

IS THE NEW GENETICS EUGENIC?: INTERPRETING THE PAST, ENVISIONING THE FUTURE

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Assessments of the implications of new technologies are inevitably shaped by interpretations of the past and visions of the future. So it is with assessments of the so-called new genetics, which is predicted to change the practices of medicine and public health in the years ahead. In the wake of the completion of the mapping of the human genome, in early 2003,¹ medicine is anticipated to become more personalised and predictive and public health more oriented to the detection of the genetically susceptible and pre-symptomatic ill. Proponents of the new genetics tend to embrace a progressive view of history, heralding the arrival of the 'post-genomic' era as one in which the individual will be empowered through being offered more choice in their health-related decisions. The individual who knows they are a potential carrier of a genetic defect will have the option of terminating a pregnancy at an early stage, while knowing that they are at risk of developing, or will develop, a genetic-related condition will allow them to take preventive action and better plan their lives. Some commentators, on the other hand, characterise the new genetics as a 'new eugenics'. As Jeremy Rifkin, for instance, writes, 'The new genetic engineering tools are, by definition, eugenics instruments', and whereas the old eugenics was shaped by political ideology, fear and hate, 'the new eugenics is spurred by market forces and consumer desire'.² Similarly, Suzanne Anker and Dorothy Nelkin note that although the 'eugenics movement declined in influence after 1935, its social agenda called into question by unfolding events in Germany', 'its legacy hovers over new genetic programs, and atavistic eugenic thinking persists'.³ However, according to this view, instead of coming through the front door of Hitler's *Lebensborn* project, eugenics is making its appearance through the back door of screens, treatments, and therapies.⁴

The question of whether or not the new genetics is, or has the potential to be, 'eugenic' has become crucial in debates about the significance of recent biotechnology developments. The 'new/old' dichotomy operates as a marker for distinguishing that which is seen to be progressive from that which is regressive. As Diane Paul observes, the word 'eugenic' has nasty connotations and often functions to mobilise anxieties. That is, 'It says: no right-thinking person could fail to object to the practice described'.⁵ However, the meaning of eugenic is obscure, and the term 'often reveals more about its user's attitudes than it does about the policies, practices, intentions, or consequences labelled'.⁶ Although often narrated as an "official" story of racist, reactionary thinkers and politicians, working with a few marginal scientists, a movement that proceeded directly from Darwin to Hitler,⁷ eugenics encompasses a

1. Tim Radford, 'Human code fully cracked', *The Guardian*, 14/04/2003), p8.

2. Jeremy Rifkin, *The Biotech Century: How Genetic Commerce Will Change the World*, London, Phoenix, 1998, p128

3. Suzanne Anker and Dorothy Nelkin, *The Molecular Gaze: Art in the Genetic Age*, Cold Spring Harbor, NY, Cold Spring Harbor Laboratory Press, 2004, p132.

4. Troy Duster, *Backdoor to Eugenics*, New York, Routledge, 1990, px.

5. Diane B. Paul, *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate*, New York, State University of New York Press, 1998, p109.

6. *Ibid.*, p143.

7. Allen Buchanan, Dan W. Brock, Norman Daniels and Daniel Wikler, *From Chance to Choice: Genetics and Justice*, Cambridge, Cambridge University Press, 2000, p29.

complex range of ideas, policies and practices. As Buchanan argues, ‘the “real” story [of eugenics is] a bewildering array of thinkers, activists, snobs, socialists, scientific visionaries and crackpots, fascists, and architects of the Scandinavian social welfare states, divided among themselves on nearly every point of doctrine and proposed intervention’.⁸ Radically different kinds of governments launched population policies inspired by ‘positive’ and ‘negative’ eugenics, but all were inspired by a belief in the applicability of science to society.⁹ Whether the new genetics can be meaningfully described as ‘eugenic’ depends crucially upon how one defines one’s terms, evaluates the past and imagines the future. Simplistic portrayals of the new genetics as eugenic involve a naïve rendering of history and politics and do little to clarify what is at stake in new genetic developments.

Proponents and opponents of the new genetics use ‘eugenics’ for different rhetorical purposes: the former as a means of emphasising the positives of the new genetics and distinguishing it from that which is to be feared, and the latter to signal the dangers of the so-called slippery slope. However, it is rare for either group to differentiate clearly between intentions, means and outcomes of policies and practices, or to specify the views of the human subject or the particular forms of citizenship associated with new genetics and eugenics, respectively. Sometimes writers object to eugenics not on the basis of the goal, such as improving the health of the population, but rather the means of its achievement. In this view, in the absence of overt coercion (as in a law or obvious forms of social pressure), policies oriented to the welfare of the population are not properly labelled eugenic.¹⁰ However, according to Paul, this approach to defining eugenics presents problems, both historically and analytically.¹¹ As noted, eugenics has had diverse manifestations, and has not, and does not, always involve overt coercion by the state, which is widely presumed to constitute the hallmark of eugenic regimes. As Kerr and Shakespeare point out, ‘eugenics was (and is) not a unified ideology or science’.¹² Francis Galton, the purported founder of eugenics, for example, believed that eugenics should be practiced as a ‘secular religion’; that is, citizens should act responsibly in their reproductive decision-making.¹³ Many other early eugenicists emphasised the voluntary character of their proposals. For example, Havelock Ellis argued that ‘the only compulsion we can apply in eugenics is the compulsion that comes from within’.¹⁴

As Paul argues, it is far from a straightforward matter to determine whether a policy is coercive and there is no neutral way to decide. Different meanings apply to coercion in different political traditions: for classical liberals and contemporary (libertarian) conservatives, coercion implies the deliberate interference of other human beings, whereas for socialists and some strands of liberalism a *situation* may also be coercive, such as the medical and other costs of caring for a child who is severely disabled.¹⁵ Some past practices are labelled eugenic because they fulfilled certain governmental objectives, despite the absence of an *explicit* eugenics policy or movement. Thus, policies adopted by the welfare states of the Scandinavian countries (Denmark,

8. *Ibid.*, p29.

9. Maria Sophia Quine, *Population Politics in Twentieth-Century Europe*, Routledge, London, 1996, p15.

10. Diane Paul, *op. cit.*, p101.

11. *Ibid.*

12. Anne Kerr and Tom Shakespeare, *Genetic Politics: From Eugenics to Genome*, Gretton, Cheltenham, New Clarion Press, 2002, p13.

13. Diane B. Paul, *op. cit.*, p105.

14. *Ibid.*, p101.

15. *Ibid.*

16. Alain Drouard, ‘Eugenics in France and in Scandinavia: two case studies’, in Robert A. Peel (ed) *Essays in the History of Eugenics*, London, The Galton Institute, 1988, pp194-195.

17. Drouard, *op. cit.*, p196.

18. Paul, *op. cit.*, p144.

Sweden, Norway and Finland), involving enforced sterilisations, have been described by many writers as eugenic, but were mostly developed in the absence of the institutionalisation of eugenics. (Sweden, for instance, was the only Scandinavian country with a national eugenics society.) Such policies, implemented in two waves (before World War I and in the 1930s and 1940s), were an integral part of the process of the construction of the Welfare State in Scandinavian countries.¹⁶ A decline in the number of sterilisations of the ‘mentally retarded’ and ‘insane’ in Denmark, Sweden and Norway from the middle of the 1940s through the 1950s, cannot be readily attributed to the revulsion caused by the Nazi crimes.¹⁷ That is, the policy change seems *not* to have been a result of recognition that sterilization had eugenic effects.

One source of confusion in debates about eugenics is the failure of commentators to distinguish between *aims/intentions* and *outcomes/effects*. As Paul explains,

Few if any women choose abortion with the aim of improving the gene pool. However, private decisions may, taken collectively, have population effects. These consequences would appropriately be labelled eugenic (or perhaps dysgenic) given some definitions – and equally inappropriate given others. And that is but one source of confusion.¹⁸

If one focuses on outcomes/effects, rather than aims/intentions or means, then policies and practices that deploy different strategies (including coercion and non-coercion) may be seen to have similar eugenic outcomes. According to the disability scholar and activist, Tom Shakespeare, eugenics – which he defines as ‘the science of improving the population by control of inherited qualities’ – may have ‘weak’ or ‘strong’ manifestations. Whereas strong eugenics involves ‘population-level improvement by control of reproduction via state intervention, such as happened in the 1930s’, weak eugenics involves the promotion of ‘technologies of reproductive selection via non-coercive individual choices’.¹⁹ He suggests that the latter is motivated by medical judgements about the value of individual disabled lives, and is the dominant form of eugenics within the British context. Further, he argues that while there is a rhetorical commitment to individual choice, trends in health care, such as the extension of screening to the whole population, and a focus on cost-benefit analysis, ‘may shift the balance’ towards strong eugenics.²⁰ Other disability scholars also see unintended eugenic outcomes resulting from an emphasis on genetic testing and reproductive autonomy.²¹ According to this line of reasoning, recent efforts to control reproduction at the population level, as in the case of Ceausescu’s pro-natalist policies in Romania (1965 to 1989),²² Israel’s subsidisation of assisted conception,²³ and China’s one-child policy (imposed 1979) and Maternal and Infant Health Law (1995)²⁴ can be considered examples of ‘strong eugenics’. The freedom of choice exercised by the many individuals who routinely undergo genetic testing and supposedly non-directive counselling²⁵ may have a similar eugenic effect. The difficulty with this argument is that it begs the question

19. Tom Shakespeare, ‘Choices and rights: eugenics, genetics and disability equality’, *Disability & Society*, 13, 5 (1998): p669.

20. *Ibid.*, p669.

21. Patricia J. Rock ‘Eugenics and euthanasia: a cause for concern for disabled people, particularly disabled women’, *Disability & Society*, 11, 1 (1998): 121-127; Adrienne Asch, ‘The disability rights critique of prenatal genetic testing’, *The Hastings Centre Report*, 29, 1 (1999).

22. Gail Kligman, *The Politics of Duplicity: Controlling Reproduction in Ceausescu’s Romania*, Los Angeles, London, University of California Press, Berkeley, 1998.

23. Susan Martha Kahn, *Reproducing Jews: A Cultural Account of Assisted Conception in Israel*, Durham and London, Duke University Press, 2000.

24. Frank Dikötter, *Imperfect Conceptions: Medical Knowledge, Birth Defects, and Eugenics in China*, London, Hurst and Company, 1998.

25. Alan Petersen, ‘Counselling the genetically “at risk”: the poetics and politics of “non-directiveness”’, *Health, Risk & Society*, 1, 3 (2001): 253-265.

26. Buchanan, op. cit., p42.

27. British Medical Association, *Human Genetics: Choice and Responsibility*, Oxford, Oxford University Press, 1998, p11.

28. Muin J. Khoury, Wylie Burke and Elizabeth J. Thomson, 'Genetics and public health: a framework for the integration of human genetics into public health practice', in M. J. Khoury, W. Burke and E. J. Thompson (eds) *Genetics and Public Health into the 21st Century: Using Genetic Information to Improve Health and Prevent Disease*, Oxford, Oxford University Press, 2000, p20.

29. Anne Kerr, 'Rights and responsibilities in the new genetics era', *Critical Social Policy*, 23, 2 (2003): 208-226.

30. Diane B. Paul, op cit., pp23-25.

31. J. Ezard, 'Scientists study media coverage of their research', *The Guardian*, 11/08/2003, p6.

32. Anne Kerr, Sarah Cunningham-Burley, and Amanda Amos, 'The new genetics: professionals' discursive boundaries', *Sociological Review*, 45 (2001): 279-303.

33. Alan Petersen, 'Biofantasies: genetics and medicine in the print news media', *Social Science & Medicine*, 52 (2003): 1255-

of *when* one may validly judge phenomena to have eugenic outcomes/effects? In some cases, it may be relatively easy to make a retrospect assessment that particular ideologies, policies or practices are eugenic; for example, the policies of the Nazi era. But it is questionable whether it is valid to label ideologies, policies, or practices as eugenic when their longer-term impact is unclear, as is the case with the new genetics.

The definitional ambiguity of 'eugenics', it can be argued, is what gives this term its rhetorical power. 'Eugenics' has been defined in line with different political and practical objectives. As Buchanan, et al, argue, 'If there was a core belief common to all eugenicists, it would have to be expressed in the most general terms: concern for human betterment through selection – that is, by taking measures to ensure that the humans who do come into existence will be capable of enjoying better lives and of contributing to the betterment of lives of others'.²⁶ That is, it is based upon the utilitarian assumption that desired ends of policies or programs are a sufficient justification for the means used to achieve those ends. Articulated at this level of generality, the beliefs of eugenicists, on the face of it, seem not too dissimilar to those expressed by many proponents of the new genetics. For example, a book published by the British Medical Association notes that, 'Genetic advances have a huge potential to benefit people. In time, the technology will doubtless lead to medical interventions which can improve the health and extend the options of families who have serious genetic abnormalities'.²⁷ Another book, on public health genetics, predicts, 'In the not too distant future ... disease prevention and health promotion programs will routinely consider whether or not to use genetic information to help target intervention activities so as to maximize benefit and minimize costs and harm to individuals'.²⁸ Such statements reveal a number of beliefs that are widely shared by many scientists, health care workers, representatives of the biotech industry and policy makers; namely, that history and science are progressive in their development and that genetic research will, in time, deliver benefits. They reveal confidence in established programs of research and little doubt that valuable technologies will emerge. Health improvements are seen to follow logically from the rational applications of objective, value-free science. As noted, belief in the applicability of science to society inspired the eugenics policies promoted by radically different kinds of governments in the past. Although it is inaccurate to draw simplistic parallels between the genetics of the present and the eugenics of the past, a focus on the transformations wrought by the new genetics can direct attention away from continuities between the past and present.²⁹ The portrayal of contemporary genetics as objective science and as progressive denies the values and biases that underlie all science and the history of genetics research. For example, between the 1920s and the early 1940s many geneticists (some of whom were also socialists) held the view that 'races' differed in their mental abilities and that the upper classes were innately more able and intelligent than the lower classes.³⁰

As the recent responses of science groups (such as the UK's Royal Society)

to news media reporting of issues such as cloning and embryonic stem cell research indicate, many scientists are deeply concerned about the impact of negative or critical portrayals of genetic research on public views and policies.³¹ In their efforts to counter what they see as unfavourable press, scientists have made considerable efforts to cast new genetics technologies in a positive light and to distinguish legitimate science from what is seen as illegitimate science, such as eugenics. In a UK interview-based study, scientists drew firm boundaries between the new genetics, which they saw as based on science and as beneficial, from eugenics, which they depicted as pseudo-science and dangerous.³² When consulted as news sources, scientists have often emphasised the beneficial applications and implications of their work and sought to differentiate the 'good' and 'bad' uses of genetic technologies' (such as therapeutic cloning versus reproductive cloning), employing familiar rhetorical devices.³³ Claims about the significant potential benefits of new genetic technologies, although often dismissed by critics as 'hype', can be seen to perform an important rhetorical role, in helping to construct the future context for the development of new genetic technologies, including support for research and development.³⁴

In the early 1990s, Marque-Luisa Miringoff observed a shift from 'social welfare' to 'genetic welfare', whereby social considerations were increasingly supplanted by genetic ones, to explain all kinds of health and social problems.³⁵ Since then, this process would seem to have advanced further through a range of policies oriented to the 'responsibilization' of individuals; that is, making people responsible not only for their own destiny but for the destiny of society as a whole.³⁶ These policies reflect the predominance of neo-liberal rule.³⁷ Although the complex nature of genetic conditions makes it unlikely that the new genetics will produce the benefits that are widely claimed,³⁸ changes are already being implemented in the organisation and practices of health care and public health on the assumption that genetics knowledge *will* find a range of useful applications in the years ahead and that individuals *will* act autonomously and pro-actively, as consumers, to purchase new drugs, therapies, and advice. In the UK, the Genetics White Paper, *Our Inheritance, Our Future*, published in 2003,³⁹ which outlines the Government's commitment to applying genetics knowledge in the National Health Service, and the establishment of UK Biobank by the Medical Research Council, Wellcome Trust, and the Department of Health, which aims to isolate the genetic, lifestyle and environmental contributions to disease,⁴⁰ signal the change in emphasis in healthcare and public health. At the international level, the World Health Organization foresees considerable potential health applications of genetic research for developing countries in coming years.⁴¹ Further, projects such as the International HapMap Project, which analyses DNA samples from populations with African, Asian, and European ancestry, in order 'to discover the genetic variants involved in disease and the individual responses to therapeutic agents',⁴² reflect belief that broad health and economic benefits will be derived from international collaborative research efforts.

1268. Alan Petersen, 'Replicating our bodies, losing our selves: news media portrayals of human cloning in the wake of Dolly', *Body & Society*, 8, 4, 71-90.

34. Nik Brown, 'Hope against hype: accountability in biopasts, presents and futures', *Science Studies*, 16, 2 (2003): 3-21.

35. M-L Miringoff, *The Social Costs of Genetic Welfare*, New Brunswick, NJ Rutgers University Press, 1999.

36. Nikolas Rose, *Powers of Freedom: Reframing Political Thought*, Cambridge, Cambridge University Press, 1999, p174.

37. *Ibid.*

38. N.A. Holtzman and T. Marteau, 'Will genetics revolutionize medicine?' *The New England Journal of Medicine*, 343, 2 (2003): 141-4.

39. Department of Health, *Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS* Presented to Parliament by the Secretary of State for Health By Command of Her Majesty, June 2003, London, Department of Health & NHS, 2003.

40. MRC, The Wellcome Trust & Department of Health, *The UK Biobank: A Study of Genes, Environment and Health*, 2002, <<http://www.biobank.ac.uk>>.

41. World Health Organization, *Genomics and World Health*. Report of the Advisory Committee on Health Research, WHO, Geneva, 2002, <http://www3.who.int/whosis/genomics/genomics_report.cfm>.

42. International HapMap Project, <<http://www.hapmap.org/whatismapmap.html>>, accessed 22 November 2004)

43. Department of Health, *The Expert Patient: New Approaches to Chronic Disease Management for the 21st Century*, London, Department of Health, 2005.

44. <http://www.dh.gov.uk/NewsHome/NewsArticle/fs/en?CONTENT_ID=4087167&chk=HMjSm.8>, accessed 17 February 2005.

45. <<http://www.dh.gov.uk/PolicyAndGuidance/PatientChoice/fs/en>>, accessed 17 February, 2005.

46. Hanson, M. J., 'Biotechnology and commodification within health care', *Journal of Medicine and Philosophy*, 24, 3 (1999): 267-287. Nelkin, D. and Andrews, L., 'Homo Economicus: commercialization of body tissue in the age of biotechnology', *Hastings Centre Report*, September-October, 1998, 30-39.

47. Hedgcock, A., *The Politics of Personalised Medicine: Pharmacogenetics in the Clinic*, Cambridge,

The increasing emphasis on 'responsibilization' and consumer choice in healthcare is reflected in a range of policies and programs. In Britain, the idea that patients are 'expert' and should be involved in self-managed programs to reduce the severity of their own symptoms and to increase their resourcefulness and self-efficacy has gained currency in recent years.⁴³ The Department of Health has underlined the importance of listening to patients and involving them in their own healthcare, and patient involvement is supported by a range of mechanisms, including Patient Advice and Liaison Services, and Patient and Public Involvement Forums.⁴⁴ 'Patient choice' ('Giving patients more choice about how, when and where they receive treatment') has recently been defined as 'one cornerstone of the Government's health strategy'.⁴⁵ The market is seen to be the key mechanism for promoting freedom of choice, which has led some writers to express concerns about the commodification of the body and the potential for eugenic outcomes through individual decisions.⁴⁶ The pharmaceutical industry is keen for personalised medicine (pharmacogenetics) to be translated into practice and, in some instances, has made considerable investment of time and money to achieve institutional and clinician support for new tests and drugs.⁴⁷ According to biotech industry representatives, the biotechnology sector is creating a new health economy, comprising 'hospitals and biotech, pharmaceutical and medical device companies', which work 'beyond borders through investments, data sharing, and product development collaborations'.⁴⁸ Gene tests are marketed on the basis that they will facilitate consumer choice.⁴⁹ Critics, however, warn that an emphasis on choice and reproductive autonomy, when taken to its extreme, will allow selective abortion not only of foetuses with serious genetic diseases but also foetuses with non-serious illnesses or of a particular sex.⁵⁰ If eugenics is defined in terms of outcomes/effects rather than aims/intentions, then market pressures and consumer demand may very well lead to the kind of genetic selection feared by many opponents of the new genetics.⁵¹

In response to widespread concerns about the potential for discrimination arising from a growing global market in genetic tests and technologies, in recent years, new human rights legislation has emerged at the supranational level. The Universal Declaration on the Human Genome and Human Rights (UDHGHR), and the International Declaration on Human Genetic Data (IDHGD), adopted by the General Conference of UNESCO on November 1997 and October 2003, respectively, outline the rights and responsibilities that apply to individuals and groups in respect of genetic information. These Declarations constitute part of the technologies of governance designed to guide the direction, and deal with the implications, of research and development that is increasingly beyond the effective control of nation states. The guidelines include provisions pertaining to the avoidance of genetic discrimination and the protection of individual and group rights. Article 6 of the UDHGHR declares that, 'No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity'.⁵²

Similarly, Article 7 of the IDHGD notes that, 'Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities'.⁵³ Significantly, Article 3 of the IDHGD includes reference to a 'person's identity':

Each individual has a characteristic genetic make-up. Nevertheless, a person's identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom.⁵⁴

This shows recognition of the dangers involved in genetic reductionism that is seen to be associated with eugenic policies in the past and presents a more complex view of the human subject and social relations than is generally embodied in policies of the nation state. Article 4 acknowledges the 'Special status' of human genetic data – including its predictive value, its potential cultural significance for persons and groups and its potentially significant impact on the family, future generations, and social groups – and the need to establish 'an appropriate level of protection for these data and biological samples'.⁵⁵

In addition to recognising the dangers of genetic discrimination, the above Declarations also underline the importance of states' responsibilities in relation to the sharing of information for research and of the benefits that may accrue. It is acknowledged that genetic information is not just an individual but a *collective* resource. States are encouraged to 'respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character ... and foster, *inter alia*, research on the identification, prevention and treatment of genetically influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population' (Article 18).⁵⁶ The IDHGD includes similar guidelines in relation to the international sharing of data (Article 18) as well as the sharing of benefits; viz., 'benefits resulting from the use of human genetic data, human proteomic data or biological samples collected for medical and scientific research should be shared with the society as a whole and the international community'.⁵⁷ The use of the language of citizenship here, as in references to 'solidarity' and 'sharing', is increasingly common in commentary on the benefits of new genetic technologies and in arguments for the public's participation in genetic research projects, such as UK Biobank,⁵⁸ and would seem to be a novel feature of new genetics discourse. That is, *all* individuals are seen to have a stake in genetic research, regardless of their class, race, ethnicity, gender, or educational status. A focus on individual choice in the use of genetic technologies however may reinforce discrimination against

Cambridge University Press, 2004.

48. Donn Szaro, 'Biotech leading the new health economy', *Refocus: The European Perspective*, Global Biotechnology Report 2004, London, Ernst & Young.

49. GeneWatch, 'Unregulated genetic testing on the High Street and the Internet', *Human Genetics and Health, Parliamentary Briefing Paper No.2*, April 2002.

50. Nordgren, A., 'Reprogenetics policy: three kinds of models', *Community Genetics*, 1 (1998): p65.

51. Jeremy Rifkin, op. cit., p128. David King, 'The state of eugenics', *New Statesman & Society*, 25/08/1995, pp25-26.

52. UNESCO, The Universal Declaration on the Human Genome and Human Rights, 2003, p43.

53. UNESCO, International Declaration on Human Genetic Data, 2003, p6.

54. *Ibid.*, p4.

55. *Ibid.*

56. UNESCO, The Universal Declaration on the Human Genome and Human Rights, op. cit., pp44-45.

57. UNESCO, International Declaration on Human Genetic Data, op. cit., p9.

58. Alan Petersen, 'Securing our genetic health: engendering trust in UK Biobank', *Sociology of Health and Illness*, 27, 2 (2005): 271-292.

59. Susan E. Kelly, "'New genetics' meets the old underclass', in Robin Bunton and Alan Petersen (eds) *Genetic Governance: Health, Risk and Ethics in the Biotech Era*, 2005.

60. Adriana Petryna, *Life Exposed: Biological Citizens After Chernobyl*, Princeton, Princeton University Press, 2002.

61. *Ibid.*, pp14.

62. *Ibid.*, p14.

63. *Ibid.*, p15.

64. Rayna Rapp, Deborah Heath, and Karen-Sue Taussig, 'Genealogical dis-ease: where hereditary abnormality, biomedical explanation, and family responsibility meet', in Sarah Franklin and Susan McKinnon (eds) *Relative Values: Reconfiguring Kinship Studies*, Duke University Press, 2001, p393.

65. *Ibid.*, p393.

particular groups who share certain genetic characteristics. Disability activists, for example, have warned of the potential for genetic testing to lead to discrimination against disabled people, while numerous commentators believe that access to new genetic technologies by a privileged few may create a genetic underclass.⁵⁹ Thus, there is an inherent tension between efforts to promote individual choice in relation to the use of new genetic technologies and the advancement of group solidarity that is presumed by the emergent biological citizenship.⁶⁰

To the extent that policies pertaining to the new genetics are not overtly class- or race-biased, and do not appear oriented to eliminating certain groups, they seem far removed from eugenics policies of the past. Everyone is called upon to play their part in tracking genetic risk or managing the effects of illness, thereby taking responsibilities of citizenship to a new level. This responsibility extends to others in the family, particularly offspring, and to future generations and other members of one's own and other groups, who may be at risk of developing a genetic-related disease. Improving levels of 'genetic literacy' is integral to promoting the common good. The growing tendency to link biology with identity that is evident with the new genetics is by no means novel, as can be seen in the history of racial classifications.⁶¹ However, what is novel about this biological citizenship is the potential of biologically-based identities and groups to generate new political economies and commercial activities as well as new disorders and identity-based illness movements.⁶² That is, pain and suffering have increasingly been rationalised and populations have become reliant on available technologies, knowledge of symptoms and legal means to gain political recognition and access to support systems.⁶³ More and more, citizens are mobilizing on the basis of a shared genetic identity, to offer support, to share experiences, and to lobby for change in health policies. The burgeoning number of patient groups organised around specific genetic conditions (genetic support groups) in recent years would seem to confirm these observations on the growing significance of genetic information for identity and social action. While support groups are diverse in their goals, aims and membership, and in the merging of the functions of providing biomedical information and support, they share certain characteristics. Most importantly, they all mobilize around an identity based on a genetically marked category.⁶⁴ For individuals, membership may be ongoing, or limited to a particular period, such as when they first learn that they or their child is affected by a genetic condition. Because support groups provide a forum for sharing experiences, through newsletters, meetings and other forums, friendships develop over time and the group itself may become a kind of surrogate family. Those who 'share a gene' tend to see themselves as being 'related'.⁶⁵ As Rayna Rapp, et al note for the genetic support groups with whom they worked in the US, the basis for this solidarity is manifold. Sometimes it is based on belief in the common experience of those with the condition; for example, those with Down's Syndrome are felt to have more in common with one another than they do with members of their own family. For others, the sense of solidarity is based on historical ethnic-racial

referents; for example sickle cell anaemia, most prevalent among those of African descent, and thalassaemia, which disproportionately affects people from Mediterranean countries, has provided the focus for political activism and mobilizations in community screening programs.⁶⁶ A shared experience of motherhood and family care also provides a basis for solidarity: as Rapp, et al observe, the activists in genetic support groups are disproportionately wives and mothers.⁶⁷

Genetic support groups have become increasingly well organized and coordinated in their political strategies. Assisted by the Internet, such groups have developed elaborate networks, which mobilize under national and international umbrella groups, such as the European Alliance of Genetic Support Groups, Genetic Interest Group, and Genetic Alliance. Such groups can be seen to reflect the development of a form of 'biosociality' which, Paul Rabinow predicts, will expand in the future.⁶⁸ By and large, they embrace the espoused values and the language of the new genetics with its emphasis on 'right to know' and 'freedom to choose'.⁶⁹ Their aims and values and 'self-help' philosophies are consistent with the ideals of active, responsible citizenship which characterize many contemporary, advanced liberal societies.⁷⁰ That is, members are not passive recipients of genetic knowledge but proactively seek knowledge and organise on behalf of family members and others affected by genetic disorders. They often work closely with departments of health in compiling genetic disease registries and in assisting in the development of public health genetics programs. They can become strong allies in the effort to fulfil clinical goals.⁷¹ Support groups are sometimes linked with public agencies, biotech companies, genetics diagnostic clinics, public health departments, among other groups, through organizations such as Genetic Alliance.⁷² Parents are often encouraged by professionals, including geneticists, genetic counsellors, paediatricians, and social workers, to join genetic support groups.⁷³ Professionals in early intervention programs may direct parents towards a local support group so that the family of a newly-diagnosed baby is linked with appropriate groups and services and is socialized by other parents and professionals to live with a disabled child.⁷⁴ By taking on such a facilitating role, professionals help to both promote the ideal of individual autonomy and achieve the new genetics' broad objective of improved levels of genetic literacy. Individuals and families are assisted in becoming responsible for managing and becoming the experts of their own conditions and disseminating information through their support groups and networks.

The profound changes in conceptions of health, self and society wrought by the developments described above bring into question many of the assumptions that have guided discussions and social science investigations in this field thus far. In particular, they highlight the inadequacy of simplistic appraisals of new genetic developments as unequivocally 'positive' or 'negative' and force us to think beyond the dichotomies of old and new, past and present, and good and bad and the frameworks of understanding that have structured arguments thus far. Recently, Karen-Sue Taussig, et al have

66. Ibid., pp393-394; Elizabeth N. Anionwu and Karl Atkin, *The Politics of Sickle Cell and Thalassaemia*, Buckingham, Open University Press, 2001.

67. Rayna Rapp, op. cit., p397.

68. Paul Rabinow, 'Artificiality and enlightenment: from sociobiology to biosociality', in J. Crary and S. Kwinter (eds), *Incorporations*, New York, Urzone, 1992.

69. Alan Petersen and Robin Bunton, *The New Genetics and the Public's Health*, London, Routledge, 2002, pp57-57.

70. N. Rose, *Powers of Freedom: Reframing Political Thought*, Cambridge, Cambridge University Press, 1999.

71. Weiss, J.O. and Mackta, J.S. (1996), *Starting and sustaining genetic support groups*, Baltimore, MD, The John Hopkins University Press, 1996, p520.

72. <<http://www.geneticalliance.org>>.

73. Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, New York, Routledge, 1999, p285.

74. Ibid., p287.

suggested the use of the term 'flexible eugenics' to underscore the complexities and contradictions of 'living in a market-driven society that places a premium on individual choice and, at the same time, largely embraces the emergent standards posed by genetic normalization'.⁷⁵ This is a useful contribution to discussion; however, the question of whether this concept is applicable beyond the US, to which it specifically refers, remains to be demonstrated. In any event, given evidence thus far, it is difficult not to agree with the authors that, 'the idea of a specifically eugenic relation to one's individual genes does not play out in simple fashion'.⁷⁶ As they explain,

For us, [the] expanding genetic worldview among all constituencies, including research scientists, clinicians, lay support groups, and more general populations, is constituted dialectically: on the one hand, an ever increasing number of actors and practices are conscripted into a world defined genetically, in which reductive determinism looms large. On the other hand, democratic possibilities open up as genetic discourses and practices come to occupy multiple locations and to conscript a wider range of actors. Some of those actors may use their new and multiple locations to contest a too-easy determinism or to develop interventions – molecular and otherwise – that they consider choice-enhancing. They may well be viewed as a vanguard in the politics of biosociality, a vanguard from which the rest of us have much to learn.⁷⁷

Crude portrayals of the new genetics as eugenic are analytically unhelpful and are historically and politically naïve. They deny the complexities and uncertainties associated with new genetic developments and evidence of diverse public responses to research and its applications thus far. Individuals and groups may engage with genetic technologies in very different ways, including resisting the imperatives which they imply. For some users, such technologies may be assessed as having *both* positive and negative implications and experienced complexly as *both* empowering and as oppressive. For others, concerns about the commodification of the body and/or the dangers of genetic selection under the pressure of market forces and consumer demand may suggest the need for a more cautious approach. Responses to genetic technologies are bound to be complex since their impacts will vary considerably and different groups have had different historical relationships to genetics and eugenics. To simply dismiss the new genetics as eugenic, and by implication unequivocally bad, denies these different positions and complex responses and suggests that there is no need for further debate about the various rights and wrongs of new genetic developments. Given the recent rapid developments in this field, such debate is urgently needed, and should include consideration of whether the future benefits are likely to be as claimed and, given the balance of potential benefits versus the likely costs and dangers, whether they should be supported.

75. Karen-Sue Taussig, Rayna Rapp and Deborah Heath, 'Flexible eugenics: technologies of the self in the age of genetics', in Alan H. Goodman, Deborah Heath and M. Susan Lindee (eds), *Genetic Nature/Culture: Anthropology and Science Beyond the Two-Culture Divide*, Los Angeles, London, University of California Press, Berkeley, 2003, p71.

76. *Ibid.*, p71.

77. *Ibid.*, p62.