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Drawing the line: an analysis of lay people's discussions about the new genetics

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"Where do we draw the line?" is a question that is frequently asked in discussions about the new genetics. In this paper we explore a range of lay people's accounts of drawing the line. We show that, beyond its rhetorical function, answering this question involves important discussions about genetic research, testing, regulation, and social provision for people who are sick or disabled. It raises difficult questions about clients' and service providers' autonomy and responsibility and about which human illnesses, conditions, and characteristics ought to be the subject of research and testing. In particular, we show how differences in the amount and type of information and advice available to clients of genetic testing, the level of social support to people with particular conditions, and people's perception of stigma, suffering, and quality of life, make drawing the line highly problematic. We end by discussing the implications of our analysis for policy making, considering how the ambiguities and tensions in lay accounts might enable, as opposed to stifle, greater democratization of the new genetics.

Introduction

Consulting the public is an important part of the scientific and market cultures of the late twentieth century. The dominant "deficit" model of public understanding of science has also been seriously challenged in the academic and policy arenas.[1] Recently, across Europe, North America, and Australasia, policymaking and funding bodies have become interested in accessing the public's views on science and technology with a view to acting upon, as opposed to "improving," lay people's knowledge and opinions. This interest has taken various forms, ranging from public debates and citizen's juries to consensus conferences.[2] Among the many aspects of science and technology addressed by these initiatives, the new genetics has become an important topic, not least because of the social and ethical issues it raises. For example, in the UK, the Wellcome Trust recently ran a public consultation exercise in London, citizen's juries were held in Wales, and in Scotland we organized a public discussion as part of the Edinburgh International Science Festival.

The tension between the promise of alleviating disease and suffering and the potential for discrimination and coercion makes the issue of "where to draw the line" with genetic science and technology fundamental to these discussions. Questions like "should we ban research into the genetics of IQ?," "Should genetic testing be commercially available without counselling?," or "Should insurance companies have access to genetic information?" are frequently asked. However, the difficulties involved in establishing firm responses to such

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complex and difficult questions prevent any clear lines from being drawn around genetic research and its application. Consensus conferences, juries, and public debates seek to avoid the simple yes/no response typical of opinion polls to elicit public attitudes. Nevertheless, they remain hampered by the complexities of the task at hand: attempting to produce resolute expressions of public opinion where such consensus does not necessarily exist.

We must welcome the democratic impetus behind these public consultation projects, and applaud the shift away from the "deficit" model of public understanding of science that they herald. However, many crucial questions about the public understanding of science in general and genetics in particular remain unanswered, especially in relation to how such understanding is accessed, analyzed, and utilized. The complexities of the public's views about genetic science and technology must be thoroughly explored before they can be usefully applied in any policy sense. Such an exploration necessitates a sophisticated analysis of the similarities and differences in lay people's accounts. This does not just involve *representing* people's views, but requires an awareness of the social context in which such accounts are expressed and of the social and cultural locations from which they are drawn. In particular, the provision of an enabling environment, in which "lay expertise" can be properly mobilized, is crucial to generating rich and detailed accounts.[3] Without such reflective appraisals of lay accounts, any attempts to promote participatory public policy through consultation are likely to be inadequate.

In this paper we discuss our approach to these difficult issues, drawing on lay accounts of acceptable practice in genetic research and services. This is part of a wider research project into the social and cultural impact of the new genetics. Professionals, journalists, and lay people have been interviewed, and a selection of the press coverage of genetics has been analyzed.[4] After providing some background details of the study design, we discuss the focus group interviews, which we conducted in two stages. This somewhat unconventional narrative style is necessary to make explicit the iterative nature of the qualitative research process and to reveal the contexts within which the data and analysis were generated and interwoven. We explain how we adapted the design of our research as our analysis of the data we collected developed. We therefore discuss the way in which we developed the interview schedule, and the range of groups we interviewed, as we became increasingly committed to using research into lay views about the new genetics to foster greater public involvement in decision making about the new genetics.[5]

The main body of the paper is divided into two discussion sections. First, drawing on our early interviews, we consider lay people's identification of a need to "draw the line" and highlight some of the tensions that prevented them from so doing. Second, we discuss an exercise in "line drawing" involving particular conditions and behavioral traits, which we developed in the later interviews. We explore further the tensions and boundaries that emerged in these lay people's accounts. This involves a discussion about how differences in lay people's social locations shaped their accounts. We conclude with a consideration of what this means with respect to public policy forums and debates, arguing that the ambiguities and tensions in lay people's accounts can enable, as opposed to stifle, greater democratization of the new genetics.[6]

The study

The lay discussions that form the basis of this paper were generated in twenty focus groups, which took place in central Scotland over the period February 1996 to April 1997.[7] While we would not argue that focus groups offer a panacaea for the limitations of survey methodology in accessing public views, they do provide the opportunity for a more detailed

account of a range of people's views. In particular, focus groups *enable* discussion and debate, encouraging participants to talk about something that they might not have previously considered in depth. When respondents are new to a subject matter (in the sense that they do not consider it routinely) the processes involved in group discussion can facilitate orientation and reflection. Focus groups might also be less daunting than one-to-one interviews, since they create an atmosphere in which respondents do not feel that they have to have an opinion on every issue, or answer all of the questions.

In setting up our focus groups, we deliberately sought to access a diversity of publics, and chose not to concentrate solely on people with direct experience of a genetic condition. The groups therefore involved a mixture of peoples and not a representative sample of the population as a whole. Most of the groups were drawn from community and support groups because of our concern to create a relaxed atmosphere conducive to discussion. Although we were aware that a group of strangers might be more open about certain details than people who knew each other, we felt that the kind of detail in the accounts we hoped to get was more likely to be fostered by familiarity between and common experiences among the participants. We were not, for example, searching for personal testimonies about sensitive matters such as abortion. Instead we aimed to facilitate participants' exploration of the variety of perspectives and options open to clients of genetic testing and the contexts within which decisions would be made.

Focus groups require researchers to take seriously the social context of both knowledge production and data generation, and to reflect on the interpretive processes involved in making sense of data.[8] Because we accessed a diversity of publics and focused on their breadth of experience, we do not provide a systematic analysis across dimensions such as race, gender, or class. However, we do consider the social location of our participants and how this shaped their accounts about genetics. As the following description shows, our groups covered a broad range of the population, demonstrating widely varied relationships to and experiences of medical science in general and genetics in particular.

The focus groups fell into three broad categories and were conducted in two stages. In the first stage the groups averaged around six participants. This number was reduced to around four in the second stage to allow people to participate in the discussions in a more in-depth fashion. The first type of groups we describe as general, since the research team was unaware of any participant having direct experience of a genetic or related health concern. There were five such groups. In the first stage these groups were: a mixed-sex, working-class group of elderly people; a working-class group of young mothers; a working-class, female, youth group; and a mixed-sex group of Chinese postgraduate students. In the second stage we also interviewed a group of women of African origin who were from a predominantly middle-class background.

The second type of group, of which there were seven in total, had some experience of an illness or behavior that may be related to genetics. In the first stage this included a mainly middle-class group of women in a support group for people with breast cancer; a working-class, mixed-sex, group of people in a support group for families affected by heart disease; and a mixed-sex, mainly middle-class, group of people with a range of physical disabilities. In the second stage we also interviewed a group of mainly middle-class mothers of children with Down syndrome; a mixed-sex, mainly working-class, group of mental health service users; a mixed-sex, mainly middle-class group of parents of children with autism; and a group of gay men, who were middle-class. We also include in this "type" four other mixed-sex professional groups, with some knowledge of genetics: in the first stage we interviewed a group of nurses and a group of teachers; and in the second stage we interviewed a group of students and staff in a law faculty who were interested in medical ethics, and a group of

public health medicine specialists.

The third type of group had direct experience of a genetic health concern. In the first stage we interviewed a mixed-sex and mixed-class group of parents of children with cystic fibrosis; and a mainly middle-class group of women who had undergone terminations due to foetal abnormality. In the second stage we also interviewed men from a range of class backgrounds who either had muscular dystrophy themselves or had an affected child; and a mainly middle-class group of women with a family history of Huntington disease (but no reported personal diagnosis).[9]

We asked a mixture of questions about general knowledge and views of genetics, inheritance, and genetic testing, followed by vignettes or exercises which explored specific issues, such as certain types of prenatal and presymptomatic testing. Brainstorming at the beginning of the session with "open" questions such as "what comes to mind when you think about genes/genetics?," was followed by more detailed probing on genetic research and explanations. We also used several vignettes of hypothetical testing situations (for example prenatal testing for cystic fibrosis following a carrier status test, and presymptomatic testing for other conditions such as heart disease or breast cancer). After these scenarios were presented we asked participants to think about the situation and thoughts of a person contemplating such a test, and about their views on genetic research and applications more generally. We also told the participants some of the preliminary ideas in our analyses and asked for their comments. The interviews were taped (except for one, where permission was refused) and the tapes were transcribed. The data were then analyzed through careful and repeated readings of the transcripts.

We found focus groups to be particularly useful for exploring the detail and sophistication in people's views of the new genetics, particularly because we adopted a relatively open-ended and free-flowing format. While the group situation undoubtedly prevented in some measure the disclosure that might occur in a more private encounter with the researchers, in our case, since most of the participants already knew each other, it also provided a supportive and comfortable environment in which people could express their views.[10] Lengthy discussions about the issues around the new genetics and health took place with little intervention from the researchers: people bounced ideas off one another, and explored the ambiguities in their own or others' views. The structure of the focus groups enabled the participants to engage in debates about difficult ethical and social issues, without placing too many constraints on the contours of that discussion. We now go on to explore the content and context of these discussions with respect to "drawing the line."

Where to draw the line?

In the first stage of focus groups (numbers 1–11) we started the session by brainstorming, then we asked about participants' views on genetic testing, genetic research, and the influence of nature and nurture on health and behavior. We then used the specific vignettes to generate discussion on clinical genetic services and research, and to explore the choices that people face when making decisions about undergoing tests and the responsibilities of those involved (clients, family, professionals). Key themes in interviewees' accounts concerned: expertise and choices about genetics; the role of nature and nurture in shaping health and behavior; control of genetics and of society, including eugenics; and the reliability and neutrality of scientific knowledge.

We found that "where to draw the line" with respect to genetic science and technology was an important underlying theme in all of these discussions, either directly or indirectly. This was usually expressed in rhetorical questioning of the new genetics, and demonstrated

concerns about the services currently available and the research being conducted as part of the Human Genome Project. It was also a way of expressing uneasiness about future developments. For example one person in the group of people with disabilities said:

G5R19 . . . but when it comes to health . . . the sort of research that I imagine is going on in medical terms I actually find it quite frightening because it's where do you draw the line between what's useful, what's curiosity and what's getting beyond even that . . . into . . . the development of a master race?

"Drawing the line" to exclude the eugenics policy as practiced in Nazi Germany, or the development of a "master race," was frequently discussed. For example, one member of the group of teachers said:

G3R21 It's something that starts as a good thing, [which] can, in the wrong hands, become a bad thing . . . research with genetics has managed to identify a lot of these very bad illnesses, [like] cystic fibrosis . . . [or] sickle cell anemia . . . but . . . if you get rid of those, will people then look to a layer up? . . . I think if we can find a cure for these ghastly things we should do that as long as . . . a line is drawn . . . I wouldn't be in favor of going on to search for the perfect whatever.

In these types of discussions, the concept of "drawing the line" to exclude "extreme" practices raised, but did not resolve, the large "gray area" around research and practice. For example, the above argument relies on a somewhat shaky distinction between "right" and "wrong" science, based on a separation between research and its application.[11] Defining "useful" research as research about appropriately "serious" conditions is also a difficult task. For example, in response to a question about what kinds of tests should be on offer, the group of women from the breast cancer support group had the following discussion:

G7R24 It depends where they stop. [laughter]

G7R25 "The master race."

G7R26 Yes. Yes.

G7R27 [Like] "nobody should be born if their eyes are of a certain shade of gray."

G7R28 Yes that's right. If there is anything wrong with someone . . .

G7R29 [Or] "they've got to have blue eyes." It has got to be a happy, sensible level. . . . You couldn't say that nobody should be allowed to grow up if they are only going to grow to three foot six tall or something.

G7R30 Yes that's right and have . . .

G7R31 You know or [have an] IQ of 180 or whatever. Where do they stop?

G7R32 Exactly.

G7R33 But I do think that they have to . . . it is great for . . . cystic fibrosis or something like that. But then do they test that when the baby is in the womb?

G7R34 Yes I think they do.

These participants are clearly uncomfortable with testing for trivial physical characteristics, but their discussion also shows a general uneasiness about prenatal testing and abortion, even for serious conditions.

This first stage of the focus groups raised issues about the morality and usefulness of research and testing and the responsibilities of the clinicians and scientists involved. We found that two main tensions emerged in these discussions. First, participants discussed how

to decide what research and testing was acceptable on the basis of its subject matter. This involved discussions about genetic research and the testing of "normal" traits, characteristics, and illnesses, and about how to decide on the severity of the condition in terms of "quality of life," suffering, and stigma. Second, much of the discussion concerned the appropriateness, or otherwise, of limiting the autonomy of scientists and clients of genetic services. This included discussion about what constitutes inappropriate coercion of clients and unfettered developments in genetic research. We now go on to consider these issues in more depth.

Acceptable subjects and subject matters

The first tension to become apparent in these discussions concerned making a distinction between acceptable and unacceptable research and testing, based on its subject matter. This involved discussions about what constitutes "normality," and differences in the severity of conditions in terms of "quality of life," suffering, and stigma. It also concerned the distinction between medical conditions and nonmedical (e.g. behavioral or physical) characteristics. For example, a person in the group of people with disabilities questioned the distinction between life-threatening conditions and physical characteristics:

G5R123 ... having tests or ... research into conditions that could be potentially life-threatening is valuable but it's where you draw the line? ... It's like refining a fine-tuned engine ... they just want to get it better and better ... how come it's acceptable to do genetic research into disabilities and certain conditions but ... research into the gene [that] means people have bright red carroty hair, isn't seen as acceptable? ... It's still part of people and a disability is still part of you.

This participant was expressing concern about drawing a line between life-threatening and non-life-threatening conditions. Her questioning of the medicalization of physical traits provoked concern about the medicalization of all impairments.

The difficulty in establishing firm distinctions between medical conditions and nonmedical characteristics was compounded by the groups' differing perceptions of "quality of life." For example, the relatives of children with cystic fibrosis (CF) (Group 8) and the group of elderly people (Group 2) had very different views on Down syndrome and CF.

G8R167 I think it's a difficult[y] ... with antenatal testing. You can have a lot of problems ... if you don't have a "perfect baby" ... you have the alternative to "get rid of it." ... I think it is quite difficult for somebody who doesn't have any experience of CF to be told that they have a CF child. Do they know what that really means ... how are they going to know? How can they make an informed choice? I have a CF child. I couldn't say she has no quality of life–she does ...

G8R172 If we were thinking about this genetic counseling, not just [for] CF, the general principle. Say it was a Downs baby or something like that you were told you were going to have. Although people might not know much about the detail I think it's more in common knowledge that you are talking about someone with severe mental disability ... at least it's the common impression and the child ... is visibly different which would obviously affect some people's reaction to it ...

In this conversation about people's limited knowledge about various genetic conditions and how this affects their choices, one participant compared Down syndrome with CF, and

highlighted mental deficiency and "visible" difference as reasons why people might choose to abort a Down-syndrome fetus. This contrasts with the following discussion:

G2R628 I think that different parents would . . . have different views [on CF and Down syndrome] . . . To some people it wouldn't make any difference, they would still have the child but others wouldn't for selfish reasons.

G2R630 Well I have got a granddaughter that is pregnant at the moment and she gets her test next Monday . . . she says that if there is any sign of Down syndrome she will abort.

G2R631 That's her choice.

G2R632 It's her choice . . .

G2R635 So different people have different ways.

. . .

AK Why did you say you thought it would be very different [for CF and Down syndrome]?

G2R637 Because these Down syndrome children, although you maybe have a lot of work with them, it's not health work.

G2R638 No.

G2R639 . . . I know . . . they have often got heart trouble when they have Down syndrome but I think that it's entirely different from . . . trying to work with cystic fibrosis . . . that is purely a labor of love. You've got to be very dedicated to do that. Whereas with Down syndrome, although they are maybe slow in some things . . .

G2R640 . . . they are retarded.

G2R641 They are lovely kids.

G2R642 That's the problem, they are too trusting—that's why you've got to keep an eye on them.

This group seems to have been arguing that having a child with Down syndrome might be more acceptable to people than CF because it is more manageable and the child suffers less.

While these particular differences reflect the different experience of these two groups, they also highlight the broader issue of the problem of defining quality of life and thus acceptable intervention. The differing availability of treatments or cures for genetic conditions, currently or in the future, was also a factor which undermined any potential for a homogenous view of medical genetic testing. For example, one of the nurses argued:

G6R56 . . . I mean who's to say that tomorrow they're not going to come up with some sort of effective treatment or cure for people with serious things and if we sort of say, "Well, I'm not going have this baby because of whatever they've got," and then the next day that somebody turns round and says, "Oh, we've got a treatment." That maybe sounds a bit over-optimistic but we don't know. I think that people do . . . I think that if you were pregnant you would be thinking that.

The potential of new scientific and medical developments in the understanding and treatment of disease and illness makes the "choices" around genetic testing and abortion even more complex. We now go on to explore the discussions around autonomy and responsibility in more depth.

Autonomy and responsibility

The pattern in discussions about the acceptability of genetic testing in the first stage of focus groups involved routine appeals to the importance of "individual choice," alongside critical discussion of the current choices available to clients of genetic services, particularly the amount of support and care that is available to the sick and disabled. For example, in the focus group of mothers, the following discussion took place:

AK . . . Do you think people have got a responsibility to take the tests, that people should be taking the tests?

G1R156 Nut.

G1R157 . . . it's up to . . . the individual person how . . . concerned they feel, if they think they're gonna be a carrier then . . . like A. was saying, through family background . . . then maybe they should take it but . . . it's a very individual decision, you have to have the information and I think we don't get enough information . . .

G1R158 And then there's this attitude in society as well that you shouldn't produce a child that's gonna be a burden on society, which is appalling.

G1R159 I mean, these choices, . . . Down syndrome, they say that if it's Downs then you abort, abort, abort, abort, I mean what for?

G1R160 'Cos it's this attitude.

G1R161 "Not normal."

G1R162 . . . this attitude that it's going to be a burden on society. 'Cos you as a parent are not going to live for . . .

G1R163 As long, so they've got to look after it, which is appalling.

In this discussion individual choice was clearly valued, but not uncritically, because there was a recognition of the social pressures that compromise an individual's autonomy. In general, participants' accounts of the choices with which clients of genetic testing are faced involved such sophisticated discussion. Several groups talked about cultural difference and the normative nature of our value judgments about medical and behavioral characteristics, contrasting as an example British and Chinese attitudes to termination on the basis of the sex of a fetus. However, cultural relativism creates its own dilemmas and problems, as the following discussion in the group from the support group for women who had terminations due to fetal abnormality shows:

G10R96 . . . and is it right that the law has to step in at some point and say "no that's not acceptable" or should it be more of a free choice?

G10R97 Again . . . we're trying to enforce on other people what we find acceptable. I mean we find it absolutely incredible that people would terminate because they're having a female child but . . .

G10R98 . . . in people's cultures there's sometimes very valid reasons for them having sons rather than daughters . . .

G10R101 . . . we are interfering in their society . . .

G10R102 Well I just find it personally abhorrent that anyone would think of ending a pregnancy because the child that they were carrying wasn't the right sex. I mean I just can't imagine anyone doing that.

G10R103 That's right but then if that child is going to be born and put in a dying room . . .

G10R106 Yes. I mean I think the [law] does have to be . . . pretty strict about what is "seriously handicapped" . . .

G10R108 . . . whether or not it is tight enough, I don't know, but it's right that the law should be . . . .

G10R114 . . . but then if you say, "you can have a termination for fetal abnormality only if your child has these illnesses" then . . .

G10R115 [It's] discrimination.

People in the focus groups were ambivalent about legal and societal controls on individual decisionmaking on abortion. Here the importance of setting limits on abortion for serious conditions was counterposed with the difficulty in reaching an adequate definition of "seriousness." Other groups also discussed social control and individual autonomy. For example, the heart disease support group members had the following discussion:

G4R138 . . . I can understand that people . . . go in and say, "We'll take a blood test," but if they are suddenly told they've got a hereditary disease, whether it's cystic fibrosis, haemophilia, or anything else . . . if they decide to have a family I dinnae like this idea where they start playing the roulette wheel on even money . . . are they going to turn round and say to the doctor, "Right give me a amniocentesis test . . . I'm sorry this one is going to have the gene that I don't want—abort," and have another attempt. I think once you decide to go ahead and start your family knowing that you are carrying a faulty gene, or an illness, or something like that . . . on your own head be it.

G4R139 I think so G. I would agree with you there.

G4R140 . . . the idea of aborting . . . as I say it's back to the Hitler adage—let's have the perfect race.

G4R141 I think it's a difficult one. Very difficult.

G4R142 This is it. I think it's got to be individuals themselves. The individual couples, to decide.

. . .

G4R145 I think it's personal too.

G4R144 I think, as G. says, there is a bit of the master race coming in here, I mean this is probably the start and then they go to other diseases and test, "Oh look, your child has got this disease and you've got that one," and I think they are trying to get the perfect . . . Hitler . . . the master race.

G4R145 Yes.

G4R146 . . . they can do some tests now that they can tell the sex of kids and you have got certain religions . . . where, "it's a female child—we'll abort it," and, "you can't have any more female children—we'll just abort it?!" . . .

This group argued for individual choice and responsibility but did not reconcile this with their concerns about the cultural values that affect people's choices by shaping the provision of genetic tests. Personal choice was considered important, but not in an unfettered way: social control was seen as both an appropriate brake and an undesirable pressure in relation to individual choice.

Interviewees in groups 1–11 also tended to stress the importance of high-quality and detailed information's being provided by professionals to clients of genetic services in order to enable informed decision making. This raised further questions about the autonomy of clients when they are dependent on expert information. It was argued, for example, that sufficient information was not always provided, but also that potential users of genetic testing were obliged to search out and take on board information and advice from the medical profession. For example, a mixed-sex working-class group of elderly people discussed information about testing:

G2R381 I think that you have got to ask your doctor. I don't think you [should have] got to wait for him to give you the information.

G2R382 You get a lot of information in these woman/mother books.

G2R383 Well some of these doctors are quite abrupt if you ask them to tell you as much as they can. They just say, "Do what I'm telling you."

G2R384 Yes, "I've no' got the time. Just get on with it."

In this discussion people are seen as having a responsibility for finding out information, yet professionals are seen as not providing it properly. This juxtaposition at once involves the client's actively seeking information and passively receiving inappropriate dismissal.

There was also significant variation in different groups' and different individuals' accounts of the extent to which information should include technical details, advice and guidance, explanations, or details about the social and ethical issues raised by genetic testing. Once more this meant the groups questioned the neutrality of professionals' information and the autonomy of clients or patients. Some people felt that people should be *advised* to participate in carrier testing before pregnancy, because it avoids difficult decisions about abortion. For example, one person in the cystic fibrosis support group argued:

G8R207 But I think a lot of couples nowadays ... I mean they decide when to have children, you know I think maybe they should be advised ... Okay, you are advised to take folic acid, you are advised to take this, that and the next thing. Why not have advice ... [to] go and get yourself tested for a carrier for this disease and that disease. That would I'm sure cut some of it down.

Others, such as one woman in the group of teachers, were overtly skeptical about the value judgments implicit in the entire testing procedure and expressed concerns about the extent to which people were pressured to comply with testing:

G3R160 ... I think the medical profession generally are not very good at explaining things in a language that everybody can understand and I think they can put a lot of pressure [on people]. I think things have moved on, but I know when I was ... pregnant ... there was pressure if I wanted this test that I had to have an abortion if it was abnormal ...

These difficulties in defining an appropriate level of individual autonomy, and social and professional responsibilities, were compounded by concerns about the imperfections and loaded nature of supposedly "neutral" information about a person's or their fetuses' genetic status. In particular, the problem of inaccuracies in diagnoses or the inability to distinguish between differing degrees of severity of a particular condition prenatally increased participants' skepticism about freedom of choice in genetic testing.

Whilst participants' accounts sometimes involved concepts similar to those used by scientists and clinicians, they also tended to highlight problems with research and testing in an open and sophisticated fashion. Although it is important to recognize that lay people's

accounts can, at times, be factually incorrect and appear confused, this does not detract from the overall detail and depth of their analysis. As we have shown, the tensions raised in relation to individual autonomy, social responsibility, and control, and the seriousness of conditions which tests may be developed to eradicate, are fundamental to deciding what constitutes acceptable practice and research in genetics. After completing this first round of interviews and analysis, we therefore felt that it was important to investigate and analyze lay views on these issues further, through more detailed discussion and probing. We now go on to discuss our subsequent approach.

Exploring the line

In the second stage (focus groups 12–20), we wanted to explore the tensions outlined above in more depth, and decided to develop the groups' tendencies to challenge their own assumptions by encouraging rich and analytical dialogue among participants. We therefore altered the interview schedule to allow us to unpack these analytical themes further. We also slightly reduced the numbers in the groups to an average of four. This allowed for greater input from each participant and gave us more insight into the ways in which opinions are formed and revised.

One of the changes involved the design of an exercise to allow us to explore the issue of "drawing the line" in more depth. This involved a set of ten disease/trait categories associated with the new genetics. We wrote these on separate cards, introduced them toward the end of the session, and asked people to use them when thinking about "where to draw the line" with genetic research and testing. It was felt that at this point in the interview participants would be sufficiently relaxed and engaged with the issues to deal with such a task. This exercise was only practical in seven out of the nine groups. In the group involving public health professionals, the participants were unusually antagonistic to the interview; such a detailed exercise seemed inappropriate, as many of the responses to other questions had been defensive or dismissive. In another group of men with muscular dystrophy (or a child with the condition), it was not possible to conduct the exercise due to time constraints.

The exercise was introduced with an explanation about how it came about, noting the references to drawing the line in the earlier groups and the difficulties in putting this into practice. It was explained that we did not anticipate firm answers to the question of where to draw the line, but that we wanted participants to tackle directly the difficulties with any attempts to do so. The prompt was left deliberately vague in order to generate an open-ended discussion. Participants were asked to talk about the acceptability of genetic research or testing using the following categories: Down syndrome; IQ; alcoholism; mental illness (e.g. schizophrenia and depression); homosexuality; thalassemia; susceptibility to breast cancer; Alzheimer's disease; cystic fibrosis; and blindness. A short explanation was given for Thalassemia (a blood condition which causes anemia and can be very serious in its major form, affecting mainly Mediterranean and Asian groups) and it was noted that Down syndrome is not strictly a genetic condition (but a chromosomal abnormality and therefore not "inherited") but that it was included because it is commonly tested for prenatally.

Nearly all the groups responded animatedly to the exercise, as we had hoped. The participants moved and grouped the cards, changed their positions, and questioned and challenged their own arguments. Although we found that there were important variations in their accounts, the groups tended to approach the exercise in remarkably similar ways by adopting particular patterns of explanation, for example. We now go on to explore the

similarities and differences in the groups' responses to the issue of "where to draw the line with the new genetics."

Acceptable subjects and subject matter: testing

All of the groups that participated in this exercise responded to the initial broad question by focusing on prenatal testing and abortion. This was seen as by far the most contentious and problematic issue. Very quickly, in most groups, the cards for homosexuality and IQ were focused on, and in some cases moved to one side, and arguments were put as to why prenatal testing for these attributes would be unacceptable. Several participants said they found the presence of the card for homosexuality offensive and challenged the researchers about their motive for using it (in response to which it was explained that the recent controversial research into the so-called "gay gene" had prompted its inclusion).

Initially the participants tended to argue that the way to define acceptable and unacceptable practice in this context was to distinguish between medical conditions and nonmedical or behavioral characteristics—a tension that we noted earlier in interviews with the first set of groups. It was variously argued that it would be wrong to test prenatally for homosexuality and IQ (and sometimes for alcoholism and mental illness) because there was doubt about their genetic basis; they were not illnesses—it was prejudice and stigma that defined them so; they did not sufficiently diminish one's quality of life to be considered appropriate for intervention; their definition and manifestation varied according to the cultural and social context; and they involved a huge range of "symptoms" or attributes. For example, the group of women of African origin had the following conversation:

G15R302 Well I would take this one out for a start.

G15R303 Yes. [agreement]

AK So that's homosexuality.

G15R304 Homosexuality is a way of life ... it's nothing to do with, it's not a disease or illness, it's not going to kill you.

AK Right so you're not keen on that?

G15R305 No.

G15R306 We'll take that one out as well I think.

G15R307 Alcoholism.

G15R308 Yes I don't think that has anything to do with genetics.

G15R309 We will have that one out as well quite quickly [IQ].

G15R310 Yes because a lot of that is nurture as well.

G15R311 Environmental.

G15R312 And there is an element of choice [with alcoholism].

Another group of women in a support group for families with Huntington's disease were more ambivalent:

G14R309 Well personally I think there's only a point [in testing] ... if we're talking about a cure. Now for example homosexuality maybe some people don't want a cure for that.

G14R310 I think that's just not worth talking about.

G14R311 Now there's this Down syndrome one the dilemma is if [you] tested positive. I mean there are some lovely little Down syndrome kids . . .

G14R319 But on the other hand there are some types of Down syndrome . . .

G14R320 Really bad.

G14R321 That can [be] really bad. Now if you had a child like that and you thought there could be a cure for it you would be grasping at straws but I think things like IQ . . .

G14R322 Yes IQ and homosexuality.

G14R323 Well unless they can . . . you don't need a cure for IQ do you unless it's a particularly low IQ.

G14R324 Well . . . this homosexuality . . . when I was young I . . . thought that . . . if somebody was homosexual they were born with an extra X . . . chromosome or minus one, I don't know how it works . . . I thought you were just born like that . . . but nowadays people announce that they're homosexual.

G14R325 Yes because it's more acceptable nowadays it's more..

G14R327 . . . it's fashionable to be homosexual.

G14R331 I'm thoroughly confused with that one, I don't know.

G14R332 But . . . if they could come up with a cure for these things yes test it. . . . do as much testing and find a cure.

G14R333 If it's a debilitative illness that can ruin your life then by all means go ahead and try and find it.

In this discussion the group found it difficult to decide whether a test or cure for homosexuality would be acceptable. There was confusion about the causes of homosexuality, as well as ambivalence over whether or not it needs a "cure." Similar issues emerged in the part of their discussion about the variations in the severity and social acceptability of Down syndrome.

As in groups 1–11, identifying conditions and traits that ought to be tested for by assessing their medical qualities and severity proved to be difficult. For example, as the criticisms of prenatal testing for homosexuality or IQ developed into a discussion about the relative definitions and experiences or quality of life of gay men or people with low IQs, queries were raised about some of the other so-called medical conditions on the list—especially Down syndrome and blindness. For example, this discussion took place in the group of parents of children with autism:

G16R229 . . . you could see that as a classical case where corrupt practices would come in. The parents would find out . . . that there was a test to find out if a child is homosexual. It could be they're completely homophobic people and . . . there might be some doctor somewhere that would give them . . . something that changed genes. . . . You could create a test to find that out . . . and then it may go on from there to finding some way of changing them.

G16R230 If there wasn't any of these types of people in the world it would be really boring.

G16R231 What do you mean . . .

G16R232 If there was testing for everything. You'd get termination for all different things.

G16R233 Well I mean . . .

G16R234 We'd all end up the same. . . .

G16R238 You're going down the road to the "master race" . . . if you were . . . to go down to the blind school down in Craigmillar Park and say "oh we've discovered a test for blindness and we would give it to parents to see if they want a termination." You can just imagine what their reaction would be.

G16R239 Perhaps we are assuming that . . . the parent would want a termination rather than just being prepared for what they're getting.

G16R240 . . . my cut-off point would be give them the test so that they could prepare for it but for the majority the test shouldn't be given in order to choose . . . a termination.

In this discussion questions were raised about medicalization and genetic determinism, as well as stigma and tolerance of difference when participants compared lifestyle choices with physical impairments. The group clearly found it difficult to argue that people should not have tests, presumably because of their commitment to individual autonomy. However, they settled upon an unlikely solution—the banning of abortion—a choice that raised further questions about inappropriate constraints on individual autonomy.

Participants frequently discussed the problems involved in defining "quality of life." They drew on their own expertise and knowledge about certain conditions to question prevailing assumptions about quality of life, as in the following examples. First, one woman in the group of parents of children with Down syndrome tried to define testing and abortion on the basis of "quality of life":

G12R204 . . . You can't really draw a line in one place but [you can ask] . . . what's going to cause pain and suffering? . . . is the quality of life . . . for a child going to be abysmal and life is going to be short and families are going to be thrown into sadness and disarray . . . to pick on extremes like that and then the line is going to be drawn somewhere . . . with . . . a condition like Down syndrome what you have really is people . . . who you know in themselves aren't suffering at all. They are healthy people . . . hopefully happy people . . . but when we were saying earlier where we want to jump on press statements where they say that a "Down syndrome sufferer did this that and the next thing" . . . the public attitude to homosexuality is . . . on that scale too . . . in my opinion there is nothing wrong with being gay. Where you do run into trouble is if you've got a population who are unaccepting and who are prejudiced against homosexuality but that would certainly be no reason to be getting into the genetics of a condition. I mean that's a very good reason to get into . . . public . . . education.

Through a process of reflection about quality of life, this participant went on to compare prejudiced views of Down syndrome and homosexuality. Similarly, in the group of gay men, after it was suggested that because Down syndrome was stigmatized, the provision of abortion for Down syndrome was acceptable, the group went on to discuss how some people might extend the analysis to homosexuality, as it is also stigmatized:

G20R282 . . . I think some groups could have put this [homosexuality] over there and somebody could have said, "well imagine you're a single mother in Westerhailes in a high-rise block and your son can be born homosexual and somebody says 'turn off the gene or have an abortion.' " We could easily be

over that side. That's what I was thinking if you were speaking to people with Down syndrome [they would have a similar perspective].

G20R283 But at the moment there is a specific test for Down syndrome.

G20R284 But how far is it going to be, going back to my science fiction realms, before there could be one for us?

Quality of life, as discussed by these groups, went beyond a consideration of impairment caused by the condition, to issues of stigma and discrimination, considered equally, if not more, debilitating. Such an awareness of both medical and sociological processes made the debate about drawing the line even more complex. Individuals' own values and prejudices also entered the equation. While the majority of people in our study were critical of genetic testing and abortion of homosexual fetuses because they saw it as homophobia, some did argue that there was a place for such a test:

G16R247 The homosexuality one that we were talking about. If you could identify the gene that was causing it and you then had a procedure that could change that to make them heterosexual. Well as a parent I must admit that if I had that option . . . yes I would be quite interested in that test being undertaken if you could actually change it to heterosexual. But that is not being anti-homosexual, it's just that it could be that there is better prospects if you're heterosexual . . . obviously well we all know people who are gay but I would probably like to think that my own boy, who is twelve, would be heterosexual. Now if one goes back to when he was born or before he was born if there was some tests I would be quite interested to find out if he . . . was susceptible to homosexuality . . . if there was something that could amend the gene structure . . . to make him definitely heterosexual . . . I would definitely be in favor of that.

As well as showing some of the ways in which prejudice shapes people's perceptions of what would or would not be acceptable practice in genetics, this quote also highlights another important aspect of these participants' discussions: appropriate testing was often defined in terms of the availability or necessity of a treatment or cure for the condition/characteristic in question. In all of the focus groups it was argued that testing should be available if a cure or a treatment was available and the illness was "debilitative," as in the above quote from the group with a family history of Huntington's disease shows. Concerns were also frequently raised about testing when no cure was available because of the "burden" of anxiety such information might bring. There were, for example, considerable doubts raised about any kind of presymptomatic testing for conditions such as Alzheimer's disease or breast cancer. It was felt that because these conditions were late-onset, the quality of life of people who might develop them could nonetheless be good. This was, however, counterpoised by appeals to the benefits of certainty (as opposed to unnecessary concern about one's genetic status) and the chance to "be prepared" for the onset of a condition, or even to take remedial steps to lessen or subvert its impact.

Research

Discussions about the values in testing led on to questions about research into genetics. The emphasis was also very much on cure, rather than on the development of specific genetic tests. For example, in the group of women of African origin, one woman said:

G15R352 Yes I was just thinking that what seems to be the issue is the assumption that if you can find a genetic test that you can prevent the occurrence of the disease

> and actually that's not what I would expect it to be about [I would prefer] that it would be a basis for understanding the disease so that you can better treat it or you can better help people . . . That would seem like a more desirable way of conducting the research.

These discussions about research were also marked by a tension between whether research had intrinsic value because it generated knowledge, or should be conducted on the basis of need. In cases where no need for intervention was seen, there was often no perceived need for research. For example, the law group had the following discussion:

AK What about doing the research then? If they're not going to apply it then why bother to research it? *(This probe relates to the previous discussion among the participants.)*

G18R237 Well that was my point about not opening the door but I think equally it would be just as useful to have . . . an act of Parliament statute specifying what prenatal testing can occur. That would be another point at which you could control it. So I guess we're just looking at the stages in the process, at what point you introduce the legal control.

G18R238 But, sorry, I think that there is a strong imperative to seek the truth and in the desire of humanity to understand itself better . . . I think that's its value. Now I realize that that is quite a naive thing to say because if they are not going to be able to develop the testing . . . then they are probably not going to do it but I have got a . . . big problem in saying . . . "no we shouldn't seek the truth because that might be abused and maligned," you're right it might be abused and maligned but I think we can . . . draw the line, to use your phrase . . . later on.

Although participants did not account fully for the social context of genetic research and practice, they did recognize the way in which funding priorities shape research and its application (in treatment and diagnostic testing). They also discussed the difficulty with removing testing facilities because this would limit some people's choices—an issue which we will now explore in more detail.

Autonomy and responsibility

As in the discussions by groups 1–11, appeals to individual choice often occurred, frequently in the form of a "default" position, mentioned when the participants were having difficulties setting parameters for testing. "Individual choice" was seen as an ideal rarely met in practice. Participants queried the medical and social or cultural pressures to comply with testing and to have abortions should the test be positive. In all twenty of the focus groups, concerns were raised about the way in which the line between "acceptable" and "unacceptable" practice is constantly shifting as more and more conditions and characteristics are linked with genetics. In the second stage of focus group discussions we were able to explore this in more depth, and found that participants were concerned about the lack of control people had over the implementation and development of genetic testing. Discussion about the "snowballing effects"' of testing, or the "cascade of intervention" and the entrenchment of genetic tests, featured in people's accounts. For example, one person in the group of parents of children with Down syndrome commented, when talking about cystic fibrosis carrier testing:

G12R177 . . . we know with Down syndrome . . . to begin with it may not seem quite big a deal because you know you give a specimen . . . and [with CF] you . . . scrape from the inside of the mouth . . . and that's no big deal the two partners do that and then all of a sudden you'd be handing over all that knowledge about yourselves and then you . . . if you do go on to have a baby then the staff surrounding you are supporting you, they would have that information and you know you're taking a chance . . . you'd be handing over, all that information over . . . about yourself.

These discussions also emphasized the role the provision of care and support for sick or disabled people plays in people's decision making about testing and abortion. Participants argued, for example, that testing takes place at the expense of proper care, and that the balance should be recast to make people's decisions less constrained. The group of gay men had the following discussion:

G20R291 . . . I don't think the test should be offered just as a test . . . there has to be support in all manner of things there shouldn't [just] be the option of, "have a test, if it's positive would you like an abortion?" [It should be] have a test and if it's positive what would you like to do . . . we have a social services group that can offer you this . . . . We have people who will come and visit you and help you with all sorts of things . . . money for special housing . . . there should be a total option for that if that's what they are going to do . . . there has to be a much greater freedom of choice . . . I don't mean the choice in taking a test but a choice in saying if as a mother you really want to keep the baby then other factors must kick in . . .

G20R293 Unfortunately maybe the level of support that people need is as much science fiction as are a lot of other things.

In addition to emphasizing the importance of social support, and how information about this can affect people's decisions, participants recognized the way holding back information also shapes people's decisions, as in the following discussion in the law group:

G18R223 I would deny the right to an abortion on the grounds of homosexuality or IQ.

G18R224 Well . . . I'm not sure that I would . . . necessarily go that far. I might say we will not make available the testing for homosexuality and IQ.

G18R225 Well I would agree with that.

G18R226 Yes.

G18R227 Yes [agreement]. So that it never becomes an issue.

G18R228 So that none of us are in a position to make a statement about the quality of life . . .

G18R230 . . . of those people.

G18R231 Well that's based on social prejudice and not medical factors.

G18R233 But the difficulty is with banning abortion under any circumstances. If somebody desperately desperately doesn't want to have a homosexual child then they'll end up going to backstreet butchers.

It is clear from these focus group discussions that issues of testing provision, treatment, and care cannot be disassociated from discrimination and stigma in society; nor can medical and nonmedical conditions or characteristics be clearly separated according to quality of life. The amount and type of genetic information was also seen as socially powerful, in

the sense that it contains cultural values and affects social behavior. The participants were strongly aware of the social context of genetics and the decisions and choices it invokes. We now go on to consider what this might mean for policy making about the new genetics.

Further discussion and conclusions

Throughout our analysis we have demonstrated the tension between individual autonomy and social constraints and the difficulty in deciding which conditions and traits it would be acceptable to research and to test for, particularly when using distinctions between medical conditions and nonmedical characteristics associated with genetics. We have argued that this means it is not possible for lay people to draw any simple lines between acceptable and unacceptable research and practice in the new genetics. When we explored these issues further, through additional data collection and analysis, the tensions in lay people's accounts became even more significant. Differences in the amounts and types of information and advice about genetic testing, treatment, and social care, and differences in people's perceptions of stigma, suffering, and quality of life were raised by lay people as they grappled with "drawing the line." Their appreciation of the interplay between cultural and subjective differences in the perception and experience of suffering and stigma brought to the fore the difficulty with using "quality of life" as a justification either for or against genetic testing and abortion. These discussions also highlighted the complex links between research, treatment, and care. Participants found research and testing with the aim of developing or providing treatment for genetic conditions more palatable than abortion. This was especially so when more clearly defined medical conditions were concerned. However, their appreciation of the "cascade of intervention" and the lack of care for people affected by genetic conditions meant that any clear boundary between good and bad practice remained elusive and slippery, especially when nonmedical conditions and traits were discussed.

Focus groups such as the ones detailed here provide an enabling environment where diversity and ambiguity in people's views can be thoroughly explored. This method also gives us an insight into how social location shapes people's views, and provides potent examples of how people's prejudices come into play when they discuss these difficult issues. Such open and sophisticated discussion contrasts sharply with survey methods which, at best, suppress ambiguity and, at worst, manufacture consensus. Rather than merely illustrating once more the ways in which lay people are confused and ill-informed about genetics, this method facilitated meaningful discussion about the many gray areas of genetic science and practice with which publics and policymakers must grapple. This research also reinforced our sense that the quality of discussion is at least partly an outcome of the quality of the questions. Without the right mix of open and challenging questions, policy consultation and discussion is likely to be stagnant and conservative. In contrast to conventional measures of lay knowledge and opinion, the results presented here provide a strong case for greater lay involvement in policy discussions about the new genetics.

Of course, this does not mean that the research presented here can be used to make firm recommendations about where to draw the line with genetic research and testing. Instead, the entire process has highlighted the interdependency and blurred distinctions between autonomy and social responsibility and medical and nonmedical categories. This leads us to reflect further on how policy discussions and decisionmaking about genetics might be improved.

When we compare the lay accounts presented here with the views presented in official (including professional) policy documents and discussions, it is striking how boundaries between autonomy and responsibility or medical and nonmedical genetics are unpacked and

challenged in the former, yet adopted and reinforced in the latter.[12] Although it would be wrong to assume that such formal discussions have no element of flexibility, it is nevertheless important to recognize that this flexibility is carefully managed. Indeed, we would suggest that the flexibility evident in the boundaries drawn in formal and professional accounts of the social context of the new genetics gives these accounts weight, whereas the flexibility in lay accounts undermines formal and professional accounts.

We have argued elsewhere that geneticists' discursive boundaries are replicated widely in government and other reports about the new genetics. We have also argued that these boundaries function to protect professional autonomy.[13] For example, professionals frequently appeal to the importance of individual choice (as did many of the lay people in our study). When professionals make these appeals they often contrast their present-day, mainstream practices with those of the past or the future, where social constraints, such as access to genetic information by the insurance industry, might limit clients' autonomy. Not only does this portray current, mainstream practices as supporting the "gold standard" of individual choice for clients, it also casts coercive influences as outside the clinic walls. Claiming to protect and promote clients' autonomy actually protects and promotes professional autonomy, as it focuses attention away from the clinic to the wider society.

In contrast, when lay people discussed autonomy in this research, their arguments tended to highlight the flaws and contradictions in these type of boundaries. This is especially true when lay people reflected on what influences clients' decisions. When they acknowledged the medical, structural, and cultural factors that shape clients' decisions, the lay people in this study did not tend to disassociate these constraints from the clients' decisions, the counseling process, or the clinical services on offer. Instead, their accounts suggest that they saw these issues as inextricably linked. These lay people's accounts were also more diverse than those of professionals because they did not, in the main, either share professionals' resources for or interests in protective "boundary work." This means that their discussions involved looser commitments to boundaries and, to a certain extent, a more insightful and open-minded approach to the tensions these boundaries can mask.[14]

Such appreciation of the tensions in professionals' discursive boundaries is not indicative of a lack of clarity in lay people's thoughts and arguments; nor does it mean that they would be unable to contribute to policy discussions. Rather, by moving beyond the uncritical reproduction of professionals' discursive boundaries, we suggest that lay people's accounts could be an important resource for critical discussion about the new genetics. This is not to say that lay people do not, or would not, adopt certain aspects of geneticists' discourse when discussing the social context of genetics. However, their critical reflection about the boundaries in geneticists' and current policymakers' accounts is more significant. We prefer to concentrate on the more novel and stimulating questions about genetic research and testing that lay people raise and to think about how to use these to facilitate more sophisticated and diverse discussion and debate.

Our research also clearly shows that it is important to take account of the differences in lay people's views about today's genetic science in policy making. An awareness of how people's social location shapes their views would also help us to understand stigma and prejudice more critically. It may also help people to confront the social inequalities and cultural values that are reflected in contemporary genetic science and technology. This is, of course, but one part of a much wider discussion which needs to take place about the responsibilities of professionals and publics. Greater lay involvement in policymaking discussions about science requires that the many publics that make up society recognize and embrace their responsibility for science and the conditions in which it is produced. After all, scientists and clinicians cannot, and should not, be solely responsible for the way in which

cultural values and social structures are reflected in their knowledge and practice. Perhaps most important, publics and professionals need to face up to the prejudice and stigma that people with disabilities, and other marginalized groups, experience—groups who are so often the topic of genetic science.

At present a narrow and privileged group of people are involved in making decisions about genetics. This group operates with a set of ethical and moral commitments which reflect and reinforce their privileged position in science and government. The richness and diversity of many people's views and experiences of genetics ought to provide both the topic and the resource for more sophisticated and accountable policy making about genetic science and services, policy making that challenges privilege, inequality, and discrimination.

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References

1 Anne Kerr, Sarah Cunningham-Burley, Amanda Amos, "The New Genetics and Health: Mobilizing Lay Expertise," *Public Understanding of Science* **7** (1998) no. 1: 41–60; Jon Turney, "The Public Understanding of Genetics: Where Next?" *European Journal of Genetics and Society* **1** (1995) no. 1: 5–20; Brian Wynne, "Knowledges in Context," *Science, Technology, and Human Values* **19** (1991) no. 1: 1–17; Brian Wynne, "Misunderstood Misunderstanding: Social Identities and Public Uptake of Science," *Public Understanding of Science* **1** (1992): 281–304; Brian Wynne, "The Public Understanding of Science," in *Handbook of Science and Technology Studies*, eds. Sheila Jasanoff, Gerald Markel, James Petersen, and Trevor Pinch (London: Sage Publications, 1995), 361–88.

2 Rachel Iredale and Marcus Longley, "Citizens' Juries: Getting Non-Scientists Involved"; Unpublished paper, 1997, University of Glamorgan, Wales; Aidan Davison, Ian Barns, and Renato Schibeci, "Problematic Publics: A Critical Review of Surveys of Public Attitudes to Biotechnology," *Science, Technology, and Human Values* **22** (1997) no. 3: 317–48.

3 Kerr *et al*, "The New Genetics and Health."

4 The project was funded under the ESRC's Risk and Human Behaviour Programme, 1994–97, Grant No. L211252003.

5 Kerr *et al*, "The New Genetics and Health."

6 Anne Kerr, Sarah Cunningham-Burley, and Amanda Amos, "The New Genetics: Professionals' Discursive Boundaries," *Sociological Review* **45** (1997) no. 2: 279–303.

7 The notation beside any direct quotes specifies the group number (G1–G20) and the participants' responses (R1, R2, etc.)

8 Sarah Cunningham-Burley, Anne Kerr, and Stephen Pavis, "Theorising Subjects and Subject Matter: The Challenge of Focus Group Research," in *Developing Focus Group Research: Theory, Practice and Politics*, eds. Rose Barbour and Jenny Kitzinger (London: Sage, 1998, forthcoming).

9 While this summary provides a useful guide to the types of groups we interviewed, it does not account for the different levels and types of experiences that members of the groups had of genetics or science. For example, the group of nurses had different amounts and types of experiences with genetics, and people in some of the groups had formal science training.

10 Cunningham-Burley *et al*, "Theorising Subjects and Subject Matter."

11 This is a distinction which often appears in scientists' accounts where they are downplaying their responsibility for the consequences of research. See Kerr *et al*, "The New Genetics: Professionals' Discursive Boundaries"; Anne Kerr, Sarah Cunningham-Burley, Amanda Amos, "Eugenics and the New Genetics in Britain: Examining Contemporary Professionals' Accounts," *Science, Technology, and Human Values* (1998, forthcoming).

12 Here we draw on our previous analysis of professional accounts, presented in Kerr *et al*, "The New Genetics: Professionals' Discursive Boundaries"; Anne Kerr *et al*, "Eugenics and the New Genetics in Britain." See also House of Commons Science and Technology Committee, *Human Genetics: The Science and Its Consequence* (HMSO: London, 1995); Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (Nuffield Council on Bioethics: London, 1993).

13 See Kerr *et al*, "The New Genetics: Professionals' Discursive Boundaries"; Kerr *et al*, "Eugenics and the New Genetics in Britain."

14 It should be noted that although we interviewed professionals on a one-to-one basis and their accounts might have been more reflexive if they had been in groups, their shared professional values and their tendency to repeat similar arguments in a variety of forums means that our argument stands.

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