

## Satellite Workshop: on ethical and philosophical issues arising from data sharing

Monday 20 September: Session 1; Wednesday 22 September: Session 2 (Times TBC)

This workshop will examine ethical issues underlying the debates about sharing data in genetics, with the aim of enriching participants' understanding of how these issues may inform and illuminate the regulatory and policy debates. Emphasis will be placed on how data sharing practices are impacting upon key ethical concepts. These will include looking at: how notions of responsibility might apply through large networks; different conceptions of autonomy and how they may be challenged by data sharing and by genomics; concepts of access to knowledge and how these apply to both personal knowledge and to the scientific enterprise. An initial workshop will precede the conference and there will be a follow up workshop after the conference closes. There will be an opportunity for participants who wish to deepen their comprehension of these issues to report back on how particular ethical issues are addressed in the main conference.

This workshop is run as part of the Ethics Programme for the Procardis consortium for cardiovascular genomics based in the Ethox Centre, University of Oxford. Procardis receives funding through the 6th Framework Programme of the European Union, project number LSHM-CT-2007-037273. Please register for this workshop when you register for the main conference. For further details please contact [helexconference@dphpc.ox.ac.uk](mailto:helexconference@dphpc.ox.ac.uk)

## HeLEX Centre for Health, Law and Emerging Technologies

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**HeLEX** is an interdisciplinary research centre, based at the Department of Public Health at the University of Oxford. The centre specialises in investigating the relationships between law, ethics, and practice in the area of emerging technologies in health.

Our current research focuses on genomics with an emphasis on biobanks, privacy, data-sharing frameworks, global governance and translational research. We have an interdisciplinary approach that uses tools and methods of investigation and analysis from the disciplines of law, philosophy and sociology.

**welcome**trust



**EPSRC**

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**For further details on the conference please contact:**

**E-mail:** [helexconference@dphpc.ox.ac.uk](mailto:helexconference@dphpc.ox.ac.uk)

**Web:** <http://helex.medsci.ox.ac.uk/>

# International Data Sharing Conference

20-22 September 2010

St Hugh's College  
Oxford

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September 20-22, St Hugh's College,  
Oxford

With the aid of technology and the support of funders, data sharing is now possible on a scale that has not been possible before. With a click of a mouse, many sequence and research datasets located in different countries around the world can be accessed with ease. Large infrastructures and many different types of bio-banks are being built to allow the comparison of many samples so that we can understand the aetiology of common and rare diseases. These developments are changing scientific practice, as well as raising a number of technological, legal, ethical and social challenges for people working in the field of genomics.

How should data-generators be rewarded for their efforts to the scientific community? Can we promise anonymity of research participants when whole sequences and phenotypic data are being used for research purposes? What is the best way to harmonise different datasets collected for different purposes? Should participants be fed back individual findings? Are our national research governance systems adequate to cope with global data sharing?

The purpose of this conference is to bring together leaders in the field to discuss the issues raised by data sharing in genomics, as well as bringing experts from other domains to add a new dimension to these debates. The conference will use a conversation format, using panels focused on specific questions to generate insights into these issues.

Rather than traditional conference formats of pre-prepared presentations, we will develop a fully discursive approach in order to stimulate debate in this area and to develop current thinking within the research community. To enable divergent views and the opinions of many stakeholders to be heard, we will pilot an interactive, conversational format for this conference using different technological tools. We will anchor and focus the conference conversations by having plenary sessions of invited speakers at the beginning and end of the conference as well as at the beginning and end of every day. These will be broadcast in real time and podcast to reach a wide audience. For the rest of the conference there will be parallel panel sessions with the aim of discussing diverse points of view.

Our call for abstracts closed on the 11th June 2010. We have selected a mixture of participants from our applicants who consist of leaders in the field, funding representatives, researchers from developing countries, patient representatives, as well as graduate students. We have secured funding for a number of bursaries for people who would not usually be able to attend such an event. The key points from each panel session will be summarised and posted on conference screens

and on our website immediately after the session, to form the basis for the next series of conversations. We will develop a web-based record of the event that will combine podcasts, blogs and panel session postings.

This conference will pilot a new way of running conferences within genomics. Because of its format and objectives, it will also have a significant effect on the thinking that underpins the way that open access policies are developed and implemented. The conference will provide a neutral space to consider the full dimensions and implications of such policies and will allow new voices to be heard. It will foster an international perspective on the issues raised by data sharing, rather than simply having national perspectives, and will also encourage interdisciplinary interactions.

Details about our student and developing countries bursaries are available on our website. Please register your interest with [helexconference@dphpc.ox.ac.uk](mailto:helexconference@dphpc.ox.ac.uk)

We look forward to welcoming you to Oxford in September 2010!

