

## Book Review

### **GENETIC DATABASES: SOCIO-ETHICAL ISSUES IN THE COLLECTION AND USE OF DNA.**

Ed by Richard Tutton and Oonagh Corrigan.

London, New York: Routledge, 2004. vii and 211 pp(incl index). ISBN 0-415-31679-0 (hb). ISBN 0-415-31680-4 (pb). £22.99

Genetic databases have been and probably will be in the spotlight of the contemporary debate over the collection and use of DNA. This book constitutes an important contribution to this debate by exploring traditional questions around genetic databases as well as raising somewhat less explored issues. This makes the book valuable for everyone writing on the topic of genetic databases. The book was first presented to a selected audience in London on 8 June 2004.

The Editors, Richard Tutton, University of York, and Oonagh Corrigan, University of Cambridge, have succeeded in bringing together ethicists, sociologists, and lawyers - from different universities of the UK, with one exception - Klaus Hoyer from the University of Copenhagen. However, it would be erroneous to draw a conclusion that the book is much too UK-centred since in most articles comparative methods are used and the situation in other countries, including Iceland, Estonia, the United States, Sweden, has been dealt with. The fact that the book contains articles both from contributors that have extensively written in this field, for instance Sue Weldon and Graham Lewis, as well as from a new generation of scientists is another achievement of the Editors.

As to the general drawbacks of this book the time issue has to be mentioned. Given that the field of genetic databases changes with every month if not faster, editing of such a book should have been completed rapidly. Regarding this book, it seems that it took more than a year for the Editors to complete editing of the book and the articles in it are therefore on some occasions not up to date. More recent articles from several contributors to this book, for example Sue Weldon, Jane Kaye, Erica Haines, Michael Whong-Barr, can be found published in journals.<sup>1</sup>

In the first chapter, the Editors provide an overview and summary of the main ideas across the book. These ideas can be divided into three topics – the issue of language and definitions, the commercial context and the concept of consent and control. The editors rightly point out that the definition of the term “genetic databases” is not clear and is widely used with very different meanings. Unfortunately, they do not aim to deliver a unified definition of the term even for the purposes of this book and therefore different authors use different terms. -

Chapter 2 is the first contribution to the topic of language. In his article „Person, property and gift” Richard Tutton reviews the gift relationship that underlies the contemporary relationship between a researcher and research participants. The gift relationship as it has been applied to blood donation is now also standard in the

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<sup>1</sup> Trames, “Human Genetic Databases: ethical, legal and social issues”, 8 *Journal of the Humanities and Social Sciences* (2004).

context of genetic research, due to the need to ensure altruism and solidarity. Also the gift relationship allows the exclusion of the person, from whom the tissue derives, from all kind of property rights in respect of the tissue and hence, makes it a potentially lucrative resource for researchers and industry. Against this background, Tutton deals with different proposals to overcome the situation and to increase the role of the person. One way to do it, suggests Tutton, is to differentiate between tissue on the one hand and genetic information on the other hand so that both non-commercial donation of tissue as well as the commercial domain of genetic information could co-exist.

In Chapter 3 „Blood donation for genetic research”, Helen Busby continues the topic of language by exploring what we can learn from donors, narratives. After a short analytical section she turns to two case studies. Within the framework of the first study, one hundred short interviews with people donating blood for the National Blood Service (NBS) were conducted. It appeared that, in general, people are not worried about what happens to their blood once it has been collected but they do not seem to know the wide range of applications that their blood can be used for. Another case study was carried out on people donating blood for a specific genetic research project. Interestingly, participants did not consider genetic research as something special in itself but Busby warns against applying these outcomes to the UK Biobank context given the scale of research protocol.

Chapter 4 is report of a case study of the North Cumbria Community Genetics Project conducted by Erica Haines and Michael Whong-Barr. They claim that the exceptionally high participation rate (nearly 90 per cent) can be explained by analysing what is meant by “participation”. Although at the first glance, the term participation is unambiguous, they still manage to show that there are different levels and styles of participation in this NCCG project.

Oonagh Corrigan introduces the topic of consent and control in Chapter 5. She argues that the multi-layered consent forms routinely used by pharmaceutical companies in drug research that give to the company the right to use the sample for the future studies overreach the boundaries of informed consent and constitute a form of exploitation of research subjects. According to Corrigan, the concept of informed consent is not suitable for providing a balance between risk and benefits of the research participants and commercial interests of the industry.

In Chapter 6, Klaus Hoyer presents his conclusions from a study that he conducted on people donating blood to the famous Medical Biobank in Västerbotten, the biobank that failed to establish a public-private partnership with UmanGenomics.<sup>2</sup> His study reveals similar results as the above referred studies of Busby, in that people seldom scrutinized the provided information before consenting and have only few fears about the misuse of their tissue – they rarely asked any questions and seemed to have decided in favour of participation even before showing up at the medical facility. He claims that such behaviour is not irrational since the function of informed consent in genetic databases is different than in traditional medical research.

For the lawyers, the most interesting chapter in this book is written by Jane Kaye. Her article, titled “Abandoning informed consent”, is based on her PhD thesis recently defended at the University of Oxford and will most likely be as often cited as her

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<sup>2</sup> <http://www.umangenomics.se>.

previous articles.<sup>3</sup> She starts with distinguishing between two concepts of informed consent – traditional informed consent as set out in the Declaration of Helsinki and consent required by the Personal Data Protection Directive 95/46/EC.<sup>4</sup> She argues that the consent sought within the framework of population based genetic databases is unable to meet either of these consent standards, furthermore, none of the consent exemptions are applicable. She concludes that a new concept is needed and proposes her two stage approach. First, at the stage of collection of information and obtaining tissue sample, only a broad consent is possible.. Second, once the specific research has been determined, researchers should have an obligation to inform potential participants about it and provide them an opportunity to opt out from the contemplated research project. Additionally, some safeguards to protect trust and participation in the research should be set out.

In Chapter 8, Emma Williamson, Trudy Goodenough, Julie Kent and Richard Ashcroft explore the issues of consent and control in the context of “Children’s participation in genetic epidemiology” using the Avon Longitudinal Study of Parents and Children (ALSPAC) as the example. A central ethical question in this chapter is whether the parents have the right to consent to the long term biomedical research on behalf of children at all and where should we set the balance between parental rights and the interests of the children.

Sue Weldon’s starting point in Chapter 8 “‘Public Consent’ or ‘scientific citizenship’” examines the limit of individual informed consent. She raises the question of whether, and to what extent, individual consent can be replaced or accompanied with public consent or scientific citizenship. One type of public consent is used in the context of the Icelandic Health Sector Database with a result that individual consent is not needed. Though people have the right to opt-out from the project, such a solution is still problematic. Scientific citizenship, a concept that aims to ensure better involvement of the public in designing and implementing scientific projects, seems to offer a more promising solution.

In the last Chapter “Tissue collection and the pharmaceutical industry”, Graham Lewis delivers an overview of corporate biobanks – these are the biobanks that pharmaceutical companies have already established for their own research ends. He distinguishes between in-house collections, clinical genomics companies as repositories, collaborations with existing public collections and other collections. The total number of samples being currently held in these collections is unknown but exceeds several hundred million. Given the scale and the fact that these collections are far less explored and publicly controlled, further ethical scrutiny should be directed towards these biobanks.

The book “Genetic Databases” provides refreshing reading on genetic databases from thought provoking angles. It remains to be seen to what extent these provoked thoughts will be reflected in the scientific literature and, what is probably more important, in the protocol for the UK Biobank.

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<sup>3</sup> J Kaye, P Martin, “Safeguards for research using large scale DNA collections” (1999) 321, *British Medical Journal* 1146-1149.

<sup>4</sup> Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. OJ 1995 L281/31.

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