

On Ambivalence and Risk: Reflexive Modernity and the New Human Genetics

Anne Kerr and Sarah Cunningham-Burley

Science Studies Unit Medical School
University of University of
Edinburgh Edinburgh

ABSTRACT This critical examination of theories of reflexive modernity with respect to the new human genetics draws on a range of empirical studies and conceptual critiques. In it we explore the ways in which genetic knowledge and testing technologies offer new choices, construct new risks and generate public and professional ambivalence. We contrast this with the processes of ordering, reduction and control suffusing these developments. We argue that reductionism and determinism continue to infuse genetic theories and methods, that scientific and social progress are collapsed anew, and that certitude and surveillance remain powerful guiding principles. Within this context, the reflexive potential of individual choice, personal responsibility and risk estimation is seriously undermined. Indeed, in the case of the new human genetics, it seems that reflexive modernisation promotes, rather than curtails, a new modern/counter-modern eugenics. This occurs through the privatisation of lay ambivalence and professionals' successful institutional reflexivity. The paper concludes with a consideration of the implications of our reflections for sociology and participatory democracy more broadly.

KEYWORDS ambivalence, human genetics, reflexive modernity, risk

Risk and ambivalence are key concepts in the sociologies of reflexive modernity (Beck 1992a and b, 1995, 1996, 1997, 1998; Bauman 1991, 1997; Giddens 1990, 1991, 1994).¹ It is argued that tensions inherent in global market capitalism, particularly risks associated with industrial development, have resulted in the breakdown of administrative, professional and expert categories and authority, an increasing lay scepticism and a new grassroots political activism. Ironically, it is technological development, not its failure, which is said to have spawned the radical processes of self-confrontation at the heart of reflexive modernity (Beck 1997). The plethora of lifestyle choices offered by modern science and technology is said to open up 'new ethical spaces' (Giddens 1994:190) by fermenting doubts about the natural order and scientific progress (Beck 1997). This can propel sociologists into critical but constructive discussions with the representatives of modern institutions (Beck, Giddens and Lash 1994) through the rejection of what Beck calls a 'sociology so specialised in the status quo that it becomes the status quo' (Beck 1997:18). Taking up this challenge, we critically examine theories of reflexive modernity, with respect to

the new human genetics. Our aim is to explore the reflexive, modern and counter-modern aspects of the science and technology of the new human genetics as well as professional and public accounts of its social dimensions. Rejecting Beck's caricature of empirical sociology as a backwater of hypothesis-testing scholars (1997, 1998), we build on our previous research into lay and professional accounts of the new genetics in Britain² and draw on other contemporary research and critical commentaries in this analysis. We also reflect on our knowledge of and occasional participation in various recent policy discussions and public debates in Britain.

In many ways the new human genetics is the science of reflexive modernity *par excellence*. It involves an alliance of global capital (notably the biotechnology industry), clinicians and scientists from an array of disciplinary and national backgrounds, and politicians and social policy-makers concerned by the growing cost of health and welfare provision. Genetic tests offer risk estimates to individuals during a process of counselling by experts, in order that they may 'plan their lives' more effectively (Giddens 1991). Giving individuals information about and control over their or their offspring's genetic makeup is heralded as a new biomedical route to liberation. The rhetoric of 'reproductive choice' (Giddens 1991; Bauman 1997) has superseded older practices such as coercive sterilisation, yet the risks of 'backdoor eugenics' (Duster 1989) have been raised by a variety of publics and commentators (perhaps most vocally expressed by the disability movement). This concern with the risks of the new genetics is also manifest, as well as managed, in the recent efforts to improve public understanding of science and to develop publicly accountable science.³ Paradoxically, the reductionism of the new human genetics, and the ever greater reliance on technology and scientific expertise that it brings, may yet provoke more public engagement with scientific, technological and biomedical institutions.

However, in other respects, the new human genetics as applied to human health remains a trenchantly modernist science. Advocates of the largely state-funded Human Genome Project and related commercial projects to map and sequence the human genome emphasise their progressive and objective character; promising to uncover 'the holy grail' of humanity and with it the key to eliminating and/or curing genetic diseases and disorders (Watson 1990). The rapid application of knowledge in the clinic is further testament to the aura of certainty and social usefulness around the new human genetics. Genetic testing offers the potential for widespread surveillance of the population's health by employers, insurance companies and the state (via health care institutions), and further medicalisation of risk (Petersen 1998).

Pre-modern structures and notions, such as those associated with kinship and destiny, are also said to be dissolved and rebuilt by modernity (Giddens 1994:56). These too remain evident around the new human genetics. A sense of fatalism about genetic disease, which can characterise the responses of people who receive a positive test result, internalises older notions of destiny. The guilt experienced by some people who have a negative test result also relates to their sense of family ties and

responsibilities, as well as their views of destiny (see Marteau and Richards 1996, for a series of personal accounts; see also Richards in that volume for a discussion of families, kinship and genetics). Biological ties can be reified or severed by genetic tests.

Beck's thesis of the contradictory fusing together of the modern and counter-modern also applies to the new human genetics. Counter-modern 'anti-progress' (Beck 1992a:11) favours 'de-democratisation' (ibid.), including bigotry and discrimination on the grounds of sex, race or disability. Paradoxically, these values are refined and reinvented as well as challenged by modernity, not least by science. In the case of the new human genetics, eugenics is reconfigured and becomes 'barbarism modernized' (Beck 1995). This dialectic between the modern and counter-modern is also evident in the renewed interest in genetic determinism and evolutionary theory, marked by the success of popular science books such as *The Red Queen* (Ridley 1993); the rise of evolutionary psychology (which unites physical anthropologists and psychologists in the quest to explain social and cultural processes in genetic terms); and the burgeoning field of behavioural genetics (Hernstein and Murray 1994; Dawkins 1976; Pinker 1997; Ridley 1997; Wright 1995; for critiques, see Beckwith 1976; Keller 1991; Shuster 1992).

This leads us to ask whether the modern and counter-modern dynamics within the new human genetics might overwhelm its reflexive potential. Professionals' constructions and management of genetic and eugenic risks and public ambivalence could pave the way towards more socially responsible and democratic science and technology, yet the old standards of reductionism, determinism, order, certitude and progress suffuse its knowledge and applications. New reproductive tests and treatments bring new choices which can undermine a sense of biological destiny, but a new genetic determinism, evident in psychology and psychiatry in particular, is powerfully reasserted. Reproductive, health or lifestyle choices also take place within the context of increasing state and market surveillance on the one hand, and a declining sense of collective responsibility, on the other, for the care, support and inclusion of those who are sick or otherwise defined as 'other' in our society.

The science and social context of the new human genetics is therefore a useful case study to explore the tensions between reflexivity and objectivity; doubt and certainty; choice and coercion; and change and convention in reflexive modernity. Such a focus enables us to consider some specific characteristics of technologies, risks and publics that tend to be overlooked or conflated in theories of reflexive modernity.⁴ However, theories of reflexive modernity allow us to develop more sophisticated analyses of the new human genetics, not least through an appreciation of the wider social and political context of which genetic theories and technologies are a part. These theories may also give an insight into how sociologists can become part of the project of reflexive modernisation, specifically in relation to the development of a new politics around human genetics.

We begin our analysis firstly by considering further some points of resonance and dissonance between theories of reflexive modernity and the context of the science and technologies of the new human genetics. Secondly, we provide a detailed examination of the lay public's accounts of and political responses to the new human genetics. Thirdly, we explore institutional reflexivity, drawing on an analysis of the discourses and practices of new geneticists and their allies. We conclude with a consideration of the implications of our reflections for sociology and participatory democracy more broadly.

Reflexive Modernity and the New Human Genetics

The sociology of reflexive modernization discovers industrial society as a contradictory historical symbiosis between modernity, pre-modernity and counter modernity, a semi-modern society that is being disembedded because of continued modernization and radicalization of modernity and re-embedded as different types of 'modern' or 'counter-modern' societal forms. [Beck 1997:38]

In order to understand what is modern, counter-modern and reflexive about the science and technology of the new human genetics we first must consider its historical context.⁵ In particular, the emerging disciplines of clinical or medical genetics cannot be considered apart from their eugenic roots. Human genetics has always involved modern and counter-modern values and practices, linking social and scientific progress with regressive policies, appealing both to objectivity and bigotry. Early geneticists, many of whom were active in the eugenics movement, and other eugenicists (including sociologists) used similar (mainly statistical) methods and addressed similar questions in studies of so-called 'feeble-mindedness' and degeneracy. Their research supported and justified the institutionalisation, sterilisation or elimination of the 'unfit', as well as suggesting 'cures' for social degeneracy such as the provision of contraception and education to the poor and under-privileged in order to reduce their birth rate.

Eugenics and genetics later diverged as eugenicists became increasingly concerned with common physical and mental traits and geneticists shifted their focus to rare disorders and more 'scientific' methods. Popular support for eugenics also diminished when Nazi sterilisation and euthanasia programmes came to widespread attention. However, the two remained linked via reform eugenics, where emphasis was placed on voluntary action and the alleviation and prevention of disease. In the late 1950s, reform eugenics was renamed human genetics, and genetic hygiene was renamed genetic counselling. This marked the growing desire within the genetics profession to disassociate genetics from eugenics once and for all, although, in practice, the priorities of reform eugenics remained.

The main clinical developments in new genetic technologies have so far been diagnostic (although new pharmaceuticals and gene therapy are also being

developed). The identification of over sixty genes or markers for genes (Yates 1996) has led to the development of genetic tests and some screening programmes for a range of diseases. In Britain, the National Health Service is by far the biggest service provider, although services vary from area to area.⁶ These services tend to be offered to people with a family history of specific conditions (for example, Huntington's disease or inherited breast cancer) in specialist regional genetics units, but there are more recent examples of screening programmes being established as part of antenatal and postnatal care (for example, pilot schemes for antenatal screening for cystic fibrosis in Edinburgh, or neonatal screening for Duchenne Muscular Dystrophy in Wales).

Notions of individual choice and personal responsibility permeate these new clinical services. Emphasis is now placed on people's rights to treatment and information about their genetic status (Stone and Stewart 1996). Genetics is also said to promote compassionate treatment of disabled and other stigmatised people and to reduce their suffering. Genetic tests have further enhanced the culture of risk in the clinic, where clinicians and clients have to embrace ever more complex risk assessments before making decisions about testing, the value of these predictions and subsequent interventions (Parsons and Atkinson 1992, 1993; Hallowell 1998; Price 1996; Rapp 1994). Results seldom come in simple 'yes' or 'no' terms, whatever the test, and this may evoke anxiety rather than reassurance for many people. In the case of antenatal testing, many pregnancies become tentative, marred by the risk of impairment (Rothman 1986). People with genetic conditions are treated as if they are temporary aberrations, in a state of 'suspended extinction' in Bauman's terms (1997); their reproductive choices can be moulded to reduce the incidence of their condition, and their eventual 'cure' will result in full assimilation as 'normal, healthy' human beings.

However, these values of doubt, uncertainty, choice, individuality and risk which permeate reflexive modernity have not entirely supplanted older modernist values of objectivity, order, progress and certainty. It is not only through defining 'the gene as the essence of identity and the basis of human difference' and promoting 'an image of the genome as a text that will "define" a natural order' (Nelkin 1994:26) that human genetics remains reductionist and determinist. The project of ordering inherent in genetic mapping reflects the traditional imperative for universal classification, and normalisation. The Human Genome Project even offers the potential of a standardised or ideal human genome (Balmer 1996; Flower and Heath 1993; Keller 1992a; Lippman 1992a; Van Dijck 1998). The rhetorical construction of DNA as the new 'master molecule' further enhances this sense of genetic determinism (Keller 1992b). The topics, methods and application of the new human genetics are also reductionist and determinist in a more routine fashion. A focus on mental and physical impairments has endured despite the shift to reform eugenics and today's new genetics. Behavioural geneticists and psychiatrists continue to conduct research

into the genetics of mental illness, such as schizophrenia and other traits, including intelligence. This resonates deeply with the eugenic research of the past, utilising updated versions of old methodologies such as twin studies, and implicitly (or sometimes explicitly) reinforcing and justifying inequities in society on the grounds of race, gender or intelligence (see Alper and Beckwith 1993).⁷ The new human genetics has also revived old colonial procedures when studying and exploiting other peoples through collecting and collating so-called 'native DNA'. Although the Human Diversity Project came to an abrupt end after being confronted by grass roots opposition, the colonisation of an individual's, a family's or an ethnic group's DNA remains essential to this scientific and corporate endeavour.

Pre-modern notions of fatalism and destiny are also reconfigured in the new human genetics, as they were in the social Darwinism of old. The cultural reification of the gene as determining behaviour reasserts a sense of destiny. However, the location of such destiny is placed firmly within the individual (and biological relations), rather than in uncontrollable external or supernatural events. In terms of individual behaviours, a 'fatalistic' approach to probabilistic risks is one possible response, where an 'at risk' individual may disregard associated lifestyle advice (Davison *et al.* 1992, 1994). Also, strong religious affiliation or kinship ties may result in the rejection of genetic knowledge, as Rapp notes in her research on those refusing prenatal diagnosis (Rapp 1998).

The dialectic between modernity and counter-modernity also remains potent. Indeed, the new human genetics marks a renaissance of biological determinism: a form of counter-modernisation that threatens reflexive modernity. Although it would be wrong to ignore the differences between the crude biological determinism of the past and today's more sophisticated and all-encompassing efforts to explain the natural order, the reification of social life remains at their core (Kaye 1997). What Beck sees as the barbarism of counter-modernity has also been reconfigured (1995:33):

Barbarism may supervene because it does not appear on the political stage, clothed in the familiar garb of brutality. It gains access through the clinics, laboratories and factories of the new biochemical industries ... The eugenics that threatens has shed all the distinguishing marks of a sinister conspiracy, and donned the robes of health, productivity, the promise of profit.

Genetic research and practice grows from, and further enhances, a 'set of ideals about a perfect health culture' (Nelkin and Lindee 1995:191), a culture in which disabled and disadvantaged people are already stigmatised (Shakespeare 1995). More generally, an emphasis on the genetic basis of disease shifts the focus from social provision to medical intervention with respect to a range of impairments, diseases and behaviours (Lippman 1991b; Rose 1994). The continued focus on the elimination or assimilation of people with genetic defects and the emphasis on the collective benefits of genetic technology (in terms of disease prevention and cure) bear much

in common with what Bauman identifies as the modernist project to eliminate or assimilate people who represent 'the other' or 'the stranger' in society, such as Jews in German society during the Holocaust (Bauman 1997). Despite his view of today's postmodern world as one where individual identities are fundamentally unstable, his description of the modernist elimination of 'neither-nors' or the 'cognitively ambivalent' (Bauman 1997:18) via enforced conformity and/or physical cleansing has a chilling resonance with today's efforts to cure and/or abort disabled people.

These ideologies and practices, at the individual and population levels, continue to reflect modernist claims to ultimate knowledge about and control of human nature. Yet they also advance them in a uniquely disturbing manner. Through the extraction and manipulation of DNA, and the patenting and commercial use of sequences and technologies, nature itself is materially as well as rhetorically constructed (Beck 1997; Keller 1992a and b). The rapidity with which these powerful new tools have been applied and the wide scope of their repercussions revitalise the modernist imperative to control human nature as never before. The modernist 'equation of knowledge with certitude' (Giddens 1990:39) is also apparent with respect to genetic tests. Despite the inevitable uncertainties in genetic knowledge and the testing process, the clinical setting often requires that genetic knowledge and test results are unreflexively applied and interpreted. The limited consultation time, pressure from clients and professionals for a conclusive diagnosis, and the medical imperative to intervene, often mean that risk estimates become definitive diagnoses which form part of a chain of diagnostic procedures, starting with counselling and proceeding to abortion, prophylactic treatment or further monitoring. Doubt or ambivalence is privatised (Bauman 1997) as individuals have to translate complex and ambivalent risk estimates into categorical decisions and meaningful life trajectories (Parsons and Atkinson 1992; Hallowell 1998). Although individuals may choose not to be screened or tested, the cultural and technological imperative remains, ever intent on improving or reconfiguring services in order to enhance their uptake.

In the United Kingdom, the state remains crucial to the funding and provision of genetic services which offer the potential for widespread surveillance of various populations – another fundamental feature of modernity (Giddens 1990). Genetic test results could be useful to employers or insurance companies, as well as health authorities and welfare services, allowing them to limit their liabilities, target future services at specific 'at risk' groups, and foster the culture of personal responsibility for disease alleviation and prevention (Lippman 1991a; Nelkin and Tancredi 1989; Nelkin 1992). Although genetic testing has yet to occur on such a widespread scale, the entrenchment of genetic testing in existing clinical services, especially antenatal and postnatal care, has already begun (Koch and Stemerding 1994). Where new tests fit old paradigms, uptake is higher and concerns are more muted; the development of new pharmaceuticals is an area where genetic technology is least contested. This is a subtle process, embedded in existing social relations where genetic determinism,

compliance with medical advice and personal health monitoring are reflected and reinforced by the medical profession, the insurance and education systems and the media (Conrad and Weinberg 1996; Kitzinger and Reilly 1997). In these ways the new human genetics continues to reflect Beck's interplay between modernity and counter-modernity which we can trace in the genetics and eugenics of old.

The new human genetics, then, involves a mixture of modern, counter-modern and reflexive values and rhetorics, as outlined by Beck, Giddens and Bauman. However, at the moment, it appears that reflexive modernisation sustains, rather than radically undermines, modernity/counter-modernity in this case. Doubts and uncertainties about the new human genetics disrupt its associations with certitude and progress only in a very limited sense. Individuals may experience ambivalence about their genetic choices, and professionals may be concerned about what they characterise as the social impact of genetics (as opposed to its broader social context), but this has yet to turn in on the science and technology of human genetics itself. So far public and professional doubts have not disrupted human genetic research or its clinical application. Instead, what appears to be happening is that 'counter modernization asserts, draws, creates and solidifies all boundaries over again' (Beck 1997:62). Much of what is claimed to be new or different from the practices and knowledge of the past turn out to be remarkably similar. Reductionism and determinism continue to infuse contemporary methods and theories. Scientific and social progress are collapsed anew. Certitude and surveillance remain powerful guiding principles. Even the special focus on physical and mental impairments and behavioural traits is not new; nor is the emphasis on compassion and suffering, both key aspects of the medical model of disability. The contemporary emphasis on individual choice and personal responsibility, and practices like expert counselling and risk estimation may have replaced some of the more extreme practices of old, but within this wider context they can be seen to be subtle reconfigurations, rather than entirely new modes of practice.

However, the new human genetics also generates debates, tensions, ambiguities and scepticism amongst individuals and institutions, especially when the social impact of the new genetics is considered. These processes may take a more radical form, reinforcing rather than undermining reflexive modernisation. Does the new human genetics foster choice, lay doubt and uncertainty in a way that undermines the modern/counter-modern project? Is there potential, through these dynamics, for a new ethics or new politics as Giddens, Bauman and Beck all suggest? In order to answer these questions we now go on to explore lay scepticism and professional ambivalence about the social context of the new human genetics.

Choice and Ambivalence: Lay Publics and New Politics

Beck, Bauman and Giddens all suggest that new reproductive technologies

subvert the very process of certainty and surveillance they are designed to support – a key process of reflexive modernisation. Freed from their ties to traditional groups, people are now said to be in a position to construct their own biographies through a new ‘plurality of choices’, including ‘the end of reproductive fate’ (Giddens 1991:219):⁸ ‘Reproductive medicine and genetic research throw open the door to a new quality of politics ... Here everyone rules himself and his progeny [*sic*] and can directly implement the values which govern him’ (Beck 1997:154).

The new human genetics does, of course, offer people new choices which were previously unavailable. However, as Bauman also suggests, the social and cultural constraints on lay people’s choices are highly limiting because people must have their choice ‘confirmed and validated’ by society (Bauman 1997:195). The power relations within the clinic and the wider cultural imperatives of health (heralded now as a universal human right) are both important constraints on choice (Bailey 1996; Overall 1992). There is evidence from studies of both lay and professional accounts, that lay people often comply with professional directions (Bekker *et al.* 1993; Lippman 1992b, 1994; Marteau *et al.* 1993, 1994; Michie *et al.* 1997). In our own study involving twenty focus-group discussions about the social implications of the new genetics, lay people’s reflections about these tests highlighted the way that the context of test provision and personal circumstances constrain people’s choices. Participants discussed the narrowness of professionals’ information about their research findings, testing and disabilities; the directive and/or cursory nature of counselling; tagging of genetic tests onto existing services; as well as the lack of proper social care and support for people who are disabled, sick or socially excluded (Kerr *et al.* 1998b, 1998c). Even if genetic tests were to become more widely available, it is questionable whether this would provide consumers with more choice, given this wider context.

The ‘colonisation of the future’ promised by the new human genetics can perhaps best be understood in modern/counter-modern terms, rather than as a driving force of reflexive modernisation. Personal and professional regulation of beauty, purity and order coalesce in the genetic counselling relationship (Bauman 1997). Experts have retained their power and resources to translate uncertainty into advice and information to the new consumers. Notions of individual choice and responsibility are rooted in a discourse of certainty, progress and responsibility. This pervades professional and media accounts of genetic testing. Genetic information is constructed as neutral facts about the human body and its social context remains unexamined. The ‘natural’ desire for a perfect child has become a common refrain, as has the suffering and distress caused by genetic diseases (Kerr *et al.* 1997, 1998a; Cunningham-Burley and Kerr 1999; Nelkin and Lindee 1995; Van Dijck 1998).

However, genetic testing also generates and amplifies lay ambivalence about science, technology and experts in the clinic and beyond – another route towards reflexive modernity. As Giddens argues, lay people’s trust in experts is conditional. Lay people may hold up scientific knowledge as an accurate reflection of the

workings of the human body (Martin 1987), yet also critically discuss the methods and institutional relations of science, thus directly challenging the dominant view of scientific practice and knowledge as morally and politically neutral (Irwin and Wynne 1996; Wynne 1991, 1992, 1995, 1996; Michael 1992; Kerr *et al.* 1998b and c).

Lay ambivalence or scepticism may also involve what Wynne has identified as wilful ignorance (1995). In relation to the new human genetics, this is manifest in non-compliance with testing or treatment, for example the low uptake of community screening for carrier status for cystic fibrosis, where no medical or reproductive context is established (Magnay *et al.* 1992). Lay people's ambivalence about medical science may also result from detailed knowledge and accumulation of formal expertise when a genetic disease directly affects them or a relative (Kerr *et al.* 1998a). Lay ambivalence may also be found in the expression of distrust in science and scientists in public discussions and debates. Various surveys of lay opinions have demonstrated other types of ambivalence: for example, at the Wellcome Trust 'Let the People Decide' event in London in 1997 a high proportion of 'Don't knows' were delivered in response to questions about acceptable research and practice. We also asked lay people 'Where to draw the line?' with genetic research and testing in focus groups (Kerr *et al.* 1998c), and found that any clear boundary between good and bad practice remained elusive and slippery. Lay people were aware of the differences in the amounts and types of expert information and advice about genetic testing, treatment and social care and the complex links between research, treatment and care of people with genetic diseases. They also had various perceptions of stigma, suffering and quality of life. As Bauman argues, lay people today believe in many things and are at least partially aware of the contradictions which this poses (Bauman 1997).

Beck and Giddens go on to suggest that this type of lay ambivalence about science and technology is the forerunner to a new form of politics. Beck argues: 'hazards exacerbate the dependence of everyday life on science, but they simultaneously open the scientific monopoly on truth to public discussion' (Beck 1995:161). Whilst he acknowledges that conflict and contradiction can mean relative powerlessness for the public, Beck argues that a new society will develop from this 'creeping revolution', which will require new 'forms and forums of consensus' (1994:29), where, 'doubt ... could be the standard for a new modernity' (Beck *et al.* 1994:33). This is elaborated in his later work, where he favours the opening up of policy-making about science and technology to pay more attention to their social contexts and to learn from those with direct experience of their social impacts (Beck 1997, 1998). Giddens advocates a similar form of 'life politics' where people actively engage with policy-making about science and technology (Giddens 1991). This is happening to a limited extent in the case of the new human genetics. Following the House of Commons Select Committee Report on Human Genetics in 1995, the Human Genetics Advisory Commission was established in 1996. The Commission and its successor, the Human

Genetics Commission, established in May 1999, are committed to listening to 'wider public views' when advising government. The Wellcome Trust and the Medical Research Council, two of the largest funders of genetic research in the United Kingdom, have also made various moves to engage with the lay public.⁹ The Wellcome Trust's Medicine in Society Programme supports public discussion initiatives and recently conducted a public consultation on cloning (The Wellcome Trust Medicine in Society Programme, 1998). The MRC's 'Genes and the Mind' also sought public opinion on genetic research into behavioural disorders (MRC 1997). There has also been a Citizen's Jury that sought the views of different groups of the lay public conducted by researchers at the University of Glamorgan (Welsh Institute for Health and Social Care 1997).

However, that a new form of politics is emerging or likely to emerge from the potency of lay people's ambivalence, as Beck, Giddens and, to a lesser extent Bauman, suggest, seems doubtful in relation to the new human genetics. Although lay people express a sense of alienation from the representatives of modern institutions, they are also reliant on them in a myriad of ways. When discussing the new human genetics lay people criticise the government for their lack of accountability, but they also look to it as the regulator of the new human genetics. In our own research we found that although participants raised many concerns about the way their views are either ignored or dismissed by policy-makers, they still tended to subscribe to the so-called 'deficit model' of public understanding of science, emphasising the general public's ignorance about science and science policy (Kerr *et al.* 1998b). This was also apparent in contributions from the audience at the Wellcome Trust event (1997) and the Welsh Citizen's Jury (Dunkerley and Glasner 1998). Indeed, the results of the Citizen's Jury were also remarkably close to what professionals in the field recommend (Welsh Institute for Health and Social Care 1997). Moreover, lay people do not actively challenge the science or technology of the new human genetics in any collective sense, with the exception perhaps of the disability movement, where a collective voice, although marginalised, is present. Thus, lay ambivalence about the new human genetics remains an as yet undeveloped critical resource, partly because it is unrecognised as powerful by lay people themselves (Cunningham-Burley *et al.* 1999).

This paralysis is compounded because it is policy-makers and professionals who determine the scope and effect of the very few public consultation exercises that have occurred. This inevitably means that they carefully construct and manage a limited set of policy questions and include few lay voices. These consultation exercises can also be viewed as part of funding bodies' public relations exercises (Dunkerley and Glasner 1998). For example, the MRC's recent consultation did not solicit the views of a very wide range of groups and buried the most controversial issue of genetic research into intelligence in a leaflet which stressed the medical benefits of knowing more about how our minds work (MRC 1997). The Wellcome Trust and the Human Genetics Advisory Commission also specifically locate their efforts at public

consultation within a wider framework of improving public knowledge and understanding of human genetics. The composition of the various government advisory bodies concerning human genetics is also heavily biased towards a supportive viewpoint. Alongside a majority of doctors and scientists sit clergymen, ethicists, lawyers, journalists and charity workers with a sympathetic stance towards genetic research and testing. Social scientists are few and far between, as are members of the lay public. Although the disability rights lobby are beginning to find a foothold in media discussions about the new human genetics which allows them to challenge the orthodoxy, these groups are not well represented on decision-making bodies. Representation of critical and lay views in the policy-making process is thus powerfully limited.

Lay ambivalence about the new human genetics is clearly apparent in the clinic and beyond; and it is unlikely to diminish as research and services expand. However, we suggest that it is currently more sedative than revolutionary, remaining largely privatised and inert. Although the boundary between professional expertise and lay ignorance is obviously blurred when we consider lay people's expertise in its wide (experiential) as well as more narrow (conventional technical) sense, such expertise needs to be valued by lay people and professionals before it can have any impact on policy and practice. The choices promised by the advocates of the new human genetics are also highly circumscribed by the personal, clinical and wider social context in which they are offered. Bodies remain docile when the options for their reinvention follow the conventions of beauty and health; and reproduction remains a fateful process because of the very ability to eliminate the undesirable in favour of a norm. Unlike the environmental crisis, the new human genetics is immediately private in its impact, and the 'citizen in the consumer' has yet to awaken (Bauman 1991). Professionals and policy-makers are still powerful managers of lay ambivalence. This suggests that their institutional reflexivity may well facilitate modern/counter-modern outcomes, and actually stifle rather than advance reflexive modernisation. We now go on to consider these processes in greater depth.

Institutional Reflexivity

The spiral of risk creation and management is at the centre of Beck's thesis about the 'risk society' (1992a). As industries develop so do hazards, and the associated industries of risk management proliferate, seeking to ameliorate these effects. This results in 'institutional reflexivity' (Giddens 1991), or a 'concealed, responsive, self-politicisation of hazards in public perception, politics and the hazard bureaucracy' (Beck 1995:12). Public relations, ranging from press releases to the domination of policy-making and advisory bodies, has become at least as important as research and its application. In the case of the new human genetics this happens in a variety of ways, for example through professionals' powerful influence

on the media and the government; their co-opting of others, such as bioethicists, into the project of expanding 'ethically acceptable' clinical genetic services; and their domination of public discussions and debates more generally (Kerr *et al.* 1997, 1998a; Cunningham-Burley and Kerr 1999; Van Dijk 1998).¹⁰

Professionals' institutional reflexivity about the new human genetics involves their acceptance of a limited set of social and ethical concerns in order to counter what they characterise as public fears about the new human genetics and to protect and enhance their professional status (see Kerr *et al.* 1997, 1998b; Cunningham-Burley and Kerr 1999 for a fuller analysis of professionals accounts of the social context of the new genetics in interviews and publications). For example, the threat to privacy, and potential for discrimination arising from the commercialisation of genetic testing are frequently raised (for example, see Mayeux and Schupf 1995; Sweeney 1997; Billings *et al.* 1992; Chapple 1992; Anionwu 1993). This treatment of risk is also apparent in the case of the Human Genome Project (HGP) (Keller 1992a; Juengst 1996). In addition to its scientific research, the HGP devotes 3–5 per cent of its budget to considering the ethical, legal and social issues (ELSI) raised by genetic research. Although this initially provoked engaged and critical debate, like much of the social research in this area, ELSI now tends to consider how best to evaluate new clinical genetic tests and address concerns about privacy, discrimination and professional and public education (Juengst 1996). Setting clear boundaries around which areas are and are not open for social consideration, also allows professionals, associated with the new human genetics, to manage concern without undermining research and practice. Discussions about the genetic testing of children is an example of this in practice: key clinicians have led the way in developing ethical guidelines proscribing the genetic testing of children, thus preserving the values of individual choice in other testing contexts (Clarke 1994).

By concentrating on knowable and confinable risks associated with the *application* of genetic technologies, professionals also side-step more fundamental questions about the values embedded in the new human genetics. The new genetics tends to be characterised as a neutral scientific representation of bodily processes and its medically based application is stressed, whereas eugenics tends to be characterised as a politically distorted pseudo-science, or abuse of genetics in the past (see, for example, Galton and Galton 1998; see also Kerr *et al.* 1998b). The new human genetics and eugenics are demarcated on the basis of their practitioners' goals and motives (as opposed to the consequences of their work). Eugenics is characterised as coercive and motivated by concern for the good of society as opposed to the new human genetics which is based on individual rights and choices (Paul 1995). One major risk is thus effectively dismissed, debate is foreclosed and an understanding of the social context of genetic research and practice is suppressed. The values embedded in definitions of disease and disability are also largely taken for granted and the social production of health and disease tends not to be considered.

Little attention is paid to the inherent uncertainties and ambivalence in genetic theories and technologies. Instead they are presented as ways to prevent suffering and increase choice (see, for example, Bell 1998; Watson 1990).

The little dissent that does exist also appears to be carefully circumscribed and disagreements do not appear to 'blow up' into highly contentious public disputes. For example, despite having different views on the medical significance and applicability of behavioural genetics, clinical and behavioural geneticists both emphasise their balanced approach to nature and nurture, in contrast to what they characterise as the excessive focus on nature in the 1920s and on nurture in the 1960s (see, for example, Plomin *et al.* 1992; Sherman *et al.* 1997). Clinical geneticists who have explicitly rejected genetic research into IQ and personality, still accept genetic research into disorders such as schizophrenia and manic depressive illnesses on the grounds that these are pathological conditions, not normal traits (Harper and Clarke 1997). However, the line between the normal and the pathological is far from clear as new broader continuums of disease are established (such as the 'schizophrenic spectrum' (Rutter and Plomin 1997)) and the term 'cognitive abilities' replaces the older and more politically fraught concept of 'intelligence'.

Professionals also tend to argue in favour of their having a key role in policy-making and education of the public, whilst at other times emphasising their lack of responsibility for the social consequences of their work. It is variously claimed that scientists ought to engage with social issues (Harper and Clarke 1997), to work with society in the application of beneficial knowledge (Cantor 1990) and to prevent the abuse of genetic knowledge, especially through open debate (for example, Nuffield Council on Bioethics 1993). For example, the American Society of Human Genetics' statement on behavioural genetics recommends the education of both the public and the press about the 'facts' about genetic differences and states that scientists have an obligation to be involved in such education (Sherman *et al.* 1997).

These various rhetorical and practical attempts to deflect criticism of the new human genetics constitute institutional reflexivity that protects rather than weakens professionals' authority through shielding professional autonomy, creating economic viability and generating public support. As Bauman (1997) suggests of experts in general, genetic scientists have successfully adapted to the new era of public scepticism and their rhetoric is far from destructive for their institutions. It is not only through their appeals to objectivity and good intentions that their status is reinforced. Their construction of risks worthy of discussion and their management of dissent within their ranks are also powerfully protective. This suggests the reversal of Beck's statement that reflexive modernisation derives from the failure of the scientific success; instead, in relation to the new human genetics, institutional reflexivity makes a success out of risk (or 'failure') (Beck 1997). The processes of reflexive modernisation thus contain strong and persistent elements of modernity and counter-modernity that are reinforced, rather than challenged, by reflexivity.

Conclusion: Towards Reflexive Modernity

The science, technology and institutions of the new human genetics and the public's responses to them clearly reflect the tensions between reflexivity/objectivity, doubt/certainty, choice/coercion and change/convention identified in theories of reflexive modernity. Modern, counter-modern and reflexive practices and values infuse the science and its social context. The new human genetics aims to eliminate and/or assimilate people with genetic disease in the name of progress; its topics, methods and applications are reductionist and determinist; and tests are offered in the context of clinical certitude and medical surveillance. This limits the radical potential of reflexive modernisation flowing from the sense of individual choice, personal responsibility and lay ambivalence that these technologies also bring. The notion of individual choice remains a chimera given the range of constraints on people's choices (in a state or market system). Privatisation of risk and lack of collective expression both further curtail the radical potential of lay ambivalence and therefore reflexive modernity.

Professionals' institutional reflexivity also protects rather than undermines their cognitive authority and acts as a powerful brake on the radical potential of reflexive modernisation. Although Beck clearly recognises the role of professionals' rhetoric in actually advancing a new eugenics this is at odds with his overestimation of the radical potential of both lay resistance and technoscientific risks in his general thesis on reflexive modernity. In the case of the new human genetics, professionals' institutional reflexivity is too protective of professional authority and lay ambivalence is too constrained to support reflexive modernisation. The possibility of even creeping revolutionary change therefore remains powerfully limited. Instead we face the very real prospect of a reassertion of a modern/counter-modern form of eugenics. As Beck (1995) has argued, professionals' 'prudishness' about responsibility and risk and their dismissal of the public as ignorant actually facilitate the expansion of commercial/privatised eugenics. Paradoxically, professionals' efforts to dispose of modernity/counter-modernity through demarcating the new human genetics of the present from the eugenics of the past actually reasserts its presence.

This suggests that, for now, theories of a more radical reflexive modernity with respect to the new human genetics remain just that. Perhaps they are just premature and change will progress as they hopefully suggest. However, the current emphasis on genetic diagnosis and abortion as opposed to treatment, and the social and economic constraints on an individual's choice and identity formation suggest otherwise. There is also no reason to think that the future commercialisation of testing (currently resisted by professionals and government) will bring added freedoms, as the market is equally constrained and constraining. Of course, the combination of various technological and scientific developments in the risk society may well be greater than the sum of its parts and more provocative technological

risks may well exist in other domains, such as food production. But, taken alone, these reproductive and/or diagnostic genetic technologies and the public's responses to them do not seem to have the radical potential that these theorists imply.

However, as Beck (1997) begins to suggest, no theory of reflexive modernity can be purely abstract, because it can still provoke criticism and therefore change. Viewed in this way, the sociological critique of the new human genetics is itself part of the process of reflexive modernisation (see also Benton 1991). More radically, when expressed in the public domain, sociological analyses of the new human genetics can generate doubt and highlight uncertainty in contemporary practices, debunk professional claims to neutrality, and challenge the notion of individual choice, thereby disrupting professionals' rhetoric and fostering greater lay ambivalence. Sociologists, scientists and policy-makers with a critical perspective on the new human genetics could also form alliances to promote better regulation of genetic research and a more thorough consideration of the responsibilities and interests of professionals, users and the broader communities in which these technologies operate. Greater lay involvement in policy-making and discussion could be also fostered. But sociologists who study lay views and/or aim to bridge the democratic deficit in decision-making about science and technology must be careful not simply to adopt in policy discussions the exclusive role of 'expert' that we have called on natural and medical scientists to vacate. By combining detailed empirical and theoretical insights into the new human genetics, we must continue to provoke and challenge, not relieve and mollify, policy-makers and experts.

NOTES

1. Beck, Bauman and Giddens all define this period in slightly different terms. Beck refers to 'reflexive modernity', Giddens to 'late modernity', and Bauman to 'post modernity'. Although none of them can be called 'postmodernists' as they eschew the notion that modernity will be superseded, and emphasise the connections between the past and the present, their theories are concerned with the latest and future developments of modernity, particularly the way in which ambivalence and risk are fundamental factors of change. For clarity we adopt Beck's 'reflexive modernity' to emphasise this position (which all three share).
2. The project was entitled 'The Social and Cultural Impact of the New Human Genetics' and was funded under the ESRC's Risk and Human Behaviour Programme, 1994–97, Grant No. L211252003. The grant holders were Sarah Cunningham-Burley and Amanda Amos of the Department of Public Health Sciences, University of Edinburgh, and the research fellow was Anne Kerr. The project began in November 1994 and was completed in July 1997.
3. For example, the MRC's consultation 'Genes and the Mind'; the Wellcome Trust's 'People Decide' event; and new Human Genetics Commission's remit to consult the public.
4. For example, Beck's discussion of risk and ambivalence in late modernity (1997) homogenises biological, chemical and industrial technologies and does not explore different public responses to different technologies.
5. See Allen 1976; Allen 1987; Adams 1990; Barker 1989; Harwood 1989; Keller 1992a; Kevles 1986; Ludmerer 1989; Norton 1983; MacKenzie 1978; Paul 1992, 1995; Proctor 1988; Roll-Hansen 1989 for further details.

6. There is also provision by private testing companies, although such commercial developments are criticised by geneticists working within the National Health Service.
7. The most famous example of this is *The Bell Curve*; but various other studies and books reinforce these themes, such as Brand's *The g Factor* (1996, but which was withdrawn from sale by its publisher); see also Pinker 1997; Ridley 1997; Wright 1995.
8. All three are careful to note that these changes have not meant an end to inequality, but its 'individualisation' (Beck 1997).
9. See the Commission's web site at <http://www.hgc.gov.uk>; the Wellcome Trust's at <http://www.wellcome.ac.uk>; and the MRC at <http://www.mrc.ac.uk>.
10. Indeed, we have first hand experience of this process. Although we did invite professional and lay people from our study to the public event that we organised at Edinburgh International Science Festival in 1997, we were struck by the extent of the contributions of the geneticists amongst the audience.

REFERENCES

- Adams, M. B. (ed.) 1990. *The Wellborn Science: Eugenics in Germany, France, Brazil and Russia*. Oxford: Oxford University Press.
- Allen, G. 1976. 'Genetics, Eugenics and Society: Internalists and Externalists in contemporary History of Science'. *Social Studies of Science* 6:105–222.
- Allen, G. 1987. 'The Role of Experts in Scientific Controversy', pp. 169–202 in H. T. Engelhardt and A. L. Caplan (eds.), *Scientific Controversies: Case Studies in the Resolution and Closure of Disputes in Science and Technology*. Cambridge: Cambridge University Press.
- Alper, J. and Beckwith, J. 1993. 'Genetic Fatalism And Social Policy: The Implications of Behavioral Genetics Research'. *Yale Journal of Biology and Medicine* 66:511–24.
- Anionwu, E. N. 1993. 'Sickle Cell and Thalassemia: Community Experiences and Official Responses', pp. 76–95 in W. I. U. Ahmad (ed.), *'Race' and Health in Contemporary Britain*. Buckingham: Open University Press.
- Bailey, R. 1996. 'Prenatal Testing and the Prevention of Impairment: A Woman's Right to Choose?', pp. 143–67 in J. Morris (ed.), *Encounters With Strangers: Feminism And Disability*. London: The Women's Press.
- Balmer, B. 1996. 'Managing Mapping of the Human Genome Project', *Social Studies of Science* 26:531–73.
- Barker, D. 1989. 'The Biology of Stupidity: Genetics, Eugenics and Mental Deficiency in the Inter-War Years'. *British Journal of History of Science* 22:347–76.
- Bauman, Z. 1991. *Modernity and Ambivalence*. Cambridge: Polity Press.
- Bauman, Z. 1997. *Postmodernity and its Discontents*. Cambridge: Polity Press.
- Beck, U. 1992a. *Risk Society: Towards a New Modernity*. London: Sage.
- Beck, U. 1992b. 'The Reinvention of Politics: Towards a Theory of Reflexive Modernization', pp. 1–55 in U. Beck, A. Giddens and S. Lash (eds.), *Reflexive Modernization: Politics, Tradition and the Aesthetic in the Modern Social Order*. Cambridge: Polity Press.
- Beck, U., Giddens, A. and Lash, S. (eds.) 1994. *Reflexive Modernization: Politics, Tradition and the Aesthetic in The Modern Social Order*. Cambridge: Polity Press.
- Beck, U. 1995. *Ecological Politics in an Age of Risk*. Cambridge: Polity Press.
- Beck, U. 1996. 'Risk Society and the Provident State', pp. 27–43 in S. Lash, B. Szerszynski and B. Wynne (eds.), *Risk, Environment and Modernity*. London: Sage.
- Beck, U. 1997. *The Reinvention of Politics: Rethinking Modernity in the Global Social Order*. Cambridge: Polity Press.

- Beck, U. 1998. *Democracy Without Enemies*. Cambridge: Polity Press.
- Beckwith, J. 1976. 'Social and Political Uses of Genetics in the United States: Past and Present'. *Annals of the New York Academy of Sciences* 265:46–58.
- Bekker, H., Modell, M., Denniss, G., Silver, A., Mathew, C., Bobrow, M. and Marteau, T. 1993. 'Uptake of Cystic Fibrosis Testing in Primary Care: Supply Push or Demand Pull?' *British Medical Journal* 306:1584–6.
- Bell, J. 1998. 'The New Genetics: The New Genetics in Clinical Practice'. *British Medical Journal* 36:618–20.
- Benton, T. 1991. 'Biology and the Social Sciences: Why the Return of the Repressed Should be Given a (Cautious) Welcome'. *Sociology* 25, 1:1–29.
- Billings, P., Beckwith, J. and Alper, J. 1992. 'The Genetic Analysis of Human Behaviour: A New Era'. *Social Science and Medicine* 35, 3:227–38.
- Brand, C. 1996. *The g Factor: General Intelligence and its Implications*. Chichester, John Wiley & Sons.
- Cantor, C. 1990. 'Orchestrating the Human Genome Project'. *Science* 248:49–51.
- Chapple, J. 1992. 'Genetic Screening: Brave New World or the Boys From Brazil?' *British Journal of Hospital Medicine* 47:487–9.
- Clarke, A. 1994. 'The Genetic Testing of Children. Report of a Working Party of the Clinical Genetics Society (UK)'. *Journal of Medical Genetics* 31:785–97.
- Conrad, P. and Weinberg, D. 1996. 'Has the Gene for Alcoholism Been Discovered Three Times Since 1980?' *Perspectives on Social Problems* 8:3–25.
- Cunningham-Burley, S. and Kerr, A. 1999. 'Defining the "Social": Towards an Understanding of Scientific and Medical Discourses on the Social Aspects of the New Human Genetics'. *Sociology of Health and Illness* 21:647–9.
- Cunningham-Burley, S., Kerr, A. and Pavis, S. 1999. 'Theorising Subjects and Subject Matter in Focus Group Research', pp. 186–99 in R. Barbour and J. Kitzinger (eds.), *Developing Focus Group Research: Theory, Politics and Practice*. London: Sage.
- Dawkins, R. 1976. *The Selfish Gene*. Oxford: Oxford University Press.
- Davison, C., Frankel, S. and Smith, G. D. 1992. 'The Limits of Life-Style – Reassessing Fatalism in the Popular Culture of Illness Prevention'. *Social Science and Medicine* 34:675–85.
- Davison, C., MacIntyre, S. and Davey Smith, G. 1994. 'The Potential Social Impact of Predictive Testing for Susceptibility to Common Chronic Diseases – a Review and Research Agenda'. *Sociology of Health and Illness* 16:340–71.
- Dunkerley, D. and Glasner, P. 1998. 'Empowering the Public? Citizens' Juries and the New Genetic Technologies'. *Critical Public Health* 8:181–92.
- Duster, T. 1989. *Backdoor to Eugenics*. London: Routledge.
- Flower, M. and Heath, D. 1993. 'Micro-Anatomy Politics: Mapping the Human Genome Project'. *Culture, Medicine and Psychiatry* 17:27–41.
- Galton, D. and Galton, C. 1998. 'Francis Galton and Eugenics Today'. *Journal of Medical Ethics* 24:99–105.
- Giddens, A. 1990. *The Consequences of Modernity*. Cambridge: Polity Press.
- Giddens, A. 1991. *Modernity and Self Identity: Self and Society in the Late Modern Age*. Cambridge: Polity Press.
- Giddens, A. 1994. 'Living in a Post-Traditional Society', pp. 56–109 in U. Beck, A. Giddens and S. Lash (eds.), *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*. Cambridge: Polity Press.
- Hallowell, N. 1998. 'You Don't Want to Lose Your Ovaries Because You Think, "I Might Become a Man." Women's Perceptions of Prophylactic Surgery as a Cancer Risk Management Option.' *Psycho-Oncology* 7:263–75.

- Harper, P. and Clarke, A. 1997. *Genetics, Society and Clinical Practice*. Oxford: B.I.O.S.
- Harwood, J. 1989. 'Genetics, Eugenics and Evolution'. *British Journal of History of Science* 22:257–65.
- Hernstein, R. and Murray, C. 1994. *The Bell Curve: Intelligence and Class Structure of American Life*. New York: The Free Press.
- Irwin, A. and Wynne, B. (eds.) 1996. *Misunderstood Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University Press.
- Juengst, E. 1996. 'Self-Critical Federal Science? The Ethics Experiment Within the US Human Genome Project'. *Social Philosophy and Policy*: 63–95.
- Kaye, H. 1997. *The Social Meaning of Modern Biology: From Social Darwinism to Sociobiology*. New Brunswick and London: Transaction Publishers.
- Keller, E. F. 1991. 'Genetics, Reductionism, and the Normative Uses of Biological Information: Responses to Kevles'. *Southern California Law Review* 65:285–91.
- Keller, E. F. 1992a. 'Nature, Nurture, and the Human Genome Project', pp. 281–99 in D. Kelves and L. Hood (eds.), *The Code of Codes: Scientific and Social Issues of the Human Genome Project*. Cambridge, Mass.: Harvard University Press.
- Keller, E. F. 1992b. *Secrets of Life, Secrets of Death: Essays on Language, Gender and Science*. New York: Routledge.
- Kerr, A., Cunningham-Burley, S. and Amos, A. 1997. 'The New Human Genetics: Professionals' Discursive Boundaries'. *Sociological Review* 45:279–303.
- Kerr, A., Cunningham-Burley, S. and Amos, A. 1998a. 'Eugenics and the New Human Genetics in Britain: Examining Contemporary Professionals' Accounts'. *Science, Technology and Human Values* 23:175–98.
- Kerr, A., Cunningham-Burley, S. and Amos, A. 1998b. 'The New Human Genetics and Health: Mobilising Lay Expertise'. *Public Understanding of Science* 7:41–60.
- Kerr, A., Cunningham-Burley, S. and Amos, A. 1998c. 'Drawing the Line: An Analysis of Lay People's Discussions about the New Human Genetics'. *Public Understanding of Science* 7:113–33.
- Kevles, D. 1986. *In the Name of Eugenics: Genetics and the Uses of Human Heredity*. Berkeley: University of California Press.
- Koch, L. and Stemerding, D. 1994. 'The Sociology of Entrenchment: A Cystic Fibrosis Test for Everyone?'. *Social Science and Medicine* 39:1211–20.
- Kitzinger, J. and Reilly, J. 1997. 'The Rise and Fall of Risk Reporting – Media Coverage of Human Genetics Research, "False Memory Syndrome" and "Mad Cow Disease"'. *European Journal of Communication* 12:319–50.
- Lippman, A. 1991a. 'Genetics and Public-Health – Means, Ends, and Justices'. *American Journal of Human Genetics* 48:1201–2.
- Lippman, A. 1991b. 'Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequalities'. *American Journal of Law and Medicine* xvii, 1&2:15–50.
- Lippman, A. 1992a. 'Led (Asray) by Genetic Maps: The Cartography of the Human Genome and Health Care'. *Social Science and Medicine* 35:1469–76.
- Lippman, A. 1992b. 'Mother Matters: A Fresh Look at Prenatal Testing'. *Issues in Reproductive and Genetic Engineering* 5:141–54.
- Lippman, A. 1994. 'The Genetic Construction of Prenatal Testing: Choice, Consent or Conformity for Women', pp. 9–34 in K. Rothenberg and E. Thomson (eds.), *Women and Prenatal Testing: Facing the Challenges of Technology*. Ohio: Ohio State University Press.
- Ludmerer, K. 1989. 'American Geneticists and the Eugenics Movement, 1905–1935'. *Journal of the History of Heredity* 30:371–3.
- MacKenzie, D. 1978. 'Statistical Theory and Social Interests: Case Study'. *Social Studies of Science* 8:35–83.

- Magnay, D., Wilson, O., El Hait, S., Baalamar, M. and Burn, J. 1992. 'Carrier Testing for Cystic Fibrosis: Knowledge and Attitudes within a Local Community'. *Journal of the Royal College of Physicians of London* 26:69–70.
- Marteau, T., Drake, H. and Bobrow, M. 1994. 'Counselling Following Diagnosis of a Foetal Abnormality: The Differing Approaches of Obstetricians, Clinical Geneticists and Genetic Nurses'. *Journal of Medical Genetics* 31:864–7.
- Marteau, T., Plenicar, M. and Kidd, J. 1993. 'Obstetricians Presenting Amniocentesis to Pregnant Women: Practice Observed'. *Journal of Reproductive and Infant Psychology* 11:3–10.
- Marteau, T. and Richards, M. (eds.) 1996. *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*. Cambridge: Cambridge University Press.
- Martin, E. 1987. *The Woman in the Body: A Cultural Analysis of Reproduction*. Milton Keynes: Open University Press.
- Mayeux, R. and Schupf, N. 1995. 'Apolipoprotein E and Alzheimer's Disease: The Implications of Progress in Molecular Medicine'. *American Journal of Public Health* 85:1280–4.
- Medical Research Council 1997. 'Genes and the Mind'. London: Medical Research Council.
- Michael, M. 1992. 'Lay Discourses of Science: Science-in-General, Science-in-Particular and Self'. *Science, Technology and Human Values* 17:313–33.
- Michie, S., Bron, F., Bobrow, M. and Marteau, T. 1997. 'Non-Directiveness of Genetic Counselling: An Empirical Study'. *American Journal of Human Genetics* 60:40–7.
- Nelkin, D. and Tancredi, L. 1989. *Dangerous Diagnostics: The Social Power of Biological Information*. New York: Basic Books.
- Nelkin, D. 1992. 'Genetics and Social Policy'. *Bulletin of the New York Academy of Medicine* 68:135–43.
- Nelkin, D. 1994. 'Promotional Metaphors and their Popular Appeal'. *Public Understanding of Science* 3:25–31.
- Nelkin, D. and Lindee, S. 1995. *The DNA Mystique: The Gene as a Cultural Icon*. New York: W. H. Freeman and Co.
- Norton, B. 1983. 'Fisher's Entrance into Evolutionary Science: The Role of Eugenics', pp. 19–29 in M. Greer (ed.), *Dimensions of Darwinism*. Cambridge: Cambridge University Press.
- Nuffield Council on Bioethics. 1993. *Genetic Screening: Ethical Issues*. London: Nuffield Council on Bioethics.
- Overall, C. 1992. 'Selective Termination of Pregnancy and Women's Reproductive Autonomy', pp. 145–89 in H. Holmes (ed.), *Issues in Reproductive Technology 1: An Anthology*. New York: Garland.
- Parsons, E. and Atkinson, P. 1992. 'Lay Constructions of Genetic Risk'. *Sociology of Health and Illness* 14:437–55.
- Parsons, E. and Atkinson, P. 1993. 'Genetic Risk and Reproduction'. *Sociological Review* 41:679–706.
- Paul, D. 1992. 'Eugenics Anxieties, Social Realities, and Political Choices'. *Social Research* 59:663–83.
- Paul, D. 1995. *Controlling Human Heredity: 1865 to the Present*. New Jersey: Humanities Press.
- Petersen, A. 1998. 'The New Genetics and the Politics of Public Health'. *Critical Public Health* 8:59–71.
- Pinker, S. 1997. 'Why they kill their newborns'. *New York Times Magazine*, 2 November:52.
- Plomin, R., Owen, M. and McGuffin, P. 1992. 'The Genetic Basis of Complex Human Behaviours'. *Science* 264:1733–9.
- Price, F. 1996. 'Now You See It, Now You Don't: Mediating Science and Managing Uncertainty in Reproductive Medicine', pp. 84–106 in A. Irwin and B. Wynne (eds.), *Misunderstood Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University Press.
- Proctor, R. 1988. *Racial Hygiene: Medicine Under the Nazis*. Cambridge, Mass.: Harvard University Press.
- Rapp, R. 1994. 'Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective', pp. 219–33 in

- K. Rothenberg and E. Thomson (eds.), *Women and Prenatal Testing: Facing the Challenges of Technology*. Ohio: Ohio State University Press.
- Rapp, R. 1998. 'Refusing Prenatal Diagnosis: The Meanings of Bioscience in a Multicultural World'. *Science, Technology and Human Values* 23:45–70.
- Richards, M. 1996. 'Families, Kinship and Genetics', pp. 249–73 in T. Marteau and M. Richards (eds.) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*. Cambridge: Cambridge University Press.
- Ridley, M. 1993. *The Red Queen: Sex and the Evolution of Human Nature*. London: Viking.
- Ridley, M. 1997. *Evolution*. Oxford: Oxford University Press.
- Roll-Hansen, N. 1989. 'Geneticists and the Eugenics Movement in Scandinavia'. *British Journal of History of Science* 22:335–46.
- Rose, H. 1994. *Love, Power and Knowledge: Towards a Feminist Transformation of the Sciences*. Cambridge: Polity Press.
- Rothman, B. K. 1986. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. New York: Viking.
- Rutter, M. and Plomin, R. 1997. 'Opportunities for Psychiatry from Genetic Findings'. *British Journal of Psychiatry* 171:209–19.
- Shakespeare, T. 1995. 'Back to the Future? New Human Genetics and Disabled People'. *Critical Social Policy* 46:22–35.
- Sherman, S., De Fries, J., Gottesman, I., Loehlin, J., Meyer, J., Pelian, M., Rice, J. and Waldman, I. 1997. 'Behavioural Genetics 1997: ASHG Statement. Recent Developments of Human Behavioral Genetics: Past Accomplishments and Future Direction'. *American Journal of Human Genetics* 60:1265–75.
- Shuster, E. 1992. 'Determinism and Reductionism: A Greater Threat because of the Human Genome Project', pp. 115–235 in G. Annas and E. Sherman (eds.), *Gene Mapping: Using Law and Ethics as a Guide*. Oxford: Oxford University Press.
- Stone, D. and Stewart, S. 1996. 'Screening and the New Human Genetics: A Public Health Perspective on the Ethical Debate'. *Journal of Public Health Medicine* 18:3–5.
- Sweeney, B. 1997. 'Genetic Advances: Great Promise Tempered with Concern'. *British Journal of General Practice*, September: 544–5.
- The Wellcome Trust Medicine in Society Programme. 1998. *Public Perspectives on Human Cloning*. London: The Wellcome Trust.
- Van Dijck, J. 1998. *Imagination: Popular Images of Genetics*. London: Macmillan.
- Watson, J. 1990. 'The Human Genome Project: Past, Present and Future'. *Science* 248:44–9.
- Welsh Institute for Health and Social Care. 1997. *Report of the Citizens' Jury on Genetic Testing for Common Disorders. What Conditions Should be Fulfilled Before Genetic Testing for Susceptibility to Common Diseases Becomes Widely Available on the NHS?* Cardiff: University of Glamorgan.
- Wright, R. 1995. *The Moral Animal: Evolutionary Psychology and Everyday Life*. London: Little Brown.
- Wynne, B. 1991. 'Knowledges in Context'. *Science, Technology and Human Values* 19:1–17.
- Wynne, B. 1992. 'Misunderstood Misunderstanding: Social Identities and Public Uptake of Science'. *Public Understanding of Science* 1:281–304.
- Wynne, B. 1995. 'The Public Understanding of Science', pp. 361–88 in S. Jasanoff, G. Markel, J. Petersen and T. Pinch (eds.), *Handbook of Science and Technology Studies*. London: Sage.
- Wynne, B. 1996. 'May the Sheep Safely Graze? A Reflexive View of The Expert-Lay Knowledge Divide', pp. 44–83 in S. Lash, S. Bronislaw and B. Wynne (eds.), *Risk, Environment and Modernity: Towards a New Ecology of Risk*. London: Sage.

Yates, J. R. W. 1996. 'Medical Genetics'. *British Medical Journal* 312:1021–5.

Biographical note: ANNE KERR is currently doing research into the social history of cystic fibrosis (funded by the Wellcome Trust). She followed her PhD studies on gender, feminism and science at Edinburgh University with a research fellowship in the Medical School on the social context of the new genetics (with Sarah Cunningham-Burley and Amanda Amos). She has co-authored a range of articles on professional and lay accounts of the new genetics and is working on a book with Tom Shakespeare on eugenics and the new genetics. SARAH CUNNINGHAM-BURLEY is currently Senior Lecturer in Medical Sociology, Public Health Sciences, University of Edinburgh. Her research interests span medical and family sociology. In addition to her on-going work on the social context and implications of the new genetics, she is conducting work on children's experiences of inequalities in health (funded by the ESRC under the Health Variations Programme) and women's experiences of combining work and parenting (funded by the Joseph Rowntree Foundation).

Address: Kerr, Science Studies Unit, 21 Buccleuch Place, University of Edinburgh, Edinburgh, EH8 9LN; Cunningham-Burley, Department of Public Health Sciences, Medical School, Teviot Place, University of Edinburgh, Edinburgh, EH8 9AG.