

3 Genetic Ambivalence: Expertise, Uncertainty and Communication in the Context of New Genetic Technologies

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Introduction

Recent developments in genetics have provoked considerable controversy about the patenting of DNA, the confidentiality of genetic data and the provision of genetic tests directly to consumers. A range of patients, professionals, industries, policy makers and publics are increasingly closely involved in negotiations about these issues, engendering what some commentators have described as 'genetic citizenship' (Ginsburg and Rapp 2001, 2002). The rights and responsibilities of donors, researchers, and service providers in relation to biobanking, susceptibility testing, preimplantation genetic diagnosis, and genetic patenting raise issues that are described by sociologist Nikolas Rose as 'the politics of life itself' (2001). The complexity of expert systems, the rise of patient activist groups, and the commercialisation of the public sector are part of this story, but the endemic risks and uncertainties of new technological developments are also relevant (Lock and Farquhar 2005; Rapp, Heath and Taussig 2001; Rapp 2003).

The problems of 'genomic governmentality' – for example how to involve more and different constituencies in the development, regulation, and application of new genetic technologies – rely crucially on processes of communication in order to achieve maximum inclusiveness and democratisation. At the same time, many people, including experienced 'genetic professionals' in fields such as genetic screening, do not feel confident 'taking a stance' in relation to debates over the use of genetic technology, the devolution of public resources to biobanking, or personal decisions, such as how much genetic information a couple might want to acquire about their potential offspring in the midst of an ongoing pregnancy. This is not surprising, since many of the situations connected to new genetic technologies are unfamiliar and may be daunting or simply awkward. However, while much public debate and media coverage of the new genetics is organised in terms of

either-or positions, for-and-against debates, or starkly polarised clichés – such as 'the reality vs. the hype' – data from an increasing number of studies of social encounters with new genetic knowledges and technologies reveals that few people, be they users or providers of genetic information, experience its challenges and demands in such 'either-or' terms. Indeed, data from studies from many countries illustrates that ambivalence and uncertainty comprise a significant dimension of many people's relationships to genetic information and technology. While this is by no means the only pattern, it is a significant one that we discuss with reference to several recent studies, and our own research, below.

'Ambivalence' is traditionally defined as conflicting or opposing impulses that are simultaneously present. In this sense, ambivalence conveys the sense not only of mixed emotions, but of *opposite and coincident views or feelings*. A second, equally common, definition of ambivalence is confusion, uncertainty, or hesitation deriving from lack of a clear direction. Hence, the adjectives 'ambivalent' and 'ambiguous' are defined in terms of being unclear or uncertain. 'Am*bi*' is the prefix denoting 'both' as in 'ambidextrous' – capable of using both hands. Ambivalence is thus similar to equivocation in denoting the presence of more than one opinion or feeling. Significantly, this lack of singularity is often perceived negatively, and on the whole it could be said that ambivalence has a negative connotation. To be ambivalent, and have 'too many' views, is to be deficient in the powers of discernment, judgement, or knowledge capable of resolving them into the 'right' one.

Consequently, synonyms for ambivalence include inconsistency, uncertainty, hesitation and thus unreliability. In terms of expertise, authority, knowledge, judgement, honesty, professionalism or reliability, ambivalence, like ambiguity, would seem to be an anathema. Synonyms for 'ambidextrous' include 'false-hearted', 'duplicitous', 'double-dealing', 'perfidious', and 'crafty', much as 'equivocation' can be seen as 'talking out of both sides of their mouths', being 'two-faced', or not knowing one's own mind.

However, much recent analysis of data collected in the midst of what can be described as the socialisation of DNA – meaning its entry into many more technical and non-technical dimensions of our lives, from clinical and forensic uses to Hollywood film and car advertising – is that ambivalence has a number of positive connotations, as well as negative ones. Thus, in contrast to the view that the 'best' and 'most correct' relationship to genetic information is simply one of clarity, accurate understanding, and rational decision making, ambivalence is in some situations a desired goal of communicative outcomes concerning genetic information, for example when full disclosure might be destructive or unwanted. Similarly, the connotations of indecisiveness, inadequate comprehension, or lack of direction that may be attributed to 'ambivalent' feelings or views are countered in many studies that conclude with calls for inclusion of a greater diversity of

voices and positions to maximise the range of different, often conflicting views, in genetic decision-making contexts such as the formulation of ethical protocols for biobanking.

These 'positive' correlations with ambivalence in the context of the new genetics – whereby ambivalent responses are seen less in terms of being inadequate, immature, and irrational and more in terms of being wise, inclusive, and empathetic – raise many questions that will be the subject of future studies. In this chapter we begin this process by exploring this question on the basis of a number of empirical studies by social scientists, as well as our own research. The first section focuses on Kerr, Cunningham-Burley and Tutton's research into accounts of the political and economic backdrop to the generation of genetic knowledge and understanding, from a range of contrasting constituencies. In this section, the aim is to consider how participants framed themselves and others when expressing ambivalence about what we have called the politics of genetic information. We also explore the different ways in which they sought to resolve and/or sustain ambivalence about these issues. This allows us to reflect upon the nature of contemporary ambivalence about genetics, particularly its implications for further research in this area. In the second section, we focus in particular upon ambivalence about genetic information in clinical and familial contexts, drawing on evidence from Franklin and Robert's study of preimplantation genetic diagnosis (PGD).

The politics of genetic information

For the 'Transformations in Genetic Subjecthood' project, nineteen focus groups were conducted, with between two and five people in each, and several public events concerning genetics were organised. Here, however, we concentrate on data from only twelve of the focus groups, which we broadly classify as 'professionals' (6 groups) and 'lay people' (6 groups) (although as we continue we will query this distinction). 'Professional' focus group members included genetic counsellors, a team of health care practitioners involved with medical genetic services, scientists involved with UK biobank, actuaries with an interest in genetics, university staff with an interest in the commercialisation of bioscience, and representatives of a pharmaceutical company. 'Lay' groups included representatives of support groups for people affected by cancer, genetic disease and Alzheimer's as well as school students, members of the Society of Friends (Quakers) and refugees. We asked a range of questions about genetic testing, patenting, biobanking and public consultation. Although the focus groups are not strictly comparable because they varied in terms of the numbers of participants, range of questions, time for discussion and location, the data gathered from these focus group sessions nevertheless provide the basis for important insights into the ways in which different groups expressed and handled ambivalence about genetics.

Professional groups

Broadly speaking, we found that participants in the professional groups explored their views with confidence, often using detailed examples of their experience. Even when they expressed a lack of 'expert' or technical knowledge about the topic under discussion, their accounts were rich, sophisticated, personal and expressed with confidence.

Some groups and individuals within groups with special interest in genetics (e.g. genetic counsellors) were, as we might expect, much more certain of their views than others. On these occasions, participants gave detailed accounts which included knowledge of the technical possibilities of new research and authoritative views on how it ought to be established, managed and regulated. This tendency was especially evident in the group of scientists with close involvement with Biobank, but it also happened in the group of university staff to a lesser extent.

In all but one case, professional focus group meetings took place at people's workplaces, which may have limited the potential for participants to express ambivalence freely. However, professional groups did express ambivalence about the topics we discussed on a number of fronts. Ambivalence was expressed by some about patenting genetic sequences or discoveries, as opposed to inventions, data protection mechanisms in large-scale research projects like Biobank and 'high tech' solutions to illness, for example predictive testing without targeted treatments. Although some groups suggested that it would be possible to mediate these concerns through schemes such as compulsory licensing, or broader research agendas where genetics was set in context, this kind of ambivalence was frequently unresolved.

There was also considerable ambivalence about participation in the research activities of the Biobank in the professional groups. Participants spoke of their sense of the scientific merit of the study, but also pointed out that they would not want to participate as individuals. For example, one participant in the group of university scientists noted:

... it's a difficult one for me in some ways, because I can see some circumstances in which in actual fact I'd rather do the ostrich and bury my head ... Curiously driven [research] is fine at the third person level when it comes down to you personally, it's ... [different] *

In part this was explained by lack of time, or cynicism about data protection, but it was also linked to several expressions of concern about a lack of personal feedback to participants. This seemed to signal a deliberate split in people's accounts of self, between their professional and their lay selves. However, on other occasions it was related to an alignment between professionals and lay selves, for example some participants' positioning as clinicians, whose purpose is to identify and treat disease, meant that they queried

large scale research such as Biobank, whilst also expressing a disinclination to participate as research subjects.

On the political front, some professional groups also expressed considerable ambivalence about public consultation, querying the dangers of institutional capture of lay participants and consultation for consultation's sake, and the difficulties of regulating given the pace of change and global reach of scientific research. Other groups were more certain that these problems could be mediated by better public education and clearer regulatory frameworks. This related to their personal sense of 'fair play' as well as their professional experience, as suggested in the following excerpt from the group involved in the Biobank who were discussing concerns that the project did not offer personalised feedback:

I mean my personal feeling about this ... it may not be same as everybody else's, but, you know, it's like ... anything that you enter into, you know. If you, as long as you are informed properly of the rules ... the terms of engagement at the start of the project, well that; I'm happy with that. So if it was me ... and I'm of the age group ... I will be a participant within Biobank, ... as long as I've been informed, and told that no information will come back to me, I'm happy to do that. I mean if they find that I am carrying some particular ... gene variant, that means I'm going to drop down dead at seventy, so be it. You know, that's the way it is.

These professional groups also demonstrated interesting instances of reflexivity about their ambivalence, or lack thereof. The genetic counselling group, who were all female and did not work together in the same unit, expressed more ambivalence than the other groups, but also commented that they would find it difficult to be so frank about their doubts in a workplace context. This contrasted with the group involved in clinical genetics, whose participants were less open to exploring ambivalence, perhaps because the interview took place in their workplace setting. Other professionals resisted exploring their ambivalence by stating that they had little knowledge of other specialist areas, so they were unable to comment (although they sometimes went on to discuss these issues anyway). A sense of disenfranchisement was expressed by others – and sometimes deliberately adopted – for example the pharmaceutical company scientists said that they steered clear of engagement with regulatory decision making and just followed the rules. Others were more concerned that they had not been consulted about Biobank, despite their expertise.

Lay groups

The lay groups were conducted at a number of settings, including the community venue in which the group usually met, and a range of other meeting places, including the University of York. Most of the participants knew each

other before the focus group, but some were less familiar with the other participants (the genetic disease support group members, who represented different groups and the refugee volunteers). These groups engaged with the questions in a sophisticated and informed manner, although they obviously drew on a range of different examples of their experiences as patients and members of the public in order to inform their analysis. This did not, however, mean that expertise was not evident. The group involved in assessing research concerning Alzheimer's disease, was clear about their expertise in the assessment of genetic research, whilst members of other groups, such as the Society of Friends, drew on their scientific and other related expertise in the course of the discussion.

The lay groups were ambivalent about the technicalities of genetic research and services, as were professionals. They expressed concerns about data protection, patenting discoveries and the value of large scale research projects like Biobank in the context of public health initiatives. The position of expert patient/carer also invoked a strong critique of our study in the group of people involved with the Alzheimer's Society, for a lack of clarity about its policy relevance in particular. However, more questions were raised about the predictive value of genetic testing, the models of causation on which they are based, and the need for high tech tests and targeted treatments, than in the professional groups. This occurred from the perspective of potential participants in genetic research and testing, but also from the perspective of an expert patient/carer (support group member), a moral/religious agent, a different kind of expert (psychoanalyst), and a worker with experience of workplace hazards.

As we might expect, there was considerable moral ambivalence in the lay groups as well. One group discussed whether disease was a test from God (refugees) whilst others raised questions about people's responsibility for crime and the influence of genetics (Friends) – these issues were not discussed in the professional groups. However, other issues about balancing altruism and self interest in participation in research projects like Biobank were discussed in both groups. Interestingly, the public groups seemed more willing to participate in this kind of research than professionals. People in several groups signalled their willingness to participate when the issue was first raised. Perhaps one participant's rhetorical question 'don't you think we have to trust?' in reference to sponsoring bodies, like the Wellcome Trust, helps to explain their greater openness. This did not exclude expressions of cynicism and alienation about the political process, however. Once again this was also expressed in some of the professional groups, but it was most apparent in the lay groups, especially in the cancer support group. The school group were also sceptical about public involvement in this kind of genetic research, because we live in a fractured society. As one participant commented, 'Maybe if it was a ... closer society, if you were closer with your doctors ...' you would be more interested. The lay groups raised similar

concerns to those expressed by professionals, although they were sometimes more blunt, especially when questioning the political economy of genetic research and its importance to researchers' careers, rather than the public as a whole. The dangers of surveillance and misuse of data were frequently raised, and seemed to be considered to be inevitable by some, although others suggested similar regulatory mechanisms to those proposed by some professional groups.

The lay groups did seem to be more ambivalent than the professional groups in the sense that they were less likely to express definitive solutions to ambivalence such as standardisation, regulation or individual choice. They also raised more questions about the technicalities of genetic research and tests, and discussed moral ambivalence more fully. However, we also found that they were more willing to contemplate participation in genetic research as research subjects. Although they shared many of the professionals' concerns about the political process, particularly around regulation of patenting and public consultation, some lay groups were more cynical about the possibilities for positive change, largely because of a sense of disenfranchisement. Others were more resigned to trusting experts, although not without some discomfort. These views were expressed from a broad range of positions, not just lay person, but carer, patient, expert, Muslim and Christian. We also found some striking parallels between some of the views expressed in the lay and professional groups. For example, the Biobank scientists and the Alzheimer's disease group both queried the relevance of our research within a broader discussion where they were explicit about what constituted good research practices.

It is interesting that professionals in these groups expressed considerable ambivalence about the Biobank, and that they were far from unanimous in their support of genetic research. Their hostility to patenting is also of interest, although perhaps less surprising given that the majority worked for the public sector, and shared patients' concerns about access to services and treatments. Professionals also seemed, for the most part, not to subscribe to the classic 'deficit model' of public understanding of science, although they were ambivalent about the meaning and nature of public participation in decision making about genetics. Lay people's sophisticated engagement with the technicalities of genetics was also of interest, as were the range of subject positions from which their accounts emerged.

This seems to suggest that the divide between lay people and experts in our study was especially narrow where their ambivalence about the political economy of genetics is concerned. The questions they raised about the technicalities of genetic research and regulation were also remarkably similar. On the other hand, there appeared to be a greater gulf between professionals and lay people in their articulation of moral ambiguity, particularly where religiosity was concerned. Professionals also seemed to be able to marshal more interpretive resources to resolve or discount ambivalence in the course of

their discussions. For example, where ambivalence was expressed about Biobank this was often framed as a personal rather than a professional perspective. However, professionals' management of ambivalence did not necessarily mean that they abrogated responsibility in the process, indeed several instances of professionals moving between their public and private selves suggest endemic tensions around their rights and responsibilities in this regard. Lay people appeared to be less able to resolve ambivalence, yet more able to explore it through the adoption of a wider range of subject positions than their professional counterparts. In other respects lay accounts bolstered rather than undermined professional authority. Their faith in regulation, although far from unambiguous, was also clearly evident.

Interpreting genetic knowledge

Authoritative knowledge, judgement, and above all truth are often thought of as *singular*, particularly when scientific 'facts' are concerned. The entire basis of the experimental method on which modern science is based, for example, relies on the ability to determine outcomes based on observable facts, and to analyse these through a process of cumulative induction. Thus, in many of the scientific contexts in which new genetic technologies are being employed it is of the utmost importance to 'get it exactly right'. The presence or not of a gene, or of certain mutations, or even the exact number of repeats within a mutation, may be crucial in determining the likelihood – or certainty – of one outcome or another. The effort to be absolutely sure that when a gene appears to be present it is in fact there is the driving force behind the enormous care taken in contexts such as prenatal screening, or PGD, to ensure there is no contamination, no errors of amplification, and no misreadings, or mislabelings, or miscountings that might lead to a misdiagnosis.

At the same time, it remains the case that, even within science, doubt, equivocation and ambivalence are crucial. The sociology of scientific knowledge has comprehensively shown that processes of proof, replication and experimental design are profoundly social, and, as such open to flexibility and negotiation (Jasanoff et al. 1995). This ambivalence of science is far from unrecognised within the scientific community itself, the hype about discoveries and breakthroughs notwithstanding. It is often argued that the hallmark of a successful scientist is to continually experience intense doubt.* Likewise, certainty is seen as one of the worst traits with which to begin a scientific career. Scientific certainties, like French burgundies and Chinese eggs, increase in value as they age.

It is consequently unhelpful to imagine that we can distinguish between something like the social or subjective benefits of ambivalence, for example in the face of the kinds of impossible choices many would-be parents have to make about a wanted but chromosomally abnormal pregnancy, and the context of scientific authority, where ambivalence is only ever compromising.

Indeed, it is a possibility suggested by a number of recent studies that the reverse is true.

For example, in her path-breaking monograph based on over 15 years researching women's experiences of amniocentesis in New York City, anthropologist Rayna Rapp (1999) found that ambivalence and ambiguity came in mixed dosages with certainty and singularity of purpose on both sides of the clinician/scientist vs. patient/family member divide. Hence, in some cases where an 'ambiguous' genetic diagnosis was presented, about which little was known, and therefore no professional certainty could be expressed, patients often had strong and unequivocal views – either to terminate a pregnancy, or to retain it. Medical anthropologist Kaja Finkler (2000) made a similar finding in her study of the way in which the 'objective truth' of genetic information enters into the highly emotive and subjective realm of negotiating kin ties. In the realm of decision making about tracing genetic predispositions through genealogical relations, for example in terms of deciding whom to contact for a blood sample, ambivalence was often expressed as a form of care: on the one hand it might be beneficial to encourage other family members to be tested, but it might equally cause them the strain of unnecessary anxiety. This is especially true given the highly ambiguous nature of much genetic susceptibility testing, which may or may not yield reliable data, and, even if it does, may not be correlated to either certainty about the future, or beneficial treatment (Franklin 2003).

These same points are demonstrated in a recently published study by social anthropologist Monica Konrad (2005) on 'the new predictive genetics' in which one of the central themes is the necessity for communication about these new technologies to be composed out of multiple and varied knowledges, voices and expertise. She claims one of the most important aspects of future health care campaigns concerning genetic testing will be the necessity to include users and patients on research drafting boards and policy committees who can provide a variety of different languages of genetic 'facts' for different constituencies. Describing the dilemma of how to allow for people who do not want to know about their genetic 'susceptibilities' or predispositions, while also knowing when to provide this information for others, Konrad notes the importance within genetic counselling of allowing counsellors to remain 'unresolved' – much as this contradicts the rational choice ethos of the entire counselling process (2005: 66–7). Such a model could be described as ethical ambivalence, or professional equivocation, that is in the interest of serving a diverse clientele.

As these studies and the evidence of the previous section highlight, it is less and less accurate to generalise about the process of transmitting genetic information in terms of established models, norms or protocols in which professionals communicate unambiguous genetic risk information to individuals or patients in the name of increased, and/or more rational choice. Different publics versed in their own 'expert' knowledge beliefs must also be

involved actively in educating policymakers if 'evidence-based care' is to have any formative influence in the evaluation of emerging initiatives, interventions and technologies.

As Konrad points out, this tendency for health professionals in the context of the new genetics to become highly skilled in shifting registers of speech, language, expertise and tone is repeatedly documented in Rapp's account of the communication 'brokers' in the clinics where she conducted fieldwork. In addition to the need to be able to become, as it were, ambi-literate, in order to 'switch-speak' within and across several knowledge registers, other situations of responsible care and professional obligation towards the disclosure of genetic information require it purposefully be made even *more ambiguous* to patients. In one of the most complex narrations of what might be called the *deliberate promotion of genetic ambivalence* by clinical professionals, Konrad describes the process of 'exclusion testing' for Huntington's disease using pre-implantation genetic diagnosis. In these cases, 'prospective parents who know they are at risk but crucially who *do not want to have their own genetic status made less ambivalent* (i.e. verified as positive or negative) through the selective screening procedures, pre-implantation diagnosis by non-disclosure effectively cuts off the flow of genetic information' (2005: 126).

Thus the field of new genetic knowledges and technologies, and in particular what we might want to call the new explicitness of 'genetic meaning', is replete with examples of ambiguity and ambivalence. This is caused in part by the phenomenon Franklin and Roberts have referred to as the 'genetic gap', meaning the difference between what genetics means in one context (e.g. a laboratory) and another (e.g. a marriage) (Franklin and Roberts 2002). Because, as good genetic counsellors know, these contexts cannot be 'resolved' in order that any one, singular, 'objective' genetic 'truth' prevails, genetic knowledge must always be acknowledged to have multiple meanings, which are equally and simultaneously true, and may well point in divergent directions. This truism also derives from what Konrad describes as the 'fundamental contradictions' (2005: 66) inherent to both the ethics and pragmatics of genetic knowledge transmission, especially of the expert, authoritative kind. For example while such information must be treated as personal and individual, and patients' autonomy protected, this goal is contradicted by the fact of genetic information inherently having meaning for others. Similarly, as Konrad notes, the very existence of tests for mutations such as the Huntington's gene creates a new chronic condition for sufferers, which is the inescapability of choosing whether or not to be tested.

These 'fundamental contradictions' require that ambivalence is sometimes promoted and protected as a component of best clinical practice and conscientious ethical care in the context of clinical genetic communication events, such as susceptibility testing. In these contexts, the use of ambivalence as a form of protection acquires a more positive connotation, as does the 'ambi-vocality' of the effective genetic counsellor.

A suggestion of many studies of the new genetics is that much greater diversity of knowledges and expertise must be incorporated into the development and provision of new genetic technologies, especially in terms of health care and reproductive decision making. This tendency, in a sense to exploit the 'genetic gaps' to achieve maximum coverage, also needs to occur as far 'up the pipeline' as possible in order to be effective – for example by involving patients in the design of scientific research, as has already begun to take place in some single-gene disorder patient groups (Rapp, 2003). It is in this way that 'promoting ambivalence' may be linked to democratisation, or the 'biological citizenship' described by Novas and Rose (2000).

Yet another dimension of ambivalence derived from Franklin and Robert's study of genetic knowledge in the context of pre-implantation genetic diagnosis, based in the Assisted Conception Unit of Guy's and St Thomas' Hospitals (where part of Konrad's study was also based), was a somewhat unexpected correlation between uncertainty and trust. This finding was described as 'uncertainty value', denoting PGD patients' appreciation of clinicians' willingness not only to discuss, but to emphasise, the many uncertainties involved in PGD.

In her fieldnotes from her first visit to the PGD clinic at the Leeds General Infirmary to begin ethnographic fieldwork in 2001, Sarah Franklin described her surprise at the explicit attitude of clinicians, nurses and genetic counsellors that their duty was to present 'the really bleak picture' of PGD, thereby 'putting the fear of God into them':

On my first afternoon, [the PGD nurse coordinator] took me to several meetings between genetic counsellors and prospective PGD patients. I am amazed how much failure is emphasised, how much they go on about how many things can go wrong, how it is all very early days for the technique and for the clinic, and how complicated all of the procedures are. They always mention an earlier misdiagnosis, in one of the clinic's two attempts so far, producing what they refer to as a '50% possibility of misdiagnosis'. They seem to want patients to be almost adamant they'll do nothing but PGD. Later a couple comes in for their third consultation. They are incredibly articulate and clear about their reasons for wanting PGD. The genetic counsellor says to them: 'This technique is for people like you – people who know PGD is not the easy option, people who know this is a very difficult technique.' (09/01/01)

As Franklin and Robert's study showed, willingness to discuss the drawbacks of PGD – a dauntingly technically complex procedure requiring both microsurgery to remove a single cell from the 8-cell embryo and successful amplification of its minute amounts of DNA – correlated for many PGD patients with increasing confidence in the PGD team. As Ben and Sally, one

of the couples at Guy's and St Thomas' Centre for PGD who were interviewed for the study, described their experience:

- Ben:* And so we had a talk with the [consultant] and the genetic counsellor from the [PGD] clinic ... They [explained] how they do it, this attaching probes to the certain genes and then looking to see this, that and the other, and then they talked us through all the, um, additional tests we have to have afterwards because it's, um, my particular translocation's biggest setback is going to be Down's. So [the consultant] said obviously this isn't 100 percent guaranteed that you won't have Down's because it's only a 2 dimensional picture that they take. So, there could be genes lying underneath other genes that they don't see ... So, he talked us through all these various ... amniocentesis, CVS tests and this, that and the other, and the ... *additional* risks that they bring into it, and would we be willing to ... have the test done?
- Sally:* It was a lot clearer that time, wasn't it, to understand? [...] I suppose it was like, you think he's just going to take [your eggs], sort your embryos out, and give you children. I think he wanted to make sure that we understood that things could still go wrong. It was very early days and um, it, it was helpful wasn't it? It really was! 'Cause we came out of there feeling quite refreshed actually 'cause we actually both felt we understood. Having spoken to the [consultant], and the genetic counsellor, we both understood fully what it meant.

As Ben and Sally explain, understanding everything that can go wrong, and having one's expectations knocked back at the outset of treatment is described as 'helpful' and 'refreshing'. Emphasis on the number of different technical obstacles which may prevent successful treatment, or lead to a misdiagnosis, and the additional risks introduced by prenatal testing are described as making the technique 'a lot clearer [to] understand'. These and other examples indicated that, at least in the context of PGD, patients valued clinicians' candid appraisal of the number of 'unknowns' involved in treatment particularly insofar as it allowed them to *manage their own uncertainty rather than having decisions made for them*. The effort by clinicians and genetic counsellors to foreground the uncertainties of treatment increased patients' *trust in them* and correlated directly to the high esteem for their professionalism. In some cases, the ability of members of the PGD team to convey the risks and uncertainty surrounding aspects of the technique, such as the unknown causes of implantation failure, led to patients describing them as 'not really like doctors at all'. In a statement that neatly captured the normative incommensurability of uncertainty, or 'ambivalence', and authoritative medical expertise, clinical best practice and professionalism these cases clearly contradicted, Tony and Melissa, another couple from the

Guy's and St Thomas' Centre for PGD, expressed their appreciation of the team through a series of double, positive and 'backwards' negatives that denote praise.

Tony: I don't look at them as doctors. Do you?

Melissa: No.

Tony: ... Not 'cause they're not professional or nothing, just because they're really, really good to you. They never ever speak down to you ... And they involve you with everything, which is great for me!

Melissa: They do explain everything and if it hasn't been successful then when we go back there the file's out, they go through everything – what they think went wrong and what's this. They're all really good.

As Tony and Melissa emphasise, a positive sense of involvement is produced by thorough and lengthy explanations of failure. The experience of not being spoken 'down to' prompts a comment that the PGD team do not seem like doctors at all. The form of this comment, as a question, elicits an affirmative negative: 'No' (meaning 'yes, I agree, they don't'). This is quickly followed by a positive qualification: 'it's not because they're not professional' – a double negative that is followed by 'or nothing'. These 'knowing' comments dialogically invoke the stereotypical patronising medical authority figure, and the polarised view of the medical expert (who has knowledge) and the ignorant patient (who has none) as the background to the comments that 'they're really good to you', 'they never ever speak down to you', and 'they involve you with everything'. Rather than being presented with a single, resolved, decisive version of 'the path ahead' through what one PGD patient described as 'the topsy-topsy world of PGD', the value of more uncertain, equivocal and ambivalent accounts of its high potential failure rates and numerous 'unknowns' was both increased trust and a more confident understanding PGD. For PGD patients, clinicians and genetic counsellors alike, the value of these *ambivalent accounts* lay in the fact of their being seen as more responsible – and indeed as professional best practice in the midst of often ambiguous genetic information.

Conclusion

As the many examples we have discussed in this chapter illustrate, there is a degree of evidence that 'ambivalent' responses to the new genetics comprise a significant social phenomenon, which may reflect particularities of the genetic 'turn' that will be better characterised by future study. While it is possible to demonstrate also that these 'ambivalent' responses can be correlated to positive 'goods', such as better communication, increased inclusiveness or

greater trust, the two studies by Kerr, Cunningham-Burley and Tutton and by Franklin and Roberts, also demonstrate that ambivalence may take a number of patterns and serve a range of functions, which, perhaps fittingly, may not resolve into a predictable pattern. Indeed, these two studies usefully depict a range of responses that suggests while the 'ambivalence patterns' characteristic of new contexts of genetic knowledge and technology may indicate a prominent form of interaction or positionality, this in and of itself may not show a consistent correlation with specific meanings, values or 'feelings' about the new genetics. Crucially, social actors' constructions of, and responses to, genetic information involve the sophisticated expression and management of ambivalence according to the complex relationships and contexts in which they are located. At times, the expression of ambivalence opens up space for reflection on the ethics of care within the family, or professional responsibilities to patients, or even one's obligations and duties as a citizen. At other times accounts of ambivalence signal frustration and alienation from biology and/or politics, which cannot be resolved. It is not the case that lay people are the victims of ambivalence and professionals are its nemesis. Ambivalence about the interpretation and politics of genetic information can be suppressed, discounted, managed or foregrounded for a variety of professional and personal purposes, across a range of clinical, political and social domains.

As a component of the emergent 'biosociality' first described by anthropologist Paul Rabinow (1992) in reference to the ways in which new forms of genetic information will become inculcated in, and be reshaped by, emergent social organisations and affiliations, such as patient groups, 'genetic ambivalence' remains a distinct, and in many ways prominent finding to emerge out of the first generation of 'socio-genetic studies' using empirical methods to investigate actual genetic encounters and the wider politics of genetic information.

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