Conclusion This study informs a deeper understanding of how epistemic trust may be built in therapeutic work with adopted children and identifies possible clinical approaches that may be used by clinicians working with this client group.

5 LINKED LIVES AND EVOLVING RELATIONSHIPS OF TRUST IN GENOMIC MEDICINE

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10.1136/bmjopen-2021-QHRN.43

Background In areas of medicine such as genomics, understanding the experiences of an individual patient is insufficient because they are likely to have family members who may be directly affected by the outcome of a genomic test. Work in this field often focuses on the perspectives of health professionals, for example, in relation to how sharing 'results' might damage familial trust.

Aim To provide new knowledge about the ways in which existing relationships of (mis)trust within families shapes patient's willingness to discuss and share information with others.

Methods Taking a qualitative longitudinal approach, we documented the journeys of patients and their families as they experienced genomic testing to understand how, over time, the process impacts on their lives and relationships. The project forms part of a Wellcome Trust collaborative award focusing on the ethical and social challenges that arise for health professionals, patients and families, working and living with genomic results. Repeat in-depth interviews with patients and their families were conducted. The purposive sample was stratified by those affected by a rare disease or cancer. Situational and diachronic/longitudinal analysis were employed.

Results Drawing on the notion of linked lives from lifecourse research, we argue that patients' views on the sharing of genetic information needs to be explored in relation to the matrix of familial relationships of trust in which they are located (or detached). This enables a greater appreciation of how trust shapes and is shaped by the sharing/withholding of different aspects of the journey through genomic testing. Moreover, the ways in which different health professionals and their practices feature in these matrices at different points in patient's journeys is also salient.

Conclusions An understanding of the complexity of such trust relationships highlights how consent processes are often deficient in capturing the range of decisions that need to be made.

Theme: Methodological innovations: exploring methods and concepts for exploring trust within research

Day 1: Thursday 18th March – 13.35-14.55

6 TRUST, LOCAL KNOWLEDGE AND LOCAL ACTION

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10.1136/bmjopen-2021-QHRN.44

This paper discusses trust and relationship in a piece of practice research that investigated health service access for people living homeless in a rural coastal town. The research used conversations with two socially disparate groups of participants; people living homeless and people providing services.

As a long term resident, staff member of the Health Service and regular attendee of a Breakfast for people living homeless, my position as a social worker was both highly transparent, and socially located between the two groups of participants.

Both experiential and observational data was collected using an inclusive action research methodology.

Reflection on the social action and the qualitative data analysis show that working with a population living with significant vulnerability requires a researcher to be authentic and dependable to ensure their trust. Working with providers with significant time restraints requires a researcher to be organised and efficient. These characteristics are different elements of trust on which both the recruitment and conduct of this research was dependent. Trust was dependent on and arose from; trust in the Health Service, trust in the Breakfast and trust in the researcher personally.

The District Oral Health Service was subsequently able to act on the basis of this locally constructed knowledge to provide access to the public dentist using the strategy designed by the people living homeless themselves. Council also used the knowledge to contribute to a significantly reviewed policy for dealing with non-compliant campsites of those living homeless.

Based on these outcomes, the paper argues for the value of practice based, action-oriented research in small communities that draws on trust in local institutions and personnel. The process and outcome of this research has implications for inclusion in knowledge building as a powerful strategy for local action on national issues.

7 MISTRUST IN ETHNOGRAPHY – SHOULD WE BE WORRIED ABOUT BETRAYING OUR RESEARCH SUBJECTS?

P Pushkar. *University of Manchester, UK*

10.1136/bmjopen-2021-QHRN.45

This article explores the analytical *usefulness* of mistrust in ethnographic research. I ground my argument through reference to my own fieldwork in which I did participant observation with political activists campaigning against cuts and privatisation in the NHS.

Engaging in relationships characterised by mistrust is unavoidable for most people and most ethnographers. I argue that although reflection on such engagements can be uncomfortable, they can shed light on what matters to researchers, namely, the nature of social relations.

Recent anthropological literature is increasingly rejecting previous conceptualisations of mistrust simply as the absence of trust. Mistrust is better theorised as a particular way of managing uncertainty in social relations. However, the recent literature on mistrust has not been applied to the relationship between researcher and subjects of research.

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

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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

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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.