In my own fieldwork, I predicted that trust and mistrust would be key themes that would benefit from investigation, particularly between activists, NHS managers and politicians. Although I also predicted that I would have to negotiate mistrust in my own relationships with people, I was surprised by how mistrust manifested itself. Activists expressed mistrust for me in various ways, and yet continued to engage with me.

Reflecting on that mistrust for me was uncomfortable. It brought to the surface the common emotional theme of the fledgling ethnographer: betrayal. But reflecting on their mistrust for me, and the different kinds of engagements and relationships that followed from that mistrust, led me to focus on mistrust itself as a particular form of engaging with uncertainty. Thinking about their relationships with me helped me to understand their relationships with other actors in health-care and policy.

8 PARTICIPATORY RESEARCH – CHALLENGING THE KNOWLEDGE SYSTEM OF DEMENTIA?

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10.1136/bmjopen-2021-QHRN.46

The knowledge system of dementia reflects the hierarchical medical system. Traditionally, scientists have been regarded as the ones who produce knowledge, have knowledge and decide which knowledge is relevant in health care and nursing for people living with dementia (PlwD). As 'patients', PlwD were objects of research or recipients of care. The lay perspective had in general little authority in the knowledge system of dementia. Particularly, PlwD's perspectives were systematically devalued against the background of a biomedical-cognitivist, deficit-oriented understanding – information provided by PlwD was considered less trustworthy. This systematic exclusion of PlwD's knowledge also applies to qualitative dementia research. However, a change in thinking has set in and PlwD are increasingly included in research as research participants.

Parallel to this, a more far reaching development is now gaining momentum: PlwD demand equal shares in research. 'Participatory research' is no longer just about being a participant, but about a share in the power to decide on the research process – from the formulation of research questions and data collection to interpretation and dissemination of results. Many qualitative dementia researchers are open to this type of research and some funding bodies are beginning to call for it.

The aim of this contribution is to theoretically discuss the following questions: How can participatory involvement of PlwD in dementia research influence trust in dementia-related health care research? Can participatory research increase trust because the plurality of perspectives is recognized as a value? Or could it reduce trust because the perspectives of PlwD appear untrustworthy?

This contribution offers a knowledge-sociological reflection and places the current turn towards participatory research with PlwD within the topic of trust in different forms of knowledge. It is argued that participatory research can change the knowledge system of dementia when local and experience-based forms of knowledge gain authority.

Day 2: Friday 19th March – 14.50-15.50

9 ON THE EDGE OF ETHICS: EMOTIONAL PRECARIY, KNOWLEDGE SEEKING AND HEALTH RESEARCH ETHICS COMMITTEES

T Marshall. *Queen's University Belfast, UK*

10.1136/bmjopen-2021-QHRN.47

Preparing for anthropological fieldwork is an emotional and physical endeavour. However, seeking ethical approval to conduct research within the NHS places (qualitative) researchers in an increased emotionally tenuous position. Firstly, researchers spend months navigating and producing copious documents to prove they are capable, and their knowledge-seeking methodology is ethical. Secondly, scrutiny of their research by a distanced bureaucratic structure has the 'power' to alter and constrain the production of knowledge. The researcher's academic and personal well-being is vulnerable amidst the tensions of proving the merits of their research methodology and adapting it to a national, biomedical biased, Research Ethics Committee (REC).

Anthropological fieldwork, in part, can be conceived as truth, or knowledge-seeking. However, can knowledge-seeking be constrained even before we enter the site of knowledge, the field? Through autoethnography, together with the writings of other authors, I will argue that the process of seeking NHS ethical approval impacts not only on empirical knowledge-seeking; it also has undesirable consequences for the researcher. Does the anonymous structure, distanced from anthropological knowledge-seeking hold the monopoly on ethics and subsequently knowledge-seeking? How then does the interplay between Kafkaesque bureaucratic regimens impact on a researcher's emotional (un)well-being? What are the emotional consequences of knowledge-seeking, particularly when research authority, control and oversight is wrenched from the autonomous researcher?

I will draw on Kirsten Hastrup's conceptualisation of anthropological knowledge and Hochschild's perspective on emotions management when faced with research precarity. In this paper, I discuss how personal experiences with health-related RECs can hinder the search for knowledge. I will also discuss the actual consequences on personal health and the potential impact on general, public health outcomes.

10 COVID-19 & COMMUNITY LIFE: A CREATIVE PARTICIPATORY APPROACH TO UNDERSTANDING COMMUNITIES AND TRUST DURING A GLOBAL PANDEMIC

V Boelman*, E Avdoulos. *The Young Foundation, UK*

10.1136/bmjopen-2021-QHRN.48

The Young Foundation, supported by The Wellcome Trust, is conducting a real-time inquiry into how Covid-19 is affecting interactions between individuals, experiences of community, and how trust in both science and health research are shaped. Between August and December 2020, we are capturing a cumulative long-term perspective, with particular focus on the ways in which trust and understanding are shaped among different groups, and the role and influence of digital.

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

R Power*, K Allison*, J Ussher, J Perz, S Sperring, C Ellis. *Translational Health Research Institute, Western Sydney University, Australia*

10.1136/bmjopen-2021-QHRN.49

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

V Lawrence*, C McCombie, G Nikolakopoulos, C Morgan. *King's College London, UK*

10.1136/bmjopen-2021-QHRN.50

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