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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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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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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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;