**Procardis: Continuing Work in Ethics**

Many ethical issues arise within the practice of medical research, such as those concerning attention to the welfare and rights of those participating. Within research into genetics, and in evolving medical practice that applies new knowledge and techniques arising from genetics, there has been particular attention to ethical issues, seen in what is commonly known as an ‘ELSI’ – ethical, legal and social implications – component added to research endeavours.

The Procardis consortium takes ethical issues very seriously and has taken the step of building an ethics strand into their research work. This work is being undertaken by Professor Mike Parker and Dr Paula Boddington, both staff at the Ethox Centre, which is situated in the Division of Public Health and Primary Health Care at the University of Oxford. Researchers at the Ethox Centre have expertise in areas of law, the social sciences, medicine, ethics, and philosophy, and within the centre there is a particular interest in ethical issues concerning medical research and concerning genetics and genomics.

Scientific researchers face many ethical issues in the course of their work, and in the field of genomics, this is especially so, as fast changes in scientific discovery and in technological capability mean that new challenges constantly present themselves. Much of the ethical work to date within the field of genetics and genomics has been concerned with clinical practice, and with genetic diseases such as single gene disorders, for instance Huntingdon’s disease or cystic fibrosis. There has been less attention to the issues arising from genetic research into complex multifactorial diseases such as cardiovascular disease. The ethics work for Procardis aims to support research scientists in such challenges, and maintains close links with the researchers to gain an understanding of the ethical issues with which they are faced. In this way, it is hoped that ethical issues can be identified and addressed in a timely manner as the science progresses, and hence help achieve best ethical practice in the conduct of genomics research.

With this aim in mind, workshops and seminars have been held throughout 2008 with researchers at three of the Procardis centres, in Stockholm, in Milan, and in Oxford. An important aspect of the workshops was to examine the ethical issues that were of most concern to those actively involved in the Procardis work. From this initial understanding, continuing work on ethics will examine particular important issues in more depth.

**A summary of the broad areas of ethical concern identified from the Procardis Ethics workshops:**

**Consent to research:**

Informed consent from those taking part has long been seen as a central pillar of ethically sound medical research. However there are many difficulties in achieving this. For example, as genomics research becomes more and more complex, it can be challenge to explain all the implications of taking part in research to those volunteering to take part.
The management of data:

Research into genomics obviously produces a vast amount of data, both because many thousands of individuals are taking part, and because large amounts of genomic data are produced from each participant. This data must be managed securely and with close attention to the privacy of the participants, whilst at the same time allowing scientists the capabilities of utilising the data to good effect in their research.

The translation of research into practical applications:

The Procardis research aims to increase our understanding of the underlying mechanisms of cardiovascular disease with the ultimate aim of leading to improvements in medical practice, such as in diagnosis. In identifying the different risk profiles of individuals for cardiovascular disease, various ethical issues arise.

Economic issues:

The use of public funding in scientific research of course requires that good use is made of the funding for the benefit of the public. Translation of results in particular in practice often involves commercial partners. Partnerships between public and commercial enterprises will present issues about the fair use of resources and these must be addressed.

The responsibilities of researchers:

A research group such as Procardis is an international collaboration of scientists taking on various roles and with many different disciplinary backgrounds. Collaborating in such networks presents its own opportunities and challenges. The technological capabilities of genomics research are developing at a speed that sometimes means that scientists working on the ground have a keen appreciation of the subtlety of ethical issues and are therefore well placed to add their insights and views to the debate about ensuring high ethical standards. There are inevitably however differences of viewpoint and of emphasis in the debates about how best to carry forward the twin tasks of producing high quality collaborative scientific research, and at the same time ensure sound protection of the rights and welfare of participants. The scientific and ethical integrity of researchers facing such tasks is a topic of great interest.

This is a brief summary only. The workshops produced fuller and detailed discussion of many issues. Over the course of the Procardis project, we will add more detail about various topical ethical issues.

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Please feel free to contact me on any matter of concern or with any comments on ethical aspects of the Procardis project.