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Short literature notices


Human genetic databases (HGDs) are collections of samples and data from large numbers of citizens that are being established in order to study interactions between genes and the environment and promise new insights for diseases and their treatments. The involvement of commercial companies and the risks to confidentiality of data and samples stored in HGDs have stirred considerable debate.

Iceland, Estonia, Sweden and the UK were among the first European countries to plan population-wide HGDs. From 2002 to 2004, the European Commission funded research on the Ethical, Legal and Social Aspects of Human Genetic Databases (ELSAGEN) in these four countries. The book provides an overview about the results of the various parts of this research. After a general reflection on American principles and European values, the first part summarises surveys of the public regarding concerns related to genetic databases. This is followed by a comparative analysis of the legal frameworks regulating HGDs in the four countries. Chapters on “ethical questions” and “political considerations” conclude the work.

Through the glasses of the public and the ELSAGEN team of these 4 countries, the wider European and international stakes are regularly targeted. Are countries “participating in an international ‘gene race’” (Estonian newspaper, quoted p. 79 by P. Tammipuu)? Is a HGD “responsible biotechnology”? (R. Kattel, p. 239)? Is the term “global public good” appropriate for HGDs, or are they mainly increasing the risk for indigenous people to be exploited (S. Wilson and R. Chadwick, p. 158)? Should HGD-legislation respond to concerns of the public or should it rather incorporate a more abstract viewpoint of “European justice” (M. Häyry and T. Takala, p. 256)?

The book is a very rich source to learn more about sociological, legal and ethical issues concerning the HGDs in the four countries. It is interesting to read that Icelanders, Estonians and Swedes seem to trust more in genetic science than the UK population. Since the methodologies used seemed to have been considerably different in the four countries, a more detailed description of the questionnaires used would have been helpful to understand such comparisons.

The book mirrors perhaps best the debate in that it oscillates considerably between optimism and pessimism. G. Arnason believes that the impact of HGDs is often exaggerated. “Science and medicine will also do very well without them” (p. 235). The legal analysis confirms that “governance structures for population genetic databases are not uniform or harmonious across Europe” (J. Kaye, p. 141). This demonstrates a “pressing need for governance reform, particularly vis-à-vis biosamples” (S.M.C. Gibbons, p. 140). “Trust” and “trustworthy institutions” are mentioned repeatedly in the book as a means to overcome difficulties related to consent and confidentiality. If “participants have good reasons to believe that they can trust the institutions which regulate the research, the people who work with the information and also the technical system which protects it, the issue of privacy should not be a major obstacle in the effort to balance participants’ interests and scientific research interests” (V. Arnason, p. 5).

Is trust more than a “magic medicine” for the problems related to HGDs? M. Sutrop (p. 190f) urges that trust
should not be blind, but authentic, i.e. based on knowledge and evaluation of risk, asking for guaranties and for trustworthy institutions that do not have conflicts of interests.

Wherever the future of HDGs lies, the book is an authentic contribution for the struggle to find adequate legal, ethical and socio-political solutions in Europe.

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