

Focus groups and public involvement in the new genetics

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Sarah Cunningham-Burley,
Anne Kerr and Steve Pavis

Introduction

The 1990s has been called the 'decade of the consumer' and the rhetoric of listening to the public, whether as users, voters, interested lay people etc., looks set to continue. It would be disingenuous to think that such attempts to involve and engage the public in a range of issues which may concern them, whether that be local health care planning, transport policies or debates and regulation around new genetic technologies, are entirely vacuous.

However, we should be sceptical. We must be aware of the interests of those involved, and wider context within which such a trend has developed. It is only then that we may be able to mobilise effective involvement and build a truly participatory democracy which informs science policy and health care practice.

The new genetics has spawned renewed efforts to generate public debate around some of the social and ethical issues involved and to promote further the public understanding of science. Such endeavours must be understood at least partly to do with science's own attempts to promote itself, its activities and its view of the world through stressing the benefits of science and the value of scientists' own expertise. The rapid development of new genetic technologies and their application in the health care arena have perhaps made concerns about the acceptability of science more pressing, in the light of an ever sceptical public. The spectre of eugenics, discrimination and other abuses mean that scientists must engage in issues of public concern and they take on that responsibility quite visibly through the media as well as within the regulatory process. But, we must reflect on that very process and how it may serve to maintain professionals' power. In relation to the new genetics, scientists' expert status extends beyond their area of technological expertise to include consideration of social and ethical issues, the very area where public debate is also considered important. They are in a privileged position within any debate about the impact of the new genetics, which can seriously limit the extent of public involvement.

The way in which the public is viewed in much discussion around lay involvement in the new genetics also contributes to an undermining of their potential contribution. The 'deficit model', which regards the public's understanding of science as inadequate and that their lack of technical knowledge means they are unable to comment on relevant issues, still prevails, despite the serious challenge from social scientists. Such a view tends to focus on the public's lack of knowledge, especially about the technical details of genetic science. And it is technical knowledge which is considered most important in averting eugenic abuse. The rhetoric goes *'If only the public understood genetic science better, then they would not be so worried about its potential abuse'*. If such a view underpins attempts to consult and involve the public, then those with technical expertise will always be listened to more and the concerns of the public can be disparaged, managed or ignored.

How can we challenge this dominant view of the public and develop the nascent attempts to engage with it? There is scope to work within the existing frameworks and the current consultative process. For example, the Medical Research Council, the Wellcome Trust and the Nuffield Council on Bioethics have all conducted public consultation exercises. Social scientists and others have also been involved in developing ways of involving the public through citizen's juries, consensus conferences, surveys, internet conferences and voting, public debates, and focus group research to give some examples. However, all such attempts must openly reflect on the way in which the public is being viewed, the role of 'experts' in the process, and on how the very method of consultation may reinforce particular stereotypes. All such attempts should carry a commitment to acting upon rather than simply improving lay people's knowledge and opinions.

Focus groups to promote effective involvement

Let's take one example of how we might promote effective grass roots engagement, the use of focus groups. These are a much-maligned method of research and consultation and certainly their use within market research can reinforce a rather passive view of consumers

or voters. This has served to belittle an approach which has a greater potential when used in other contexts. Academic sociologists have used focus group research to investigate lay views and experience of a range of issues, including the new genetics. Their approach prioritises active involvement and dialogue among the participants in discussions: this can give substance to lay knowledge in all its diversity and move concerns well away from narrowly defined technical expertise. Research carried out in Scotland employed this method to study lay views of the new genetics (see Box 1).

We chose focus groups because we felt that they would enable discussion and debate, encourage participants to talk about issues they may not usually think about and because they allowed us to bring a diverse range of people into the research process. We felt that the group discussions were potentially empowering, as people were able to express, but more importantly explore, their views in a supportive environment. Our approach to the focus groups meant that issues relating to fundamental concerns about the context of genetic research and associated health service practice could be discussed:

Box 1 Focus groups looking at the social impact of genetic technology

The use of focus groups to investigate the 'Social Impact of the New Genetics' led us to reconsider the value of the method both in terms of accessing lay knowledge and in promoting lay participation in the public sphere.

Our research involved interviews with scientists, clinicians and journalists; an analysis of selected written media coverage, including the specialist professional press; and focus group research with a range of population groups or publics. This took place over two years and nine months and gave us access to a broad range of perspectives on the social and cultural impact of the new genetics. Our intention to reflect the diversity of publics, rather than to be representative in a more traditional sense, meant that we usually engaged with existing groups (for example, support groups or community groups). Groups were therefore small and participants usually known to each other. We did not want simply to search for differences in participants' accounts in terms of class, gender or ethnicity, but sought to understand the way in which people's social location more broadly influenced their views. Therefore we interviewed 20 groups: six who were directly affected by a genetic condition (e.g. people with disabilities, parents of children with Cystic Fibrosis); four with a professional interest in genetics (e.g. nurses and public health medicine specialists); five with an indirect link to genetics as their lifestyle or condition has been associated with genetics (e.g. gay men and a support group for people with experience of heart disease); and five other community groups/friendship networks (e.g. elderly people attending a day centre, and a group of Chinese students). No payment was made to group members to attend, although a financial contribution was made to one of the groups for the hire of a room in their building (the organisation was a charity which promoted independent living for people with disabilities). The participants were engaged as actively as possible in the research process. The project was explained in detail and feedback was offered via reports. The work was conducted recursively, and the analysis was fed back to later groups to enable deeper and more pertinent theorising. In the later focus groups we developed techniques to enable detailed exploration of issues raised in the earlier sessions.

Philosophical and existential questions were asked, and group members reflected on services, practices and policy. This did not involve asking participants to give accounts of, or 'imagine', their courses of action as consumers of genetic services. Instead they were asked to comment on the social and ethical issues raised by genetic tests and services. This allowed for a wide ranging discussion and did not put participants in an uncomfortable position by expecting them to disclose their personal views on sensitive subjects such as abortion.

The interaction between participants meant that ambivalence and ambiguities were expressed and discussed in detail. Views were challenged and moderated; and unique, shared knowledge was revealed.

These focus groups highlighted the powerful pressures existing to delineate professional expertise and lay ignorance. There was a strong resistance amongst lay people and professionals alike to recognise that the accounts in these focus groups constitute a form of expertise which places a positive value on their opinions and experiences. Invariably, when the groups were being set up, people expressed anxieties about their lack of relevant knowledge. A lot of reassurance was required to convince people that they would be able to talk about the new genetics whether or not they felt they had high level of technical proficiency in the subject. People were also highly sceptical about their involvement in policy making, arguing that their views were not considered to be important. This lack of confidence and history of exclusion means that, within the present structures truly inclusive and meaningful debate about the new genetics, would be very difficult. The processes of decision-making about funding and clinical application need to be revised if they are to become publicly accountable. This would require significant shifts in power and the creation of many more democratic fora.

Our experience of conducting these focus groups has led us to relate the research method to wider issues of participatory democracy in a more concrete fashion. We have begun to ask how do we create these fora and do focus groups help? As a direct result of our commitment to actively involve lay people in public debates and policy discussion about the new genetics, we organised a public discussion about some of the issues raised by our research at the Edinburgh International Science Festival 1997. This event 'The Public Image of the New Genetics' involved a short panel discussion about the trustworthiness of geneticists, the role of the media and the level of public understanding of genetics, as well as the public's role in decision and policy making, followed by contributions from the audience. The event was open to the public and research participants were invited to attend. Although this gave people who might otherwise have been silent an opportunity to express their views in public, it also highlighted the ease with which professionals can dominate public discussions. In addition, it showed clearly (as did the focus groups) that there is no resolute public opinion about the new genetics (or any other issue for that matter). This suggests that processes which can deal with the inevitable ambivalence which a wider range of lay people will express and the diversity present in different publics, need to be developed. Moreover, open contestation of expert knowledge should be a feature of all democratic processes.

we did not have a narrow remit simply to find out lay views on one narrow issue such as genetic testing. This approach proved effective: we found that the participants in the groups had a range of highly relevant knowledge, what we have called 'lay expertise'. This involved a sound understanding of the context of scientific developments and the limits of scientific approaches, as well as experiential and cultural knowledge of the likely impact of new genetic technologies. While a few people had direct experience of genetic related health concerns, all participants were able to discuss concerns about discrimination, definitions of disease and quality of life and the tensions around individual choice and collective issues. Importantly, our research told us that we should not be searching for straightforward answers to the complex questions which the new genetics poses. Public involvement should not be relegated to simple for or against arguments. Rather, the exploration of ambiguity, ambivalence and tensions should be the central aim of attempts to promote public engagement in the new genetics. This will generate much more meaningful debate and hopefully policy and practice that is more sensitive to diverse concerns.

In order to generate truly participatory methods of involving the public in important decisions about genetic science and its health care applications, the divide between expert and lay knowledge must be eroded. This means that the consultation process must be guided, not by those who have a vested interest in protecting their own expertise, but by citizens themselves. New alliances between social scientists and communities can be forged, which collectively may challenge existing power structures. There is a chance now that this can happen; the rhetoric of listening to the public can be used to develop methods and approaches which encourage participation from diverse publics as well as from marginalised groups. Devolved governments may encourage this process as we all work towards developing a new civil society and a more democratic science.

Sarah Cunningham-Burley, Department of Community Health Sciences, Medical School, University of Edinburgh, Teviot Place, Edinburgh EH8 9AG, UK. E-mail: Sarah.C.Burley@ed.ac.uk

Anne Kerr, Lecturer in Sociology, Department of Sociology, University of York, Heslington, York, YO10 5DD, UK. Email: eak3@york.ac.uk

Steve Pavis, Head of Sociology, Queen Margaret University College, Edinburgh, UK. Email: SPavis@qmul.ac.uk

Notes

Sarah Cunningham-Burley is senior lecturer in Medical Sociology at the University of Edinburgh. This article is drawn from material taken from: Cunningham-Burley, S., Kerr, A. and Pavis, S. (1999) *Theorising Subjects and Subject Matter in Focus Group Research* in Barbour, R. and Kitzinger, J. (eds) *Developing Focus Group Research*, Sage, London pp186-199; And Cunningham-Burley, S. *Public involvement and the new genetics*, Splice of Life, 1999 (see www.geneticsforum.org)

Further reading

Kerr, A., Cunningham-Burley, S. and Amos, A. (1998) *The New Genetics and Health: Mobilising Lay Expertise*. *Public Understanding of Science* Vol. 7: 41-60

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