusion and a lack of political influence (Bhui et al., 2018). Questions of disempowerment are often raised in service user meetings and are more broadly discussed in user-led activist groups, but they are rarely captured, or presented, in research or professionalised evidence.

Fundamental to ethnic inequalities in risk of diagnosis and pathways to care is the persistent presence of ethnic inequalities in broader social and economic domains, including employment and housing, and in the outcomes from educational achievements (Jivraj and Simpson 2015). In addition, risks of exposure to racism and discrimination within the UK have not changed significantly over the past 20 years (Virdee, 1997; Karlsen and Nazroo, 2014), and levels of prejudice against ethnic minority people have also remained remarkably high over time (Kelley et al., 2017).

Such social and economic inequalities have been shown to relate to the increased risk of severe mental illness experienced by ethnic minority people. There is a strong correlation between these forms of disadvantage and both the risk of severe mental illness and the risk of coercive treatment (Synergi Collaborative Centre, 2018). However, how these disadvantages are experienced, how they shape people's lives and people's interactions with health and social care services, and what this means for service design, is inadequately understood and rarely studied. In effect, the mechanisms behind these inequalities have not been traced and, therefore, cannot be addressed. It is here that progress can be made by placing centre stage the experiences and knowledge of those ethnic minority people with lived experience; that is, by adopting participatory approaches.

PARTICIPATORY APPROACHES TO RESEARCH AND POLICY DEVELOPMENT

Over the last two decades, mental health service users have become increasingly involved in research on a continuum of levels from consultation to user-led and user-controlled research (Faulkner and Layzell, 1999; Rose, 2001; Staddon, 2013). A variety of terms have been used for the range of approaches taken to enable user involvement in research and policy work, most commonly: 'co-production', 'co-creation' and 'co-design'. Although all of these share similar underlying principles, the terms are sometimes used in different ways in different contexts, and sometimes interchangeably. In fact, their origins are somewhat diverse, with roots in commerce, product or public service delivery design, politics, education, philosophy of knowledge and a range of social science approaches to research.

For example, co-design and co-creation are terms often used in business to describe the involvement of customers in designing/developing products and processes. Co-design is also used in the health sector to describe processes that place service users and communities at the centre of service redesign. While co-production is often used to describe the engagement of communities in research practice.

We use the terms 'co-production' and 'co-creation' to broadly refer to the practice of co-producing knowledge and applying it. In practice, this means members of relevant communities, such as service users, carers, practitioners and commissioners, among others, working with researchers to:

- Transform their concerns/problems into research questions or priorities for research (i.e. co-designing the research agenda and process) at the outset.
- Work collegially as co-researchers in all phases of the research (i.e. study design, data collection, data analysis, dissemination of findings). Typically, this is an iterative or cyclic process, alternating between action and critical reflection. Then, in later cycles, continuously refining methods, data and analysis based on the understanding developed in earlier cycles (Baum et al., 2006).
- Co-design/co-create action plans as part of this cycle, which can involve changing current practices, structures, or policies.
- Participate throughout all phases of the work, where "participation is more than just taking part", but involves generating activity underpinned by real choice (Cornwall and Jewkes, 1995, p. 1668).
- Build sustainable networks of support to allow the work to continue and develop further.

Involving service users in these ways has been systematically encouraged through research regulation, ethics and governance (for example, through protocols on Public and Patient Engagement). However, despite this context, there is a surprising lack of representation of ethnic minority users' views on service design and delivery, especially in relation to severe mental illness. Indeed, the recent Framework for Mental Health Research points out that there is a need for greater involvement of ethnic minority people (Department of Health, 2017). Furthermore, service users from ethnic minority groups point to power imbalances in these settings, stemming from marginalisation and discrimination, which operate as barriers to equal involvement (Kalathil, 2013). Addressing these power imbalances is crucial if progress is to be made.

USING PARTICIPATORY ACTION RESEARCH TO ADDRESS POWER IMBALANCES

Participatory Action Research (PAR) sets out to deal with the marginalisation of people with lived experience and the power imbalances that underlie this marginalisation, which can operate even in the most committed pieces of co-production/co-creation work. In addition, in order to tackle inequalities, PAR emphasises collaboration with the communities being researched, as partners in research design, in dialogue about knowledge and in the development of interventions and health policy (Belone et al., 2016).

To achieve this, it strives to meet the following core objectives (adapted from Kindon et al., 2007, p. 14):

- Aims 'to change practices, social structures and social media which maintain irrationality, injustice and unsatisfying forms of existence' (McTaggart 1997 cited in Reason and Bradbury 2006: 1).
- Treats participants as able, informed and reflexive agents, capable of participating in all aspects of the research process.
- Integrates values and beliefs that are core to the participating community into the central core of interventions, outcome measures and knowledge generation.
- Treats diverse experiences within a community as an opportunity to enrich the research process.
- Measures the credibility/validity of knowledge generated according to whether the resulting action solves problems for the people involved and increases community self-determination.

As described earlier, the need for such an approach arises because those most affected by inequalities are most often excluded from the knowledge-making, or the decision-making, intended to address them. For this reason, participatory approaches to research acknowledge and set out to address power inequalities, both in society and those that are inherent in the researcher-participant relationship, by using co-production/co-creation of research processes. An important goal of participatory approaches is to reverse power dynamics, so communities become co-researchers rather than participants only.

Synergi is placing a PAR approach at the core of its work because it has an explicit political agenda for promoting social justice ('action') and transforming current practices and power structures, beginning with the research process itself (Maguire, 2000). Heavily influenced by Paolo Freire's liberatory approach to education, and Foucault's notion of power as relational, PAR emphasises the importance of democratising knowledge through expanding who participates in the knowledge-making process (Gaventa and Cornwall, 2008). This emphasises an approach to co-production/co-creation where people's lived experience is considered a legitimate source of knowledge and where people are regarded as agents capable of analysing their own situations and designing their own solutions.

PAR recognises the existence of a multiplicity of ways of knowing about and viewing an issue, and assumes "those who have been most systematically excluded, oppressed or denied carry specifically revealing wisdom about the history, structure, consequences and the fracture points in unjust social arrangements" (Fine, 2008, p.213). So, not only is the location of power in the research process distinct between PAR and conventional research, but the view of what constitutes knowledge and how it can be acquired is also different.

Thus, in PAR, all forms of knowledge – lay, experiential, professional and academic, for example – are placed at the same level (Chesnay, 2016). One type of knowledge is not privileged over another (as it has tended to be in conventional research and professional settings); instead, they are subject to equal, careful and critical scrutiny. To achieve this, PAR emphasises the process of research as much as the 'action' or products of research, valuing the extent to which skills, knowledge and capacities are developed through the research experience (Kindon et al., 2007). It is characterised by a commitment to mutual learning, where academic researchers, community members and professionals learn from one another.

OUR APPROACH TO PARTICIPATORY ACTION RESEARCH

It is crucial to ensure that professional discourse is centred on what is at stake for patients and the public. For this to happen, the views of service users and the public must be heard. Not hearing, or paying attention to, such views leads to negative position taking, rather than more creative and progressive uses of disagreement as a window to better understanding.

More fundamentally, it is also important that we recognise that power-imbalances continue to operate, even if we aim to treat different sources and types of knowledge equally. We recognise that power inequities within the co-production/co-creation relationship cannot be entirely eliminated through Participatory Action Research processes (Grant et al., 2008). Indeed, it may well be that service users 'learn' to present their experiences in ways that count as 'legitimate' sources of evidence when engaged in participatory activities, particularly when hierarchies of evidence, where academic/technical evidence sits above experiential evidence, continue to exist (Renedo et al., 2018).

In this context, our starting point is to rely less on larger public organisations, professional bodies and familiar experts, and to privilege those with lived experience (broadly defined as including service users, carers and those providing formal care) to hear hidden voices. These hidden voices, we argue, hold insights into how health inequalities arise and are sustained, how racism operates and how we can empower people and communities to direct change.

This does not mean neglecting evidence from academic and professional sources. Rather it means working to produce a critical synthesis of the full range of evidence and bring the different strands of evidence into discussion with each other – revisiting and reconsidering academic and professional knowledge in the context of insights gained from service user-generated knowledge. Importantly, the purpose of utilising and mobilising multiple sources of evidence is not to corroborate study findings. Rather, the insights from different forms of evidence may complement each other and give a fuller picture of the problems we aim to address (Willig, 2013).

To do this, we aim to work together with those with lived experience as colleagues with a range of different skills to offer, learning from each other in the process and allowing us to jointly develop new insights. To do this, we will recruit co-researchers with lived experience of severe psychological distress, and who identify with ethnic minority status, to work with the research team throughout the process. This will involve refining the research questions, designing the research instruments, carrying out data collection, conducting analysis and disseminating and applying findings.

Co-production/co-creation may involve multiple methods designed to increase participation, empowerment, relevance and impact of research. Within this framework we will be running a number of activities. For example, the Synergi photovoice project (where those with lived experience have told their own stories through photographs and narratives with the goal of promoting social action (Wang and Burris, 1997), a priority setting survey (which builds on the Synergi photovoice activity), and Creative Spaces workshops (where we discuss and develop alternative solutions that can be applied in local contexts).

CONCLUDING COMMENTS

The Synergi Collaborative Centre's programme of work is to reduce the longstanding ethnic inequalities in severe mental illness. We argue that it is crucial to have a framework for research and policy work that is fundamentally participatory in nature to make progress in this area. Such an approach allows a full range of experiences and alternative viewpoints to be brought together in a coherent way. However, in doing this, we argue that it is essential to forefront, interrogate and make visible the experiences of service users with lived experience. It is by bringing this evidence into dialogue with academic, professional, policy and clinical knowledge that we will gain additional insights into how inequalities operate and how they might be addressed.

To do this, we will place a Participatory Action Research (PAR) approach centrally in our work. This follows the tradition of a range of approaches taken to enable user involvement in research and policy work, such as 'co-production', 'co-creation' and 'co-design'. However, PAR emphasises the importance of democratising knowledge through expanding who participates in the knowledge-making process – with an explicit political agenda for promoting social justice ('action') and transforming current practices and power structures, beginning with the research process itself. In the context of our work, this particularly means addressing the lack of representation and the marginalisation of ethnic minority service users in participatory approaches to research and service design.

Using the principles of PAR, Synergi aims to work together with those with lived experience as colleagues to jointly develop new insights.

We urge readers to engage with us, to look at our website and sign up to our mailing list, and to respond to invitations to participate in this work.



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ABOUT SYNERGI BRIEFINGS

Synergi Briefings provide evidence summaries, and reflect Synergi's position, approach and values, to build a fairer health care system, and to improve population health. Although embedded in the published evidence, there is much evidence in practice and in unpublished sources, or on websites, or in the memories of organisations that work with ethnic inequalities. We welcome these other sources of evidence and will place them in co-production spaces to develop shared narratives of evidence, and actions which can be taken, to prevent and reduce ethnic inequalities in the experiences and outcome of severe mental illness, and which take account of multiple disadvantage.

We welcome use of the content and discussions about progressive approaches to enhance health and social systems.

Our briefings are free to use, but please do provide the citation as suggested inside the front cover.

Website

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