

While a growing body of quantitative evidence explores changing social attitudes and behaviours, the lived experience of individuals and communities is often separated from these statistics; this project gives individuals the opportunity to reflect on, and document their lived experience of Covid-19 so that we may better understand the relationships between lived experience, beliefs, perceptions of truth, and accumulation of knowledge.

An innovative approach brings together 140 participants on an online qualitative platform to complete weekly digital diaries, creative arts-based tasks, photo and video submissions, and quick polls among others, to provide insights on various issues as the situation evolves. We have also trained 15 Peer Researchers through our Peer Research Network, who are deeply embedded within their communities, to conduct bi-weekly telephone interviews with 30 digitally excluded individuals.

The methods used enable a highly interactive, flexible and participatory approach in a fast-evolving context. The combined approach ensures that we are capturing diverse voices and viewpoints, allowing us to create a representative picture of what is happening around the UK as the pandemic continues to unfold.

We will share insights about how trust in different sources and types of information evolve over the period as the UK faced a winter of local lockdowns, and the role of local communities in challenging and reinforcing those views. We will also reflect on the strengths and challenges of participatory research during this period.

Theme: Trust and power: exploring dynamics of power, mistrust, and access among excluded groups

Day 1: Thursday 18th March – 13.35-14.55

11 'YOU ARE AT THEIR MERCY': DISCLOSURE AND TRUST IN LGBTQI+ CANCER CARE

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Background Lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) populations represent an 'ignored epidemic' and a 'growing, medically underserved population' in cancer care, with preliminary evidence that these communities experience disproportionate cancer burdens and unique psychosocial challenges (e.g. lower satisfaction with care, greater cancer-related distress).

Methods The Out with Cancer study is the first international study to explore the experiences of LGBTQI+ people diagnosed with cancer, using a mixed-methods approach (survey, semi-structured and photo-elicitation interviews). This presentation focuses on disclosure and trust in cancer care, from the perspective of LGBTQI+ people with cancer and healthcare professionals.

Results LGBTQI+ participants (to date survey n=342; interviews n=105; data collection is ongoing) often reported careful control around disclosure of their sexual and gender identities or intersex variations in cancer care, in part, due to

embarrassment, discomfort, and fear of negative reactions. Previous negative healthcare experiences contributed to distrust in cancer care, reluctance to disclose LGBTQI+ status and fears of inequitable treatment. Some participants reported explicit discriminations in cancer care, however, micro-aggressions (e.g. cis-heteronormative assumptions) and systemic absences of services and information tailored to the needs of LGBTQI+ people with cancer were more commonly reported. Healthcare professionals reported lacking confidence working with LGBTQI+ cancer patients, attributed to insufficient knowledge of the needs of these patients, uncertainty of correct terminology, and feeling embarrassed and uncomfortable discussing topics such as sexual needs. Furthermore, healthcare professionals reported lacking information and resources to guide the provision of quality clinical care and decision making with LGBTQI+ patients (e.g. such as the impact of hormone therapies on cancer treatment).

Conclusions These findings highlight the need to develop resources for LGBTQI+ people with cancer and healthcare professionals, which facilitate access to information and care that is culturally informed and relevant to the needs of LGBTQI+ communities.

12 ETHNICITY AND POWER IN THE MENTAL HEALTH SYSTEM: EXPERIENCES OF WHITE BRITISH AND BLACK CARIBBEAN PEOPLE WITH PSYCHOSIS

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Aims Persistent inequalities exist in how individuals from minority ethnic groups access mental health care. A failure to investigate how these inequalities are experienced and what they mean to people with psychosis has privileged professional narratives and hindered our understanding of how they are sustained. The aim of this study was to investigate the long-term experience of living with psychosis and navigating mental health services within different ethnic groups.

Method In-depth interviews with 17 black Caribbean, 15 white British, and 3 non-British white people with psychosis as part of AESOP-10, a 10 year follow up of an ethnically diverse cohort of individuals with first episode psychosis in the UK. We sought to prioritise the meaning that mental health services held for participants and attention was also given to the role of the interview context in shaping the stories, specifically the differences in social positioning between the narrator and researcher.

Results Participants' accounts of their journey through mental health services highlighted ethnic differences in experiences of powerlessness and control. Among black Caribbean participants, feelings of mistrust, and experiences of disempowerment during the negotiation of care, were mutually reinforcing. High levels of need, coupled with alienation from services, contributed to negative patterns of service use in this group. White participants recounted substantial, though fewer, experiences of disempowerment, and more instances of shared decision making that for some helped protect positive aspects of their lives.

Conclusions Against a background of entrenched social and economic disempowerment, services were experienced as disempowering by many black Caribbean people, compounding and perpetuating a sense of alienation. Concerted efforts by

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