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# The genetic conception of health: is it as radical as claimed?

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**ABSTRACT** The so-called new genetics is widely predicted to radically transform medicine and public health and deliver considerable benefits in the future. This article argues that, although it is doubtful that many of the promised benefits of genetic research will be delivered, an increasingly pervasive genetic worldview and expectations about future genetic innovations are profoundly shaping conceptions of health and illness and priorities in healthcare. Further, it suggests that debates about the normative and justice implications of new genetic technologies thus far have been constrained by bioethics discourse, which has tended to frame questions narrowly in terms of how best to ensure the protection and promotion of the rights and freedoms of the individual. Sociologists and other social scientists can help broaden debate in this field by exposing the assumptions underlying the genetic conception of health and exploring the implications of associated developments.

**KEYWORDS** *bioethics; conception of health; new genetics; personalized medicine; public health*

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## *Researchers set to find 'genetic signposts' for eight diseases*

One of the biggest projects ever undertaken to identify the genetic variations that may predispose people to or protect them from eight major diseases is to begin after receiving almost £9 million of funding from the Wellcome Trust.

The Wellcome Trust Case Control Consortium (WTCCC) is a collaboration of 24 leading human geneticists, who will analyse thousands of DNA samples from patients suffering with different diseases to identify common genetic variations for each condition. It is hoped that by identifying these genetic signposts, researchers will be able to understand which people are most at risk, and also produce more effective treatments ... (*Newswise*, 28 September 2005, <http://www.newswise.com/articles/view/514931/> (accessed 2 November 2005))

*'Gene code-card' will help doctors treat patients*

A card holding patients' genetic details could help revolutionise the way doctors prescribe drugs, according to scientists in Israel. Researchers at Technion's Rappaport Faculty of Medicine and Carmel Medical Centre are examining ways in which a patient's genome – the entire genetic make-up – could be stored on a card which a doctor could swipe onto a computer to help choose appropriate medication. Team leader Professor Ariel Miller said such advances were 'not far off' . . . (*Guardian*, 9 January 2006: 7)

News stories about new genetic innovations have become commonplace in recent years. From the 1990s, in the wake of the Human Genome Project (HGP), the HapMap Project and other 'gene-mapping' initiatives, there are great expectations that genetics will radically transform conceptions of health and illness and the nature of healthcare delivery in the future. Genetic developments are said to hold the 'key' to 'unlocking the secrets of life', and through enhanced understanding of disease processes, allow control over life itself. Press coverage is replete with metaphors of 'discovery' and stories of heroic feats, presenting a generally positive portrayal of developments afoot (e.g. Conrad, 1999, 2001; Petersen, 2001, 2002; Kitzinger et al., 2003; Holtzman et al., 2005; Petersen et al., 2005; Racine et al., 2006). Editorials of science and clinical journals also reflect the high expectations for genetics for the understanding and management of disease and anticipate important effects on healthcare, especially the healthcare professions and on wider society (Miller et al., 2006). In the future, it is argued, medicine will become 'predictive' and 'personalized', allowing identification of those 'at risk' of developing illness and the use of drugs 'tailored' to the genetic profile of the individual. The Genetics White Paper, *Our inheritance, our future: Realising the potential of genetics in the NHS* (Department of Health, 2003) outlines an array of applications of genetics in the NHS in the future, including testing for single gene disorders, improving preventive and monitoring services for those at risk of developing disease and developing new drugs and novel therapies. In public health, genetics is expected to find applications in new strategies of prevention and risk-minimization, based on a better understanding of the interactions between genes, environments and lifestyles. According to public health experts, genetic epidemiology will help disentangle the contributions of genetics to population health, assisted through the formation of large-scale human genetic databases ('biobanks'), which are being established in a number of countries (see TRAMES, 2004; Tutton and Corrigan, 2004; *Critical Public Health*, 2005, vol. 15, no. 5; Petersen, 2005). Clearly, human genetics is a field rich in metaphor and full of expectation. New forms of expertise are emerging and new institutional arrangements and networks are being forged on the premise that genetics *will* deliver what is promised. But are these promises likely to be fulfilled? Is the genetic conception of health as radical as its proponents claim?

As I argue, although it is doubtful that many of the promised benefits of

genetic research will be delivered, an increasingly pervasive genetic worldview and expectations about new genetic technologies in the future are profoundly shaping conceptions of health and illness and priorities in healthcare. Concepts of the natural and the normal are being transformed and consequently meanings of health and illness and disability. The increasingly pervasive genetic worldview, I contend, is reinforced by a range of policies and programmes and supported by diverse constituencies. This article identifies some of these initiatives and interests and highlights a number of implications of developments thus far. New genetic technologies give rise to many substantive questions, including: how should one assess claims about their future applications and benefits? Do the potential benefits of the technologies outweigh the risks? What is the nature of these risks and can they be adequately regulated? Are particular developments more worthy of support than others? Who is most likely to own and have access to genetic data? What are the implications of technologies for the distribution of resources in healthcare and public health? Which groups stand to gain and which are likely to be disadvantaged by particular developments? And, how are technologies shaping how we perceive the body, health and illness, and self and society? Debate about the diverse normative and social justice implications of genetic developments thus far, however, has been constrained by the discourse of bioethics, which has tended to frame questions narrowly in terms of how best to ensure the protection and promotion of the rights and freedoms of the individual. As I argue, sociologists and other social scientists can help broaden this debate by exposing the assumptions underlying the genetic conception of health and illness and exploring their diverse implications. While some important social science contributions to the field of genomic/genetics have been made in recent years, much critical deconstructive work remains to be done.

### **The reconfiguration of ‘nature’ and the conception of health**

A major theme of social science work on human genetics in recent years has been the potential, or perceived potential, of genetics to ‘reconfigure’ or ‘design’ ‘nature’ (e.g. Rose, 2001; Chapman and Frankel, 2003; Glasner, 2004; Glasner and Rothman, 2004; Jasanoff, 2005). The notion of a fixed and immutable ‘nature’ separate and separable from ‘culture’ is seen to be challenged by recent developments in genetics and other life sciences. Technological advancement, so the argument goes, allows unprecedented control over life processes and, by implication, over ‘natural’ events such as disease, as suggested by innovations in the fields of genome mapping, cloning and embryonic stem cell research. Science and media portrayals of human genetic ‘breakthroughs’, such as those above, reflect a conception of health as an ideal state of freedom from disease, the predominant causes of which are seen to be due to ‘faults’ in the makeup of the human organism (the genome). In this conception, the significance of ‘culture’, which shapes

the institutions and environments which humans inhabit and which predispose to disease (poor working conditions, polluted air, soil and water, ozone depletion, lack of access to balanced diets, adequate healthcare, etc.) tends to be ignored or assigned secondary importance to genes.

Adherence to the conceptual separation between 'nature' and 'culture' is in line with the view that social development and self-understanding necessitate liberating humans from the constraints of nature (Rheinberger, 1995: 257). As some writers indicate, however, 'nature' has never existed independently of its representations. Indeed, as Bruno Latour points out, to speak of 'nature' and 'its' representations suggests that there could be a domain of reality existing outside society, history and politics (2004: 32–41). As has become increasingly evident, the concepts of 'nature' and 'culture' and how they are seen to be related varies through time and across contexts. For example, in the early post-Second World War period, explanations that strongly emphasized the influence of nature fell out of favour as a consequence of widespread abhorrence to the Nazi eugenic programme. However, in the late 20th and early 21st centuries there has been a turn towards explanations of human health and social behaviour that emphasize the influence of 'nature'. In the field of social behaviour, the privileging of 'nature' over 'culture' is evident in the socio-biology of the 1970s and, more recently, the rise of evolutionary psychology (Rose and Rose, 2000).

In medicine, increasingly, genetics is seen to provide the answer to the 'riddle' of disease; whereas in public health, it is seen to offer insight into the status of the health of populations and to hold the potential for new strategies of risk management. In many contemporary societies, the increasing emphasis on 'nature' in explanations of social behaviour and health corresponds broadly with the ascendance of neo-liberal philosophies and policies, the liberalization of markets and attacks on welfare provision. Processes of individualization, consumerism and the commodification of the body and of healthcare constitute the preconditions for the emergence of the genetic conception of health. Writing in the early 1990s, Miringoff documented the rising significance of genetic explanations, or what she terms 'Genetic Welfare', for a range of issues, at the expense of Social Welfare, which has historically sought to improve human life by alterations to the social environment through organizational and institutional change. As Miringoff argued, matters of birth, death, disease, disability and quality of life are increasingly subject to genetic interventions, which reflect a shift in our vision of our abilities (Miringoff, 1991: 6). Since the early 1990s and in the wake of the 'mapping' of the HGP and other genetic research developments, a focus on genetic explanations for disease and behaviours has intensified, reflecting an increasingly pervasive 'bio-politics' (Foucault, 1980). Although the notion of sovereignty as power over life has a long history in the West (see Agamben, 1998), more and more biology is becoming the basis for social classification and citizenship identification

(Petryna, 2002; Rose and Novas, 2005). The growing number of patient support groups organized around particular genetic conditions would seem to confirm Paul Rabinow's (1992) observation on the emergence of new forms of 'bio-sociality' and citizenship. Increasingly, patient groups organize and work to advance the interests of those who *share* an identity based on the common experience of *having* a genetic condition. Such groups often have close links with and share the goals of health professionals and lobby for research into particular genetic conditions (see Mackta and Weiss, 1994; Rapp, 1999).

The wide appeal of genetic explanations can be explained by their resonance with broader discourses on self and society. The notion that genetics defines one's identity and one's destiny is deeply rooted in the dominant western cultures, in discourses of individuality and individual responsibility (liberalism and humanism), biological differences in human types and diseases 'running through families'. The idea of the genetic 'fingerprint', the unique biological identifier that can be used to identify the dead body, the missing person, a biological relative or perpetrator of a crime has become widespread since 1986, when the technology was first used to solve a widely publicized British murder case (Nelkin and Andrews, 1999: 191). A number of cases since then have relied heavily on evidence derived from DNA samples, often resulting in the conviction of the accused. For example, the conviction in December 2005 of Bradley John Murdoch for the murder of British tourist Peter Falconi in the Australian outback relied heavily on DNA evidence from the T-shirt of the accused, believed to be deposited in the course of attacking Falconi's partner, Joanne Lees. (At the time of the trial, Falconi's body had not been found; [http://en.wikipedia.org/wiki/Peter\\_Falconio#Prosecution\\_evidence](http://en.wikipedia.org/wiki/Peter_Falconio#Prosecution_evidence) (accessed 16 January 2006).)

### **The promise of 'personalized' medicine**

For pharmaceutical companies, the idea that a single 'faulty' or 'defective' gene may cause disease has strong attraction, since it implies the need for a diagnosis through a simple gene test and then treatment with drugs. The field of pharmacogenetics, which promises to offer drugs 'tailored' to the individual's genetic makeup (e.g. Herceptin for severe breast cancer) is claimed to be moving rapidly into the clinic, assisted by the prodigious networking of the pharmaceutical companies and, in the UK at least, efforts to change the culture of genetic testing within the healthcare system (Hedgecoe, 2004: 106–21). Science and news media portrayals of genetic discoveries and technology 'breakthroughs' reinforce the impression that a range of new, 'personalized' genetic applications is 'just around the corner' (Petersen, 2001; Holtzman et al., 2005; Miller et al., 2006). In October 2005, for example, the journal *Nature* reported that Japanese companies had developed a machine that would allow doctors to check patients' DNA from a single drop of blood before writing a prescription (Cyranoski, 2005).

Interestingly, the announcement came very soon after the publication of a report from the UK's The Royal Society, which argued that pharmacogenetics had been 'overhyped' and that its implementation will be a 'gradual rather than revolutionary process' and that it will take 15 to 20 years to live up to its promise in clinical practice (Royal Society, 2005: 41). Media reports and science commentators rarely question the feasibility or desirability of such developments or ask whether 'consumers' want such drugs and who is likely to have access to them and at what cost. A number of normative and justice issues arise from this field, including, apart from those of access to drugs, the distributional affects associated with investments in the field and the adequacy of established procedures of informed consent (Hedgecoe, 2004: 166–73). The development of 'personalized' medicine arguably compounds a more general medicalization of phenomena and the tendency for pharmaceutical companies to turn otherwise healthy populations into patients (Moynihan and Cassels, 2005; Law, 2006). The development of pharmaceuticals for specific population groups, particularly ethnic and racial minorities, whom, it is asserted show different responses to certain drugs, also raises the question about the potential for pharmaceuticals designed for one group to be used for germ-line intervention designed for such a group, with eugenic outcomes (Duster, 2003: 174). These issues are likely to become acute *if* 'personalized' medicine ever reaches a stage of development where it is able to be 'mainstreamed' into healthcare.

The ideal of 'personalized' medicine is compatible with an increasingly market-driven and commodified healthcare system. The individual is expected to take the initiative in relation to their own healthcare and risk management, monitor their bodies, diet if deemed necessary, take regular exercise, avoid 'risky' behaviours, take appropriate preventive action and, in cases of illness, manage illness 'successfully' (Frank, 1995). Access to 'adequate' information about one's genetic health status and about treatment options in healthcare is seen to provide the precondition for 'informed choice'. The expectation is that those who are currently well (the 'pre-symptomatic' ill) who have a family medical history for a disorder should undertake gene tests for that disorder where these are available and track risk through the family by 'drawing the family tree' (Petersen, 1999). Self-management is facilitated through 'direct-to-consumer' marketing and the sale of 'over-the-counter' genetic tests, thereby effectively bypassing the clinician and taking diagnosis and, in some cases, treatment directly to the individual via the Internet and High Street. In recent years, single gene tests have been developed for a range of conditions, including cystic fibrosis, haemophilia, Tay Sachs disease, thalassaemia, inherited haemochromatosis and inherited breast and ovarian cancer. Recently, however, the value of many such tests has been questioned, with claims that they are often 'rushed to market' without studies to prove they benefit patients (Sample, 2006: 5). Concerns have also been raised about whether 'consumers' can be considered to be adequately 'informed' when

information deriving from tests is probabilistic and decision making occurs without adequate counselling support and/or under tight constraints of time (Malinowski, 1994).

### **Criticisms of and opposition to developments**

This 'geneticization' of health and healthcare has not occurred without critical comment and outright opposition. Commercial involvement in genetics research, and the associated commodification of the body and its parts, has been an issue of considerable concern to many people (Whitt, 1998; Boyes, 1999; Hansen, 1999; Pálsson and Harðardóttir, 2002). Worries about ethics and privacy, potential discrimination against disabled people, discrimination in employment and insurance, possible misuse of samples for cloning or other questionable purposes, and profiteering by pharmaceutical and biotechnology companies have been revealed by opinion polls (Everett, 2003) and focus groups with lay publics (Wellcome Trust and MRC, 2000). Efforts by companies to patent genes linked to particular diseases, for example Myriad Genetics' (USA) securing of a European patent related to the BRCA1 breast cancer associated gene and to monopolize the market in gene testing, has been challenged by doctors, researchers and a number of governments (Gottweis, 2005: 198–9). NGOs, such as Britain's GeneWatch UK, disability groups, feminist scholars and right-to-life groups, are among those who have also raised questions about the applications and implications of new genetic developments, such as genetic testing, pharmacogenetics and cloning research.

The assumption held by many proponents of new genetic technologies that 'consumers' are unequivocally supportive of and will welcome these technologies is questionable. In the UK, in 2002, the Human Genetics Commission undertook a review of and consultation on genetic testing services provided directly to the public. This revealed confusion about genetic testing, and concerns about commercial interests seeking to promote nutritional and other products, confidentiality of test results and about what such results might mean for insurance premiums (Mayor, 2003). The UK's GeneWatch has raised concerns about unregulated genetic testing on the Internet and High Street, for example in relation to the accuracy of information and the potential harms posed without proper advice and counselling (GeneWatch, 2002). Publics' and activists' concerns about genetic testing are shared by some policy makers. In Australia, marketing of genetic tests direct to the consumer was recently considered by the Australian Law Reform Commission and the Australian Health Ethics Committee as part of their inquiry into the legal and ethical issues surrounding the protection of human genetic information. In response, the Australian government recommended 'regulat[ing] more effectively in vitro diagnostic devices used in genetic testing provided directly to the public' as well as 'health related home use genetic tests' (ALRC and AHEC, 2005).

As some commentators have argued, positive results from such tests are difficult to interpret since some of those who carry a mutation linked to a disease do not develop the disease. In prenatal testing and testing for 'late-onset' conditions, questions have been raised as to whether it is valid and 'safe' for individuals to make decisions about termination or medical treatments or life plans (e.g. whether or not to start a family) on the basis of a genetic test alone. With breast cancer, for example, tests for BRCA1 and BRCA2 mutations linked to the disease can neither predict whether women will develop breast cancer, nor reveal information on the possible age of onset, severity or course of the disease (Byravan, 2004). However, some researchers and healthcare workers have suggested prophylactic bilateral mastectomy (i.e. the removal of both breasts) for women deemed 'at risk' of breast cancer, as indicated by tests showing they have a mutation (see, for example, [breastcancer.org](http://www.breastcancer.org/research_genetics_013105.html), [http://www.breastcancer.org/research\\_genetics\\_013105.html](http://www.breastcancer.org/research_genetics_013105.html) (accessed 15 January 2006)).

The premise that the implications of genetic tests are limited to the individual who is tested can be challenged. The inheritable nature of conditions means that, in medical treatment, 'the patient' is not just the individual but the whole family (Richards, 1996). Women tend to bear most responsibility for tracking genetic risk within the family and may experience guilt and anxiety in relation to past, present and future generations that may be affected by a genetic condition (Hallowell, 1999). Family members' rights in relation to privacy and the implications of knowing versus not knowing one's diagnosis are concerns that have been raised (see, for example, Malinowski, 1994; Chadwick et al., 1997). Although the demands and dilemmas facing people whose conditions have been diagnosed as 'genetic' would seem to be similar in many respects to those facing people with other health conditions, knowing that one's condition is inheritable and may be passed on to others is likely to pose particular demands on those affected. These may become salient at certain critical junctures, such as when individuals are planning to have children or when they meet a partner (Parsons and Atkinson, 1992; Cox and McKellin, 1999; Petersen, 2006). At such times, issues of identity, risk and responsibility for others are likely to take on heightened significance. Recognizing that genetic information is qualitatively different from other medical information ('genetic exceptionalism'), some writers have argued that the use of genetic tests requires special consideration in relation to informed consent, privacy and provision of healthcare (Suter, 2001; Green and Butkin, 2003).

The claim that genetic tests will provide the basis for a 'predictive' medicine is also questionable. As Holtzman and Marteau (2000) point out, the complexity of the genetic basis of most common diseases will mean that it is unlikely that genetics will allow the prediction of disease in the future. Except for some rare conditions of 'high penetrance', such as Huntington Disease, increasingly it is recognized that social and physical environments and lifestyles play a role, and perhaps a more significant role, in

determining diseases. Focusing on the genetic basis of disease diverts attention from the potentially major contribution of these factors and the necessity for collective responses to health problems. As Evan Willis (2005) argues, there is a tension between the individual and collective interests in the uptake of new genetic technologies. While there may be opportunities arising from an increased understanding of the genetic basis of disease, an overemphasis on genetic contributions can lead to the neglect of the environmental factors that may influence the overall incidence of disease in the population. For example, the incidence of cancer is widely known to be linked to a host of non-genetic factors, including pesticides, radiation, organochlorides, diet and exercise, a fact that can be obscured by the 'geneticization' of cancer (Epstein, 1998, 1999). The idea that diseases are 'caused' by single gene mutations is reinforced by the newspaper press and other media, with almost daily stories of new gene 'discoveries', 'finds' and 'links', frequently including predictions by cited or quoted scientists of imminent new treatments. These stories almost invariably neglect consideration of non-genetic and 'multifactorial' explanations for disease, involving the interactions of multiple genes and environments (Petersen, 2001; see also Conrad, 1999). The view of genes as causative can lead to a blaming-the-victim approach to treating illness and the stigmatization of the ill: illness is seen as an inherent failure of the individual rather than an outcome of an 'unhealthy' social or physical environment.

Finally, a number of critical scholars, particularly those working in the field of disability studies, have warned of the potential for the routine use of genetic technologies in healthcare to lead to eugenics 'through the backdoor' (Duster, 1990; see also Allen, 1996). As Shakespeare (1998) comments, while there may be a rhetorical commitment in healthcare towards individual choice, this is likely to be compromised in a healthcare system where screening is extended to the whole population and there is an emphasis on efficiencies. Economic pressures create imperatives to screen out the unhealthy and the disabled. Thus, the 'weak eugenics' of the current health system, which is an outcome of 'reproductive selection via non-coercive individual choices', may gradually shift towards 'strong eugenics', which characterized the coercive population policies of an earlier period (Shakespeare, 1998: 669). Other disability scholars have also warned of the devaluing of the lives of the disabled and the prospect of discrimination arising from an emphasis on prenatal testing for genetic 'defects' (e.g. Newell, 1999; Ward, 2005). In genetics-based medicine, 'the right to choose' available to some may inadvertently lead to the restriction of the rights or life chances of others through selective reproduction (eugenics), discrimination against those diagnosed with conditions or the creation of a genetic 'underclass' (Rifkin, 1998; Kelly, 2005). Duster's (2003) warning in relation to pharmacogenetics' focus on specific population groups, noted earlier, has particular pertinence here. The use of 'new' in 'new genetics' may serve rhetorically to mask an affinity and continuity with the

programmes and practices of the 'old' eugenics; that is, the same selective outcomes may be achieved via new mechanisms (Petersen, in press). None of these outcomes are inevitable, of course, but they are potential implications that have been identified by critics and commentators of the new genetics and need to be acknowledged and become part of public and policy deliberations in this field.

## **Genetic conceptions of population health**

Debates thus far have focused predominantly on *medical* knowledge and practices; that is, on how genetics will change conceptions of disease and healthcare at the level of the individual and in the clinic. Less explored have been the implications of a growing genetic worldview for *population health*. In the 1990s, health professionals and policy makers increasingly focused their attention on the genetics of whole populations, through studies seeking to map genetic diversity in different groups and to ascertain the contributions of genes, environments and lifestyle to health. A field of public health genetics began to emerge, informed by the discipline of genetic epidemiology (see Khoury et al., 2000). The promise is that greater understanding of gene–environment–lifestyle interactions will lay the groundwork for new medical treatments and preventive measures 'tailored' to the needs of subgroups with particular genetic characteristics (e.g. Khoury, 1996: 1720; Zimmern, 1999: 137). Most discussion within this field, however, has concentrated on the potential for new medical treatments with relatively little discussion of environmental measures for the so-called genetically 'susceptible'. Indeed, in public health genetics, 'environment' is an ill-defined concept, and often used as a synonym for 'lifestyle'. The uptake of genetic knowledge in public health threatens to challenge traditional conceptions of public health with their focus on changes to host–environment–agent relations via alterations to living and working conditions and changes in lifestyles (Petersen and Bunton, 2002: 96–8).

The recent rapid development in a number of countries of population-wide human genetic databases, dubbed 'biobanks', comprising DNA data along with personal medical and lifestyle information, is perhaps the most obvious manifestation of the concern with the genetic health of populations. The emergence of biobanks reflects widespread belief among health professionals and policy makers in the potential of genetic epidemiology eventually to untangle the genetic and non-genetic contributions to disease. The concept of a database that includes genetic and personal information is not entirely new. Registers of patients with genetic diseases have been established in a number of countries for more than 30 years (WHO, 2002: 113–14). However, the scope, format and size of the new generation of genetic databases is unprecedented, sometimes including the entire populations of countries. In recent years, a number of countries have developed,

or announced their intentions to develop, biobanks, including Iceland, Estonia, Japan, France, Sweden, Canada (Quebec), USA, Australia and the UK.

Although biobanks vary in their organization and mix of personal and genetic information, they tend to share the goal of searching for 'susceptibility genes' for complex diseases in order to improve health and medical care and stimulate local economies (see, for example, Martin, 2001; Austin et al., 2003; TRAMES, 2004; Tutton and Corrigan, 2004; Petersen, 2005). National pride and competition and proponents' concerns to exploit the benefits of the so-called biotech revolution are 'drivers' of many developments. For example, in a medical newsletter published in 2005, a supporter of the developing Western Australian Genome Health Project wrote that the project will 'position WA biomedical research as a world leader by capitalising on the amazing resources – 30 years of health data on the entire population as well as the maternal and child health research database (McEvoy, 2005). Arguments for people's participation in biobank projects are often couched in terms of future benefits for the health of 'the public', with strong appeals made to 'genetic solidarity' and 'altruism' (HGC, 2002; Wellcome Trust et al., 2003). (On this, see Petersen, 2005.) In making the case for why people should participate in UK Biobank (which, in January 2006, announced its intention to begin recruiting within 'weeks'), Chief executive of UK Biobank, Rory Collins commented that: 'We are asking people to donate an hour of their time plus samples to establish the causes of diseases', adding 'it's a gift, and they get no information back, good or bad' (Coghlan, 2006: 8). In the early establishment phase of UK Biobank, proponents emphasized the economic and scientific benefits of the project and fears about the economic and political risks of the UK not being involved when other countries were (USA initiatives in the area were noted) (House of Lords Select Committee on Science and Technology, 2000). Similar benefits have been claimed for the Icelandic Health Database and the Estonian Genome Project.

With the urgency to develop biobanks, little attention has been paid to how research data are likely to be used, who will own data and whether projects are likely to represent a good use of resources. Ethics discourse in this area has tended to limit discussion to the issue of informed consent, as though this were the main or only issue worth consideration (Petersen, 2005). The broad governance implications have not been extensively studied thus far. (A notable exception is the research of Herbert Gottweis and his colleagues at the University of Vienna, who, at the time of writing, is completing an international study exploring the rise of biobank initiatives as an aspect of a transformation of health policy, biomedical governance, and biopolitics. See <http://www.univie.ac.at/transformation/Elsa/ELSAenter.htm> (accessed 26 January 2006).) Such collections, it is clear, pose considerable challenges for established conceptions of ethics and governance, particularly given the long-term prospective nature of research

and uncertainties about research uses and applications (Petersen, 2005). Some projects, such as the Icelandic Health Database, which includes patient information for the entire country, have been the focus of concerns about commercial involvement and ‘selling off’ the country’s genetic heritage (Pálsson and Rabinow, 1999; Pálsson and Harðardóttir, 2002). At the same time, however, such collections have served to generate some debate about identities – for example, among Icelanders about the existence of a shared ‘Viking gene’ (Pálsson, 2004) – emphasizing the contemporary significance of genetics to self-definition.

As with medical genetic applications, however, the development of such resources has given rise to concerns and some opposition. In 2004, the Icelandic project was judged to be unconstitutional after citizen complaints that the project fails to offer personal privacy to participants (McKie, 2004: 2). In the UK, ‘consultation’ workshops undertaken by UK Biobank revealed unease about genetic research in general and worries about this particular project, including commercial involvement, possible misuse of samples for cloning or other questionable purposes, potential discrimination against disabled people, loss of participants’ anonymity, profiteering by pharmaceutical and biotechnology companies and employers and insurers gaining access to information and misusing it (Wellcome Trust and MRC, 2000: 3–4; People Science and Policy Ltd, 2002) Some scientists and critics of the venture have expressed reservations about its methodology, including reliance on incomplete medical records and participants’ recollections of past behaviour and exposure to environmental risks. One fear is that incomplete data on lifestyle and environment will lead to a bias towards ‘over-emphasising the genetic influence on disease processes because it is the only thing on which Biobank will provide hard data’; i.e. genetic reductionism (Gibson, Hansard 3 July 2003).

In the USA, a biobank project announced in 2004 by the National Human Genome Research Institute in Bethesda, Maryland, aims to overcome the problem of using unreliable environmental data and the results from medical misdiagnoses by using microchip devices placed around participants’ bodies in order to keep a continuous check on their heart rate and blood oxygen levels, exposure to radiation, consumption of food, alcohol and tobacco and so on (Coghlan, 2006). This implies forms of surveillance and intrusion into people’s lives that are likely to be judged unacceptable to many people, even if it can be assumed that individuals would wish to be involved in a project of little apparent value to themselves. The prospect of surveillance may become acute as biobanks begin to share data – a prospect that has been increasingly discussed by some co-ordinators of biobank projects.

Concerns about population-based genetic research, in particular underlying assumptions about the genetics of differences of ‘race’ and ownership of DNA, have been also raised in relation to international ‘gene-mapping’ initiatives such as the Human Genome Diversity Project (HGDP) and the

HapMap Project. According to their proponents, these projects constitute resources that can be shared among scientists worldwide. The former project, launched in 1991 by a group of population geneticists, with the goal of 'mapping' diversity in hundreds of human so-called 'isolated' populations through cataloguing similarities and differences between them, has been especially controversial, having been criticized on the basis of poor science and racism (M'Charek, 2005). The project aimed to generate cell lines and DNA from blood, hair or saliva samples taken from geographically diverse populations with distinct cultures and language in order to gain insight into current genetic diversity and its evolution as well as the history of human migration throughout the world. Geneticists argued that it would also advance understanding of genetically inherited disease, though this was a secondary objective (M'Charek, 2005: 3). Indigenous groups protested at the outset of the research programme, including in relation to issues of patenting and the commercial exploitation of DNA. The project was accused of 'bio-colonialism', 'bio-pirating' and 'prospecting' and was dubbed by the World Council of Indigenous Peoples as the 'Vampire Project' (M'Charek, 2005: 13; see also Petersen and Bunton, 2002: 164–6).

The HapMap project, launched in 2002, as a follow-up to the Human Genome Project and designed to trace genetic variation within the human genome, is more directly focused on human health. This also has its critics, though has been less contentious than the HGDP. The genetic determinism underlying large-scale projects of this kind, and their failure to deliver promised treatments, are among criticisms made (Gottweis, 2005: 196). According to its webpage, the HapMap project is,

a partnership of scientists and funding agencies from Canada, China, Japan, Nigeria, the United Kingdom and the United States [who aim] to develop a public resource that will help researchers find genes associated with human disease and response to pharmaceuticals.

Further, the project 'is expected to be a key resource for researchers to use to find genes affecting health, disease, and responses to drugs and environmental factors'. It is claimed that information will be 'released into the public domain' (<http://www.hapmap.org/> (accessed 26 January 2006)). The website outlines how ethical concerns will be addressed, including protection of privacy, and acknowledges potential problems, including the 'undermin[ing of] established cultural or religious traditions or legal or political status' and the potential for stigmatization and discrimination, arising from the 'misinterpretation' of information arising from the project. The assurances offered about attention to 'community engagement' and the project's commitment to 'greater openness and trust' suggest that lessons have been learnt from the HGDP.

## **Bioethics discourse and critical social science**

The attention paid to 'ethics' in the HapMap Project is indicative of a more general increased attention to ethical considerations in genetic research beginning in the 1990s. The HGP was a significant factor contributing to the development of bioethics discourse, with a small proportion (around 5%) of the budget allocated to ELSI (Ethical, Legal and Social Implications) initiatives. However, during the late 1990s and early years of the 20th century a growing number of ethics committees, commissions and workshops have addressed the ethics of new genetic developments. For example, in the UK, the Human Genetics Commission was established in order to advise the Government on the implications of developments in this field. Recently, sociologists and some other social scientists have begun to analyse the assumptions and implications of bioethics knowledge and practice (e.g. Evans, 2002; Haimes, 2002; Corrigan, 2003). Evans (2002), among others, has argued that ethics' reliance on the frameworks of moral and analytic philosophy and on commissions and on matters of formal procedure has served to 'thin' debate on substantive issues, such as the direction of research and the ownership of knowledge. The use of certain legitimized mechanisms (e.g. focus groups) in 'public consultations' and the appeal to the language of citizenship in arguments for people's participation in projects, evident for example with UK Biobank (see Petersen, 2005), may serve to divert attention from considerable widespread concerns and objections to genetic research. Issues of politics and power, the political economy of genetic science and technologies, and the specifics of time and place are obscured by the focus on the application of abstract, universal principles to issues; i.e. 'principlism' (Evans, 2000).

Bioethics discourse reflects and legitimizes particular conceptions of health and illness and healthcare. The predominant focus of bioethics on the promotion of individual autonomy, particularly through the protection of rights (e.g. informed consent) serves to reinforce a particular view of the 'normal' individual and of what is required to achieve optimum health and wellbeing. For example, the bioethics debate surrounding 'the right to know versus the right not to know' (Chadwick et al., 1997) reveals a culturally and historically specific view of individuality; i.e. the person as a relatively unconstrained rational decision maker and information processor. In this conception, constraints of socio-economic background, ethnicity, gender and so on, tend to be overlooked. This view of the individual is consistent with the broader construction of the 'health consumer' within increasingly de-regulated healthcare systems (Henderson and Petersen, 2002). Troy Duster (2003) refers to the 'trained incapacity' of bioethicists, philosophers and those working in clinical fields to appreciate the social, economic and political dimensions of problems. As he argues,

There is an overwhelming tendency for ethicists, medical specialists, clinical geneticists, philosophers, and the best-intentioned guardians of a notion of rights

and obligations in Western societies to concentrate their ethical gaze on the states of minds and physical conditions of individuals – to the near exclusion of the fate of the social groupings to which individuals belong. (2003: 157)

The limitations of bioethics in addressing the unique challenges posed by genetics and other biotechnology developments, however, are becoming increasingly evident. In particular, there is a need to broaden debate about the diverse implications of proposed and existing developments. It is here, I would contend, that sociologists and other social scientists with an interest in new genetic developments have a key role to play.

Given its critical, relativizing stance, sociology is especially well placed to offer insight into the normative and social justice implications of genetics and other biotechnology developments (DeVries and Subedi, 1998: xiii). As DeVries and Subedi note, 'A sociological approach lifts bioethics out of its clinical setting, examining the way it defines and solves ethical problems, the modes of reasoning it employs, and its influence on medical practice' (1998: xiii). Genetic research and development concerns the fundamental issues of life and death and life chances, the implications of which urgently need the insights of sociology and other social science disciplines. The potentially far-reaching implications of new genetic developments, some of which have been outlined in this article, call for in-depth analysis and critical commentary, including in relation to the politico-economic aspects of developments and to the question of who benefits and who is disadvantaged from the use of particular technologies. The emergent sociology of bioethics is a welcome move towards a more explicitly normative approach to new genetic and other biomedical technologies. A major challenge confronting sociologists and other social scientists is how they may develop this work so as to contribute usefully to debate and policy-relevant work in this field in the years ahead.

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