

## EDITORIAL

# Genomics and public health virtual issue introduction

Since it began nearly 20 years ago, the Human Genome project has generated enormous discussion and debate. Touted as the biggest scientific effort globally since the Moonshot, even allowing for a fair degree of ‘genohype’ about the implications and consequences, it is clear that the results of this global scientific research effort will be enormous. In those debates, the journal *Critical Public Health* has played its part, and this review attempts to catalogue and evaluate that contribution. Papers appearing over the period since 1990 have been both analytical and empirical in their focus and, in an overall sense, have sought to introduce the sense of the scepticism that is characteristic of the social sciences. With this social science focus on the relationship between the individual and society, the papers, both individually and collectively, have sought to relate the individuals and their genetic makeup to the wider social context. Some of the papers have been empirical in nature, while others have been more analytical reviews of the issues involved, especially what might be called the social relations of the genetic biotechnologies that have arisen out of the project.

Four broad overall themes are evident from the collected papers on this topic. Two have been the subject of special issues of the journal. The first was in 2002 (Vol. 12, nos. 2 and 3) edited by [Robin Bunton](#) and [Alan Peterson](#) (2002a, 2002b) on the Foucauldian-influenced theme of genetic governance. The internationally based papers filled two issues of the journal and were concerned with epistemological and ethical issues arising out of the new genetics. Two Finnish papers open the collection; [Jallinoja \(2002\)](#) analyses screening and counselling as well as the interpolation of ethical arguments into the discourse of physicians around genetic counselling. Based upon interviews with health professionals and the analysis of textual material, he argues that professionals use a combination of new and old ethical formulations. In the second Finnish paper, [Helen \(2002\)](#) focuses on the implications of developments in genetic biotechnology, especially antenatal screening and advanced fetal diagnosis for abortion. He uses the concept of ‘ethicalisation’ to assess the individualisation of risk and implication for the self at the existential level. [Willis \(2002\)](#) also addresses the individualisation of public health problems that have followed the new genetics. Taking three specific case studies, he shows that the classic tension between the individual and society that goes to the heart of public health is being redefined by the development of genetic biotechnologies.

In their Foucauldian-informed empirical study of Canadian genetic testing for late onset disease (Melanoma), [Polzer, Mercer and Goel \(2002\)](#) consider the logic of risk and surveillance in the genetic governance era as individuals take on the identity of ‘carriers’ and have to calculate ‘risk’, and ‘choices’ within the prevailing neoliberal discourse. [Kelly \(2002\)](#), in an empirical study of genetic outreach programmes in rural Kentucky, examines the emergence and framing of the ‘genetic underclass’ concept. She argues that

disadvantage, whether it be geographical, social or economic, has a multilayered impact that accentuates the consequences of genetic counselling in a manner that clearly will become more widespread in the future.

In the paper by [Ward \(2002\)](#), the impact of the new genetics on people with learning and other intellectual disabilities is examined. She details a fundamental tension in prenatal screening between being cast as a matter of informed choice for parents on one hand, and a commitment to preventing impairment on the other. She crystallises the fundamental decisions that loom, ones indeed with eugenicist overtones: 'is society better off without its impaired members?'

This thematic series of papers continued in the next issue (Vol. 12, no. 3). [Gottwies \(2002\)](#) analyses the governance of genomics towards a massive sociotechnical project. The process of reaching compromise and binding decisions are a work in progress, he argues, with many obstacles not the least of which is gaining public support for policies. In her paper, [Herbert \(2002\)](#) considers the narrative and ideological elements of the new genetics. A welcome if somewhat unusual feature of this paper is that the author comes out of the biological science world herself, with an appointment at the Harvard Medical School. She argues that a false, one-sided view of health is emerging that views genetics as the key to all biologically related health problems.

[Ettore \(2002\)](#) considers the relationship between reproduction and genetics in her paper. Interviewing European experts, she illustrates how surveillance medicine works through the presentation of 'flawed genes' and gendered social relationships as the social implications of the new genetics are teased out.

The Finnish connection is maintained in the paper by [Poutanen \(2002\)](#), who documents the launch of genetic screening in Finland (especially Thalassaemia and Cystic Fibrosis). He relates the development in ideological terms to neo liberal governmental ideas and considers the issue of how and how much of the complicated predictive information should be communicated to the public. The paper by [Lemke \(2002\)](#) focuses on the issue of risk management and the capacity of genomics to construct risks and 'apparatuses of insecurity' in the genetic discourse which may, he argues, be used for regulatory purposes.

The important question of how genetic identities are socially constructed is the topic of the paper by [Ellison and Rees Jones \(2002\)](#). This is a second theme that is evident in *Critical Public Health* papers. The problem they identify is that the social constructs such as 'race' and 'ethnicity' used for these purposes have limited validity and may be misleading and generate inaccurate and unrealistic expectations of their usefulness for public health research. The race and ethnicity theme is also explored in subsequent years. [Martin \(2005\)](#), responding briefly to the paper by Ellison and Rees Jones, argues that their conception is inadequate for use in practice and points to the paradoxical usage of the terms. [Smart \(2005\)](#), responding to the same paper, argues that the decision-making scheme of Ellison and Rees Jones is based on an understanding of the socially constructed notion of the concepts of race and ethnicity could usefully be employed by professional communities.

The other paper to explore a 'race' theme (as well as set a *Critical Public Health* record for the number of joint authors!) is that of [Simon Dyson and his collaborators \(2007\)](#). In their empirical study of antenatal screening for Sickle cell/thalassaemia, they show how the concept of race is open to a variety of interpretations and is often used in medical discourse in a manner more akin to 'scientific racism'.

The third theme, also the subject of a special issue (Vol. 15, no. 4), has been the ethical and other issues surrounding biobanks (especially trust as well as the nature and

possibilities of public participation). The contributors, individually and collectively, express a degree of doubt about whether the way that public involvement and consultation are being pursued will generate sufficient trust on the biobanks for them to realise their potential success. In his introduction, Peterson (2005) situates the question of trust and public involvement as central to the success or otherwise of the various biobanks around the world. In his contribution, Bovenberg (2005) considers the options for the governance of biobanks in the absence of an international system of ethics. He considers the special nature of biobank ethical issues and argues for all data used by such banks to be considered special in nature. Levitt and Weldon (2005) explore the nature of trust in biobanks, and argue that the special nature of biobank genetic data requires a clear set of obligations on both sides to fulfil the mooted promise. In their multidisciplinary contribution to the special issue, Scott, Phillips, Moore and Du Plessis (2005) consider the concept of ethicality in relation to biobanks. Reporting on an empirical study in New Zealand, using focus groups amongst both indigenous Maori and non-Maori respondents, they argue that the abstracted language is a significant issue in allowing the debates to be socially positioned. A more general paper on the ethics and equity implications the Human Genome Project had appeared the year previously. Phua (2004), writing from a Malaysian perspective, argues for the need to rethink the relationship between these advances and issues of equity.

In the same special issue, the issue of informed consent in biobank research is critically considered in the Norwegian context by Skolbekken, Ursin, Solberg, Christensen and Ytterhus (2005). From focus group research and other sources, the authors conclude that participation in biobank research is based upon trust in both the researchers and the regulation of research rather than the specific knowledge of what they are consenting to. They argue that process issues are important if informed consent is to be effective. The issues of trust and consultation are also considered, this time in the Australian context by Stranger, Chalmers and Nicol (2005). Reviewing the Australian government's attempt to develop a regulatory framework involving public participation, the paper charts a degree only of 'lip service' to the need to consult widely that may lead to distrust in the future. Wallace (2005) considers these issues of public and stakeholder consultation as employed by the funders of the UK biobank, calling for more ethical debate and public scrutiny of the project. Finally Hoeyer and Tutton (2005), also in the UK biobanks context, consider what they call the language games of ethics as a mode of regulation that allows the discourse of ethics to absorb critics and sceptics.

The fourth and final theme concerns the implications of genomics in the specific case of breast cancer. In their empirical paper, Grant et al. (2006) ask the question of whether women's expectations of breast genetic counselling in Scotland are being met. Their findings point to the complex social context of genetic breast counselling; that neither genetic information in general nor risk in particular is well understood by the women. Nor are the possible unintended consequences and consequences for families. In this context also is the paper by Crabb and LeCouteur (2006), who examine popular media accounts of prophylactic mastectomy in the Australian context. The surgical removal of healthy (in the sense of asymptomatic) breasts for preventive purposes, in the genomic era, according to their discursive analysis is being cast as responsible self-management of genetic risk within gendered discourses.

Since its inception, *Critical Public Health* has been at the forefront of debates about the likely social and societal implications of genomics in all their social, political, ethical, economic and policy ramifications. Where bioethics has been a focus, this has been considered in an applied form. The lessons of public health remain apparent: that there is

much more to wellbeing than individual health; that as social and economic life changes rapidly in the early decade of the twenty-first century, it is essential to look beyond the biomedical issues to the social and political aspects of public health; that the implications of developments such as genomics do not stand somehow in isolation, but the wider context needs to be considered of structural inequality, as it relates to class, gender, ethnicity, disability and sexuality. Above all, the strong sense of critique of existing forms is apparent. But this is necessarily critique in a negative form; everyone hopes that the promise of genetic medicine to reduce the burden of suffering from genetically caused disease is realised. Instead the papers in *Critical Public Health* in this topic represent critique in its positive sense of scepticism; about these new technologies, new forms of governance, the impact of globalisation, of the unintended as well as intended consequences. Scepticism involves careful evaluation and attempts to understand what such developments will mean for the sort of society in which we live.

## References

- Bovenberg, J. A. (2005). Towards an international system of ethics and governance of biobanks: A 'special status' for genetic data? *Critical public health*, 15, 369–383.
- Bunton, R., & Petersen, A. (2002a). Genetics, ethics and governance. *Critical public health*, 12, 95–102.
- Bunton, R., & Petersen, A. (2002b). Genetics, governance and ethics. *Critical public health*, 12, 201–206.
- Crabb, S., & LeCouteur, A. (2006). 'Fiona farewells her breasts': A popular magazine account of breast cancer prevention. *Critical public health*, 16, 5–18.
- Dyson, S. M., Cochran, F., Culley, L., Dyson, S.E., Kennefick, A., Kirkham, M., et al. (2007). Ethnicity questions and antenatal screening for sickle cell/thalassaemia (EQUANS) in England: Observation and interview study. *Critical public health*, 17, 31–43.
- Ellison, G. T. H., & Rees Jones, I. (2002). Social identities and the 'new genetics': Scientific and social consequences. *Critical public health*, 12, 265–282.
- Ettorre, E. (2002). A critical look at the new genetics: Conceptualizing the links between reproduction, gender and bodies. *Critical public health*, 12, 237–250.
- Gottweis, H. (2002). The governance of genomics. *Critical public health*, 12, 207–220.
- Grant, A. M., van Teijlingen, E.R., Forrest-Keenan, K., Torrance, N., Wilson, B.J., & Haites, N.E. (2006). Does breast cancer genetic counselling meet women's expectations? A qualitative study. *Critical public health*, 16, 281–293.
- Helen, I. (2002). Risk and anxiety: Polyvalence of ethics in high-tech antenatal care. *Critical public health*, 12, 119–137.
- Herbert, M. R. (2002). Genetics finding its place in larger living schemes. *Critical public health*, 12, 221–236.
- Hoeyer, K. L., & Tutton, R. (2005). 'Ethics was here': Studying the language-games of ethics in the case of UK Biobank. *Critical public health*, 15, 385–397.
- Jallinoja, P. T. (2002). Ethics of clinical genetics: the spirit of the profession and trials of suitability from 1970 to 2000. *Critical public health*, 12, 103–118.
- Kelly, S. E. (2002). 'New' genetics meets the old underclass: Findings from a study of genetic outreach services in rural Kentucky. *Critical public health*, 12, 169–186.
- Lemke, T. (2002). Genetic testing, eugenics and risk. *Critical public health*, 12, 283–290.
- Levitt, M., & Weldon, S. (2005). A well placed trust? Public perceptions of the governance of DNA databases. *Critical public health*, 15, 311–321.
- Martin, P. (2005). The paradox of race/ethnicity. *Critical public health*, 15, 77–78.
- Petersen, A. (2005). Biobanks: Challenges for 'ethics'. *Critical public health*, 15, 303–310.
- Phua, K. -L. (2004). The Human Genome project and genetic research: What are the implications for ethics and equity? *Critical public health*, 14, 191–200.
- Polzer, J., Mercer, S. L., & Goel, V. (2002). Blood is thicker than water: Genetic testing as citizenship through familial obligation and the management of risk. *Critical public health*, 12, 153–168.
- Poutanen, S. (2002). The first genetic screening in Finland: Its execution, evaluation and some possible implications for liberal government. *Critical public health*, 12, 251–264.
- Skolbekken, J. -A., Øystein Ursin, L., Solberg, B., Christensen, E., & Ytterhus, B. (2005). Not worth the paper it's written on? Informed consent and biobank research in a Norwegian context. *Critical public health*, 15, 335–347.
- Scott, A., Phillips, H., Moore, A., & Du Plessis, R. (2005). Ethics in practice: Conversations about biobanks. *Critical public health*, 15, 359–368.

- Smart, A. (2005). Practical concerns that arise from using race/ethnicity as 'the most reliable proxy available'. *Critical public health, 15*, 75–76.
- Stranger, M., Chalmers, D., & Nicol, D. (2005). Capital, trust & consultation: Databanks and regulation in Australia. *Critical public health, 15*, 349–358.
- Wallace, H.M. (2005). The development of UK Biobank: Excluding scientific controversy from ethical debate. *Critical public health, 15*, 323–333.
- Ward, L. M. (2002). Whose right to choose? The 'new' genetics, prenatal testing and people with learning difficulties. *Critical public health, 12*, 187–200.
- Willis, E. (2002). Public health and the 'new' genetics: Balancing individual and collective outcomes. *Critical public health, 12*, 139–151.