Parallel session – Participatory Research (22 March 11:30 – 13:00)

012 DEMOCRATISING THE RESEARCH PROCESS: REFLECTIONS ON THE CO-PRODUCTION OF FOCUS GROUPS

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10.1136/bmjopen-2019-QHRN.12

Background Conventionally, focus groups are facilitated by academic researchers who mediate discussions with public participants. The researchers consider in advance group composition, topic guides and within-group dynamics.

As part of a mixed methods evaluation of a health care improvement programme, we co-produced a series of focus groups with a patient representative.

Aim To critically reflect on the process of developing and undertaking focus groups in partnership with patient representatives, and make recommendations for others considering using a similar approach in health research.

Methods Focus group materials were co-designed with a patient representative and piloted with a patient and public advisory panel. We conducted three focus groups with individuals who had undergone surgery in the last two years (surgical groups) and individuals who had not (non-surgical group). Each group was co-facilitated with the patient representative who later contributed to discussions to interpret the findings.

Results Co-production during planning stages provided a unique patient perspective about how to communicate information to the public and emphasise the patient perspective. We re-framed the topic guide to acknowledge that the patient journey is experienced along a continuum, not bounded by time or contact points with care providers. Co-facilitation of the groups enabled transparency, legitimacy and balance of contribution across academic and lay representatives. Rather than following convention and leading a focus group, researchers' roles shifted and they became co-facilitators. Focus groups benefitted from instances where the patient representative usefully sought to extend discussions and pursue emergent topics, where academic members might have tacitly sought to stick to the topic guide and keep discussions within the remit of the study objectives.

Conclusion We suggest that this process of co-production, when instituted as part of a critically reflective team approach, democratised the research process and supported stronger engagement within the groups themselves.

013 RULES OF ENGAGEMENT: ETHICS ISSUES IN PARTICIPATORY RESEARCH

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10.1136/bmjopen-2019-QHRN.13

Background This paper contributes to the literature on ethics in participatory research by looking at the Researcher-in-Residence model and its application within health services research.

Objectives This paper looks at one model of participatory research, the Researcher-in-Residence. The model places the researcher as a member of the delivery team to enable knowledge mobilisation and knowledge coproduction. We draw on recent literature on the ethics of participatory research to develop a framework that can support analysis of the ethical issues as experienced by Researchers-in-Residence. We examine several ethical issues that the researchers had to address at different points of the research process and reflect on different coping and negotiation strategies.

Methods The data that form the basis of this paper were collected iteratively as part of two different qualitative and participatory evaluations of integrated care in East London. Data for this paper consisted of the two researchers' personal journals and field notes, including reflections from fieldwork and communication with the wider research team.

Results and conclusion We offer a critical reflection on how the four ethics principles of respect for autonomy, beneficence, non-maleficence, and justice often have different implications for researchers engaged in participatory research, particularly when examined in terms of the contrasting norms of procedural ethics and everyday ethics. In line with other literature on participatory research, we found the institutional ethics review process offered no guidance, as it forced us to jump through hoops to fit an iterative process into requirements developed with a sequential steps process in mind. The paper suggests that, whereas the requirements of ethics committees, based on an ethics of principle, at times fail to offer appropriate guidelines for this methodological approach, an ethics of caring based on relationships can offer a complementary framework to address some of the thorny challenges that emerge from everyday practice in participatory research.

014 GOING NATIVE IN ORDER TO MAKE A DIFFERENCE? TENSIONS OF LONGITUDINAL PARTICIPATORY RESEARCH

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10.1136/bmjopen-2019-QHRN.14

There is a growing criticism of both 'pull' and 'push' approaches to implementing evidence-based change, with the increasing prominence of co-production, also referred to as action research, participatory research, engaged scholarship and integrated knowledge translation. This paper draws on an auto-ethnography conducted over a nine-year period by a qualitative researcher embedded in a large-scale knowledge mobilisation partnership between a university and a range of local healthcare and third-sector organisations. It traces an individual journey from being a relatively disinterested observer, focusing on researching organisational change, towards becoming an enthusiast of co-production, promoting the practical impact of longitudinal research on the organisational structures and functions within the partnership.

At the same time, the paper highlights four dilemmas that longitudinal qualitative action researchers have to manage:

- Conflicting identity: being 'too academic' for practitioners and 'not academic enough' for fellow researchers;
- Compromising research rigour in order to quickly produce results fed back to non-academic partners;

- Achieving a balancing act between being critical (in an academic way) and constructive (in a practice-oriented way);
- Maintaining your own voice while truthfully reflecting the (often conflicting) voices of multiple stakeholders.

Resolving these tensions may require ‘compartmentalisation’, whereby two different sets of outputs are produced: for example, a series of high-quality critical journal papers for an academic audience and a series of practice-oriented reports for a practitioner audience. The obvious negative consequences of this approach include the constant need to wear ‘multiple hats’ and invest extra labour. The biggest difficulty, however, is achieving and maintaining ‘*embeddedness*’ in a healthcare organisation, which is a prerequisite for enabling change, without losing *critical distance*, which is a prerequisite for producing high-quality critical qualitative research. Constant self-reflection and peer-debriefing with trusted colleagues are some of the strategies that can alleviate, if not completely resolve, this tension.

015 BUILDING SUSTAINABLE PARTNERSHIPS WITH LOCAL RESEARCHERS FOR QUALITATIVE HEALTH SYSTEMS RESEARCH

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10.1136/bmjopen-2019-QHRN.15

Background International health projects are increasingly engaging local researchers to ensure that interventions are cost-effective and locally relevant. Yet, locating research partners in low and middle-income country settings is not always straightforward particularly when projects are inter-disciplinary, the methods unfamiliar, and the setting, new. Since July 2017, we have initiated a research partnership in North-East India and Sierra Leone to assess surgical need and health system capacity for a global surgery project.

Aim Our presentation will describe our experiences identifying and engaging local stakeholders including government, ethical review bodies, but particularly research teams in India and Sierra Leone to co-design and execute qualitative health research. With a view to inform future global health research, we identify challenges and opportunities for building qualitative health research capacity in both sets of researchers and positioning qualitative research within interdisciplinary health research projects.

Methods Our approach to collaboration for qualitative health research in India and Sierra Leone involves a process of co-designing protocols and ethics applications; jointly producing data collection tools; iterative and cooperative data collection, transcribing and analysis; and co-writing publications and policy briefs.

Expected results This presentation will describe the early stage processes of building local research collaborations for carrying out qualitative health research in low and middle-income countries (LMIC). We identify challenges as well as practical strategies and technological aids to develop cross-country partnerships.

Conclusions While several global health research projects will involve similar processes for building sustainable partnerships with local researchers, less is documented on how early stage collaborations are forged and the challenges overcome particularly in low-resource settings. This presentation contributes to addressing this gap, laying a pathway for future qualitative health research in LMICs.

016 RARE BUT STILL HEARD: HOW INNOVATIVE METHODS CAN ENHANCE RESEARCH INCLUSION

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10.1136/bmjopen-2019-QHRN.16

Background Primary Sclerosing Cholangitis (PSC) is a rare, chronic, and incurable liver disease characterised by the inflammation and scarring of the bile duct. The speed and aggression at which the disease can progress may vary between individuals. Both the cause and the underlying triggers for its progression and severity remain unknown. Those living with PSC are more at risk of colorectal and biliary tract cancers, and many will eventually need a liver transplant. As with any transplant, there is uncertainty in waiting for an appropriate donor and people can die in the meantime. Living with such continuing uncertainty can cause enduring and substantial psychological distress. Yet, little research focuses on the mental health and wellbeing of people with PSC and their families.

Objective To understand the experiences of those living with PSC, and their families, in terms of their mental health and wellbeing.

Methods Asynchronous Virtual Focus Groups (AVFGs) were undertaken with people diagnosed with PSC, and their family members. AVFGs were chosen as an appropriate method of data collection for this group as the rarity of the disease meant that participants could not be sampled from close or clustered geographical areas. AVFGs allowed people, across the UK, to participate in this study from their home, without substantial cost or travel.

Results Participants’ narratives centred upon their experiences of receiving a diagnosis, contact with health professionals, their support systems and advice they’d give to someone who was newly diagnosed.

Conclusions Uncovering narratives from people affected by rare diseases, such as PSC, has often meant substantial cost or travel for the participant, or their simply not being included due to distance. AVFGs allow for greater inclusion in studies which have the potential to provide positive benefits to the participants.

017 ENGAGING DISPLACED PEOPLE IN ARTISTIC AND CULTURAL ACTIVITIES USING PARTICIPATORY ACTION RESEARCH

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10.1136/bmjopen-2019-QHRN.17

Background Many European organisations provide creative activities for displaced people, including refugees and asylum seekers, that aim to reduce social isolation and counter prevalent mental health issues including anxiety, depression, non-affective psychosis and post-traumatic stress disorder.¹⁻³ A growing body of evidence suggests that taking part in artistic and cultural activities benefits human health and wellbeing,⁴⁻⁶ though this research has been mostly non-collaborative in nature. Although creative activities are seen to provide major benefits for displaced people, researchers need to