

A comparative study of participation and non-participation in the North Cumbria Community Genetics Project

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Project Background

Aims and Rationale: Our study sought to compare and contrast the perceptions and attitudes of those who have agreed to donate samples to the North Cumbria Community Genetics Project (NCCGP) with those who have declined. It was based on the premise that we know little about the views of those who have actually been asked to donate to a genetic database.

Achievements

Biobank donations: Our project is one of only two studies to interview actual donors (the other being the EPEG project, also funded by the Wellcome Trust). Unlike EPEG, however, an important element of our work has been to address non-donors' reasons for refusal. Thus, our study has provided much needed empirical data to add to normative discussions of why people do and do not donate.

Nature of participation and non-participation: Our study has provided a more nuanced understanding of the nature of participation in genetics research. Our data reveals the complexities in the *levels* and *styles* of participation, which a simple two-way distinction between those who decide to donate and those who decide not to donate does not reflect.

Reasons for refusal: Our project has enhanced understandings of 'refusals' to donate. The desire to help was rated as equally important by 'refusers', as participants. Some refusers had donated to other medical projects but could not supply the NCCGP with samples due to a combination of local factors (e.g. funding of the NCCGP) and wider concerns over the control of genetic data and the fact that no one (not even the NCCGP team) could know future uses of their donation.

Altruism, reciprocity, and benefits-sharing: Our study suggests that participants are not as straightforwardly altruistic as is usually assumed and that those who do not participate are as equally altruistic as their participating counterparts. Donors are motivated by the expectation that they or those close to them may someday benefit from advances in medical research. Since reciprocity (as opposed to one way gift-giving) is a vital component in donation, our study has emphasized the importance of benefit-sharing.

Informed consent: Our work provides empirical insight into discussions of informed consent. In the case of the NCCGP, one reason for the successful participation rate is also a key reason to be concerned. Most women found it easy to donate their afterbirth since the material was to be otherwise discarded. However, the ease of the decision meant that they asked few questions about the project, which, in turn, impacted their levels of understanding of what they were donating to and for. This raises questions regarding the quality and level of informed consent.

Value of cross-disciplinary research: Our project also provides a case-study of the benefits that can be achieved when using sociological theory and empirical methods to address normative bioethical debates. An overall achievement of our work is that we are in a position to ask the sorts of questions raised above regarding the nature and use of concepts such as ‘donation’, ‘altruism’, and ‘consent’. Our work has also added to sociological debates (e.g. Bauman, Giddens, Foucault, Osborne) on the nature of modernity and ethical reasoning/behaviour.

Contributions: Our study is already assisting: a) future discussions on the ethical implications of genetic databases; b) policy making in this area, and c) the wider socio-cultural significance of such databases.

Implications

Uses of the term ‘community’: Whilst it is acknowledged that biobanks raise questions for entire communities, and not just for individuals, our project suggests that the concept of community must be empirically investigated and properly theorised. Terms such as community consultation, consent, and participation must be fully deconstructed so that their usefulness and limitations are recognised and false claims regarding levels of community approval are avoided.

Informed consent: As mentioned above, if women are uncertain about what they donated, how clear can they be about the rationale of the research to which they contributed, or about the nature of the uses to which their information and samples would be put? Thus, we argue that in future studies researchers and policy-makers should attend to the processes of achieving a response rate, not just the actual rate itself.

Recruitment and participation in UK Biobank: All the above points have clear implications for the design and conduct of the UK Biobank, particularly in the recruitment of donors and for understanding how and why potential donors might participate. In addition, it is clear from our study that attention needs to be paid to the social context of the targeted population in case particular (hitherto unidentified) characteristics of that population affects levels and styles of consent, altruism, participation and refusal.