**Continuing collaborative work on ethical issues in the use of genetic data: data sharing**

The collaborative team at the Ethox Centre mentioned in the last newsletter have been examining the impact on scientific practice, specifically within genomic research, of data sharing practices and policies.

The sharing of genomic data has many obvious benefits. It can make the research process far more efficient in the use of resources, and can greatly speed up scientific discovery. However, steps must be taken to ensure the protection of research subjects and to ensure effective and efficient regulation of access to such data. Different genomic research projects are sharing data in different ways. In some research projects, such as Procardis, more specific consent is given for research on certain conditions, whereas in others broader, more open-ended consent is given for wider use in legitimate scientific research.

There are differing requirements for data sharing for different types of projects. What is however clear is that policy initiatives are having an impact upon scientific practice. The group have written a piece describing some of these major changes. In this article, they also discuss four major areas of concern that need to be considered in order to ensure that the sharing of genomic data has maximum benefits for all concerned, whilst also protecting those who have generously agreed to participate in research. These areas were highlighted in work that members of the group have conducted with a range of scientists in the Ethox Centre project, Governing Genetic Data Bases (www.ggd.org.uk). These areas are: the difficulties of acknowledging individual contributions to the generation of data; the way that these policies change the responsibilities towards participants; the implications that this has for maintaining public trust; and the new mechanisms that have been developed for oversight of access to data. The views expressed in the article are not necessarily those of individual members of the Procardis consortium, nor of the consortium as a whole. Indeed, the article highlights the need for debate in an area where different viewpoints are possible. The group hopes to develop debate in these important issues in this field where science, technological possibility, and policy are all evolving rapidly.


**Forthcoming workshop on direct to consumer genetic testing**
The research of the Procardis programme aims to deepen our understanding of cardiovascular disease and an ultimate aim of such work is to make improvements in prevention and treatment. Such developments may take many years before widespread practical applications are possible. One recent and controversial development in genomic applications is the rise of direct to consumer genetic testing companies, such as those providing personal genotyping. Results are given to consumers of genetic variations conferring attributes such as the genetic variation that makes Brussels sprouts taste bitter, to variations that have been linked to certain diseases and other traits. Some companies are reporting results for genetic associations including links with coronary artery disease and heart attack. However, many are skeptical about the utility for individuals of much of this information at this relatively early stage of our understanding; some associations found in the scientific literature are not yet sufficiently well validated for clinical use.

The Ethox Centre and the Programme for the Ethics of the New Biosciences are holding a one day workshop ‘Direct to Consumer Genetic Testing’ in Oxford on May 21st to explore ethical and regulatory issues around the development of marketing genetic tests direct to the public. Speakers will include experts from the fields of science, business, law and ethics.

For further details, and to reserve a place, contact rachel.woodcock@philosophy.ox.ac.uk.

**Seeing genetic research into heart disease in its wider context**

The journal *Bioethics* recently published a special issue on the social determinants of health. Paula Boddington contributed an article to this, ‘Heart disease and inequality: ethical issues in the aetiology, treatment and prevention of heart disease’ (*Bioethics* 2009, 23, 2, 123-130, doi:10.1111/j.1467-8519.2008.00713.x). Heart disease is a complex condition that is a leading cause of death worldwide. Genetic factors are important, but the aetiology is complex. Therefore, when considering ethical issues arising in genetic research into heart disease, it is important also to place this work in a larger context. The highly complex causality of heart disease means that many different facets of social and economic life are implicated in its aetiology. The very untangling of causes for heart disease thus raises social, moral and political issues. These include the proper role of the individual and of larger social forces in its aetiology, prevention and treatment. Strategies for addressing a condition of such complex causality can be highly diverse, from pharmaceutical to social interventions, and value issues attach to the choice and presentation of such strategies. For example, prevention strategies may raise complex issues of responsibility and of judgements of what it is to ‘live well’. Treatment strategies such as the widespread use of medication are potential downstream applications of research into cardiovascular disease but these too raise complex ethical and social issues that need to be understood and debated.
The editors of this *Bioethics* issue emphasised the importance of examining ethical issues arising from the social determinants of health in their editorial, ‘The ethical implications of the social determinants of health: a global renaissance in bioethics’ (Wendy Parmet and Patricia Illingsworth, *Bioethics* (2009) 23,2: i-iv).

It is important that in examining ethical issues arising from genetic research, the societal dimension is also included.

**Other continuing work**

Other work continuing for the Procardis ethics programme is examining issues of the protection of privacy in genomic research, consent to research and associated issues in research governance, the roles and responsibilities of researchers, and feedback of incidental findings.