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Approving a participatory research proposal: Perspectives from a Research Ethics Committee Chair and a researcher in Ireland

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Introduction

This case concerns a participatory health research project that was submitted for approval to a Research Ethics Committee in Ireland. All researchers wishing to undertake research linked to general medical practice need to submit an application to the Ethics Committee outlining the aims, design and methods, including how people will give consent to participate, how anonymity will be dealt with, potential harm and risk minimised, etc. The case is in two parts. The first part was contributed by a medical academic, based on a time when he chaired the Irish College of General Practitioners Research Ethics Committee. He outlines the Committee's response to an application for approval for a participatory research project. The second part is a short reflection by a health care academic, who was part of the team that submitted the application.

The case

Part 1: Perspectives from the Chair of the Research Ethics Committee

In November 2010, while I was Chair of the Research Ethics Committee of the Irish College of General Practitioners, we received an application for a project entitled "RESTORE: REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings". It was quite different from the kind of research proposals we were used to. The committee mostly deals with small investigator led projects from GPs or their trainees who, typically, want to survey patients or their colleagues (using questionnaires or interviews) about various health related issues. We also receive occasional applications from GPs who are involved in trials (primarily post marketing drug trials) for pharmaceutical companies. The RESTORE project application was for the Irish component of a huge European study regarding how to improve the healthcare of migrants. It was replete with concepts and language with which the committee was unfamiliar. We were used to randomised controlled designs, cohort studies and descriptive studies. This study was going to use a participatory approach and would involve action research and co-design with stake-holders. This was all very new to us and it was somewhat difficult for us to grasp what exactly all these terms meant. More troubling to us, though, was the paucity of information on exactly who was going to participate in the study and what precisely was the 'intervention'. We understood that migrants would be involved in the study. We recognised these immediately as a vulnerable group and so we wanted to know how they would be recruited. We wanted to know the sample size and to see the interview schedule. We wanted to know which 'stakeholders' were involved and how were they to be selected. How would informed consent be obtained? What did they mean by migrants 'co-producing' the research'? Surely, they are research subjects and need to be protected by standard ethical procedures of being provided detailed participant information and giving informed consent. How can they be researchers and the researched at the same time? The proposal mentioned information being provided in the different languages of the migrants – What languages? What migrant groups? This was all a bit too vague for us to feel our usual degree of comfort.

In the end, we recognised that we had to trust the integrity and expertise of the research group. We came to realise that the very fact of using a participatory approach showed a high degree of sensitivity to the vulnerability of the group that was the focus of the research. We also had to accept that not all the information we were used to having at the outset of a study would be available until the study group commenced their work. We did ask for some clarification of the methods of participant recruitment and we sought some assurance about the availability of translators/ cultural mediators. We asked that the participant information be simplified. It was a bit too jargonistic even for us, never mind for potential research participants. We wanted to ascertain the burden of time and effort that participation would impose on the participants although, ultimately, we had to accept that this could not be predetermined either. It would really be up to participants themselves, in the end, to judge how much they wanted to put into the research. This was a steep learning curve for both the committee and the researchers. I feel the researchers have come to recognise that a clinical research ethics committee can struggle with the philosophy and methodology of participatory research and that this methodology needs it to be described more clearly in language the committee can understand. The committee have also learnt that there is an entirely different approach to research on health and social issues now emerging that is based on very different concepts of research design and a radically different philosophy. They have also come to appreciate that, sometimes, they have to trust that the researchers share the committee's concern for the protection of research 'subjects'. In participatory research this concern is manifest through the 'subjects' being co-designers and co-producers of the research. They are inherently protected from exploitation by the research methodology itself. This being the case, the role of the research ethics committee becomes somewhat less clear. However, there are ethical issues in undertaking participatory research which researchers and ethics committees still need to tease out and learn how to deal with. Perhaps this is something that could be explored in a participatory research project!

Part 2: Reflections from the researcher perspective

I was the lead investigator for this project. The two key learning points for us researchers were that:

1) No matter how much we think we are making complex concepts about participatory research clear, it is likely that we will have to try harder!

2) It was really valuable to say very explicitly in the subsequent ethics applications for this project when and where co-researchers informed the decision making. For example, the recruitment strategy in the RESTORE project has been co-designed with migrants who were community partners in the project. It was important and helpful for the ethics committee members to know that the suggested strategies were considered acceptable by them for their wider community. Furthermore, this also highlighted resilience and expertise among migrants to balance out the inevitable concerns of the ethics committee about their potential vulnerability.