Procardis Ethics Newsletter 8
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Procardis ethics publications:

Implications of genomics research for relatives:

Relative Responsibilities: Is there an obligation to discuss genomics research participation with relatives?, Paula Boddington, Public Health Genomics published online May 4, 2010, DOI: 10.1159/000294207

This paper directly addresses recent suggestions made from different quarters about the question of the implications of genomics research for family members. This question is one of many that demonstrate the difficulties faced by genomics research arising from a central feature of the standard model of ethics drawn up on the context of clinical research: the fact that traditionally, for many good reasons the individual subject of research is placed at centre stage. The implications of genomics information for related individuals can present us with difficult conundrums.

Abstract:

One of the many ethical challenges presented by research in genomics is that, although informed consent to research has traditionally been a matter for the individual participant, genomics research carries potential implications for genetic relatives. There are specific issues that arise when research is focused around populations or around family groups; this paper deals with the place of relatives of participants in genomics research more generally. Recently, in response to this challenge, recommendations have attempted to tread a middle ground by retaining traditional models of informed consent whilst suggesting that potential research recruits should be encouraged to discuss participation with their families. It is argued here that this may produce an unfair account of the responsibilities of research participants; that it may ignore the very many difficulties of communication within families about genetics and health; and that it may create unrealistic hurdles to the ethical conduct of research. Research conducted in the context of clinical genetics and on health communication more widely is drawn upon to illustrate these points. A clear recommendation is made that providing materials that may assist research participants to communicate with family members may be beneficial and may raise ethical standards, but that it may be unwise to burden participants with the suggestion that they owe specific obligations to genetic relatives to discuss research participation with them.

Legal issues and identifiability of genomics information:

In April, the maximum fine possible for violations of the UK data protection act increased to £500 000 (approximately 600 000 euros). Although the imposition of such large fines on organisations such as universities and other research institutions is hopefully unlikely, this does provide an extra impetus for ensuring full compliance with the law. This paper, written with members of the HeLEX Centre at Oxford, discusses the protection of individuals’ information in conducting genomics research and gives some clear recommendations for ensuring full compliance.

Podcasts:

Links to the podcasts mentioned in the last newsletter are now active. There are now a number of podcasts available on different topics from various members of the Oxford Bioethics Network.

Ethics and genomics research: introduction:
http://media.podcasts.ox.ac.uk/medsci/helex/helex-boddington-genomics.mp3

Ethical issues raised by genome-wide association studies:
http://media.podcasts.ox.ac.uk/medsci/helex/helex-boddington-procardis.mp3

Genomics research, individuals and families:
http://media.podcasts.ox.ac.uk/medsci/helex/helex-boddington-families.mp3

Conference on data sharing in genomics:

The provisional programme for this conference is now available:


The ethics workshops will take place on Monday 20 September, from 9.50 to 12.30, immediately before the start of the conference itself, with a further roundtable discussion over lunch on the last day, from 12.30 to 13.30 on Wednesday 22 September. These workshops are open to any members of the Procardis consortium as well as to anyone attending the conference. They will provide an opportunity to look critically at ethical and philosophical ideas that underlie debates about the sharing of data, looking specifically at how such issues shape the discussions of the conference.

Support materials for these workshops will be made available closer to the date.