INNOVATIVE HEALTH TECHNOLOGIES PROGRAMME

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Transformations In Genetic Subjecthood

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RESEARCH FINDINGS

KEY FINDINGS

The overall aim of the research was to understand recent transformations in genetic subjecthood in relation to the production, consumption and governance of human genetic knowledge and technology. The project focused upon how people positioned themselves and others in accounts of the control, donation and ownership of genetics. More specifically, the research explored:

- People's accounts of control and responsibility, particularly involvement in the design and oversight of genetic research.
- The discourses of 'at-risk patients' and 'informed consumers', especially in terms of the governance of genetics.
- The links between these discourses and other broader notions of citizenship and participatory democracy.
- Notions of genetic responsibility, particularly in relation to social and ethical aspects of donation.

- People constructed a range of subject positions for themselves and others in the course of discussions about the social aspects of genetics, and moved between these positions depending on the topic being discussed and the way in which the discussion was organised.

- Professional and lay perspectives on genetics could overlap. People shifted between positioning themselves and others as experts in a particular field, depending on technical, personal or political knowledge and experience, whilst at other times professing ignorance of or alienation from the topic at hand. Political or moral affinities were sometimes more important than professionalism or laity.

- People gave different accounts of participation, research and governance when discussing the design and oversight of UK Biobank, and the negotiation of genetic patents. There was a tension between expressions of frustration with the public's lack of education in genetics and frustrations with lack of transparency in research governance. However, these criticisms were often muted in more public fora.

- Similarly, when consumers and patients were invoked in discussions, consumption was sometimes cast as passive and unthinking, at other times active and involved, just as positive and negative qualities were mapped onto patienthood depending on the context.

RESEARCH TEAM

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People constructed a range of subject positions for themselves and others in the course of discussions about the social aspects of genetics, and moved between these positions depending upon the context of the discussion. There were no clear boundaries between what we might typically think of as a 'professional' and a 'lay' perspectives upon genetics, because people shifted between positioning themselves and/or others as particular kinds of experts, based upon technical, personal or political knowledge and experience, whilst at other times disavowing or rejecting expert positioning by professing ignorance or alienation from the topic at hand, or constructing other subject positions where political or moral affinities were more important than professionalism or laity.

Although there were, at times, similarities in the ways in which people who had come to the discussion as a result of political, professional or personal interest in genetic disease conceptualised participation or governance, there was also tremendous variety between the accounts expressed in these types of groups, depending upon the context of their discussion. For example, scientists who specialised in genetics expressed frustration with the public's lack of education in genetics and linked this to the difficulties in recruitment for and governance of large scale genetic research, whereas members of public interest groups expressed frustration with scientists' lack of transparency and accountability when it comes to research governance, whilst at the same time linking this to a need for greater public education about the social and ethical aspects of genetics. The discourse of public deficit was common to many of the accounts examined in this project, but it linked to a range of contradictory claims about the pros and cons of genetic research and services.

This analysis also holds true when consumers and patients were invoked in discussions about genetics. Genetic subject positions were flexible and often contradictory. This means that they sometimes featured in reflexive discussions where ambiguity and differences between people were recognised and considerable ambivalence was expressed about genetic research and service provision. However, in other contexts these flexible identities were expressed in contexts where participants adopted a common set of discourses, based upon fairly narrow notions of scientific progress, public good and individual choice.

Given the complexities of the data this research has generated, it is important to concentrate on a small set of particular themes to give us analytical purchase on both the diversity and similarities in participants' subject positions and interpretive repertoires across the range of substantive topics in which we are interested. We are therefore investigating four analytical avenues in more depth:

1. Constructing Expertise

Accounts of expertise are intimately tied to notions of people's responsibilities and their abilities to contribute to decision-making, based on their knowledge or experiences. Expertise took diverse forms in these interviews and events, depending both upon the context of the discussion and the range of people it involved. Speakers and participants appealed to different types of expertise in both hierarchical and non-hierarchical ways, but also made reference to their own lack of expertise. This undermines any clear distinction between lay and professional expertise, and suggests that authority is achieved through flexible use of different types of expertise.

2. Constructing the Moral Arena

People constructed and inhabited a moral arena as they discussed ethics, governance and citizenship, with respect to the responsibilities and accountability of all of the stake holders concerned with contemporary genetics, including patients, professionals, policy-makers and corporations. Although we can understand some groups' arguments as the products of their social and discursive context, and we can identify some broad claims common to certain groups, we cannot trace, in detail, certain subject positions onto particular claims or arguments. People mobilised a range of arguments, ontologies and principles when discussing the social aspects of genetics in our study. There was considerable and often sophisticated discussion of the myriad risks associated with genetics, and ambivalence about how to manage these risks. Similarly, the complexities and paradoxical effects of governance were also explored in depth. These arguments were far more apparent than more cliched notions of 'the slippery slope', or 'designer babies', yet a range of fairly predictable 'solutions' to these ethical and regulatory problems were nevertheless often invoked, particularly notions of balance, impartiality and standardisation. Similarly, generalised appeals were often made to 'the public good,' the importance of good health and the prevention of suffering.

3. Exploring 'Public Involvement' Through an Analysis of Conference Talk

The 'public' were constructed in various ways at the conferences and meetings which we analysed as part of the study. It is striking that people who had been invited to attend some of these events because they did not have expertise in genetics sometimes mobilised other kinds of expertise as a way of distancing themselves from the an amorphous 'public'. Expressions of patients' or families' identities were sometimes constructed in opposition to physicians' or scientists' identities, but at other times these identities seemed to be interchangeable, especially when a common discourse of partnership, dialogue and progress in eliminating disease emerged through the course of the discussion.

4. Participation in UK Biobank

People's notions of participant, lay public, or private corporation, are the product of particular discursive contexts. In small discussion groups there seemed to be considerable ambivalence about the merits of participation in this type of research as donors and members of oversight bodies. At times this ambivalence challenged what we might call the institutional version of participant found in official documents about initiatives such as UK Biobank and the wider discourses of consumerism, personhood, and informed consent that underpin their idealised notion of the participant. However, in public meetings in particular, these critical positions were often subsumed within a broader optimistic discourse of social and scientific progress, so the institutional version of 'participant' remained. This suggests that there is more ambivalence about participation in this type of biomedical research than official discourses or events imply.

Public involvement in policy making about genetics, and the ethics of genetic research and service provision more generally, are highly contested at the 'micro-level' of debate and discussion, even amongst groups with apparently strong commitments to participatory democracy or scientific progress. Yet, this ambiguity and ambivalence was less apparent in other contexts where a number of common rhetorical appeals emerged in the course of discussions, for example advocacy of informed choice, public involvement and professional humility. These contexts were sometimes public conferences and meetings, but ambivalence was also bracketed or transcended in some of the focus groups where participants constructed a strong shared vision of future research, service provision or governance, be that positive or negatively construed. Although expert positions were often ephemeral and indeed contested, discourses that privileged scientific progress, institutional ethics and public education cut across ambiguity in many of the focus groups and public meetings, even when the professionals we might expect to make these types of arguments were in an apparent minority. These discourses came to the fore as a result of a range of organisational arrangements and inter-personal dynamics that meant that consensus, balance and technical expertise were often implicitly and sometimes explicitly privileged.

These results suggest that the organisation and outcomes of public consultation exercises and other forms of genetic governance where a range of stakeholders are involved are prone to domination by particular discourses, which are predicated on fairly narrow notions of the goals, realities and governance of genetic research and services. Although this may be useful for policy makers keen to move forward with particular research programmes or services, the ambiguities and differences between participants are only temporarily suspended, so the success of these projects are by no means guaranteed, and may even be undermined as the processes of bracketing difference and forging a limited kind of consensus become more apparent. Perhaps by focusing upon the process rather than the outcomes of these kinds of consultation events, providers, participants and policy-makers could develop a more nuanced and sophisticated treatment of ambiguity and difference, and in so doing move more towards more innovative and reflexive procedures and policies for dealing with future genetic research, services and governance.

About the Project

Recent developments in genetics have provoked controversy about the patenting of DNA, the confidentiality of genetic data and the provision of genetic tests directly to consumers. Patients, professionals, industries, policy makers and the public are all involved in negotiations over what rights and responsibilities particular individuals have with respect to the control and ownership of genetic information. This project documented and analysed a range of discourses about these issues through an analysis of the different subject positions that people adopt and mobilise when discussing these issues, and the ways in which these positions can be linked to particular arguments concerning genetic research, services and governance. It explored how the immunities, obligations and entitlements of citizens, businesses and public bodies were constructed in discussions about the control and ownership of genetic information, and focused upon how people positioned themselves and others in accounts of the control, donation and ownership of genetic information in clinical, commercial and policy settings.

This research has generated a rich dataset on a wide range of groups' accounts of the various subject positions that people might occupy in relation to genetic research, service provision and governance, and how those subject positions relate to discourses about the development of these aspects of contemporary genetics. This includes discussion of expertise, patienthood and citizenship. Nineteen focus groups were conducted with people with a broad range of experiences of the clinical, scientific, ethical and legal aspects of genetics. We also included groups who were less directly affected by these issues but whose perspective is important given that developments in genetics have implications for the community as a whole. A further set of groups involved members of a range of public, charitable and professional bodies, including research funding panels, health care trusts, ethics committees and magistrates. We also organised and analysed two conferences about the social aspects of genetics with participants from a diverse range of backgrounds, and we observed three further such conferences with a similar mixture of participants.

These investigations suggest that by focusing upon the process rather than the outcomes of the events and procedures which characterise genetic research, service provision and governance, policy-makers, providers and participants could develop a more nuanced and sophisticated treatment of ambiguity and differences, and in doing so could move toward more innovative and reflexive procedures and policies for dealing with future developments. This approach could equally apply to other fields which are also contentious.