

# Governing Biobanks - What are the challenges?

**2008 International Conference  
St. Anne's College  
University of Oxford**

**24<sup>th</sup> -26<sup>th</sup> June 2008**

Convened by the Ethox Centre University of Oxford

In collaboration with the Centre for Law and Genetics  
Universities of Tasmania & Melbourne

**welcome**trust



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**CONFERENCE PROGRAMME**

	<b>TUESDAY 24<sup>th</sup> JUNE 2008</b>
12.30 - 14.00	<b>Pre - Registration &amp; Welcome Refreshments</b>
	<b>Tsuzuki Lecture Theatre</b>
14.00 - 14.15	<b>OPENING PLENARY</b>  <b>Setting the Interdisciplinary Context</b>  <b>Welcome : Dr. Jane Kaye</b> The Ethox Centre, University of Oxford, UK
14.15 - 15.15	<b><i>Scientific Values and Private Interests in Genomic Resources</i></b>  <b>Prof. Martin Bobrow</b> University of Cambridge, UK
15.15 - 16.15	<b><i>What Are the Foundations of Governance for Biobanking?</i></b>  <b>Prof. Tim Caulfield</b> Health Law Institute, University of Alberta, Canada
16.15 - 16.45	<b>Refreshments</b>
16.45 - 17.45	<b><i>Analytical Frameworks for Understanding the Governance Of Biobanks</i></b>  <b>Prof. Susan Leigh Star</b> Center for Science, Technology & Society, Santa Clara University, USA
17.45 - 18.30	<b>Plenary Panel Discussion Session</b>  <b>Commentator : Prof. David Weisbrot</b> President of the Australian Law Reform Commission, Australia
18.30 - 20.30	<b>Conference Welcome Reception</b>  <b>Garden Marquee – St Anne’s College</b>
	<b>WEDNESDAY 25<sup>th</sup> JUNE 2008</b>

08.00 - 09.00	<b>Light Breakfast – College Dining Hall</b>		
	<b>Tsuzuki Lecture Theatre &amp; Seminar Room 7</b>		
09.00 - 10.45	<b>PLENARY II – Actors, Networks and Practices</b>		
	<p>This plenary explores how people and technologies converge in the governance of biobanks. It seeks to identify the individuals and groups that have a part in governance; understand the ways that governance is constituted through their actions and interactions; explore the co-production of governance, technologies and practices; consider the impact of vision and expectations in these relationships (promissory science and anticipatory governance); and asks how databases might influence the social relations that surround science.</p> <p style="text-align: center;"><b>Speakers:-</b>  <b>Dr. Christine Hine</b>, Department of Sociology, University of Surrey, UK  <b>Prof. Peter Glasner</b>, CESAGen, Cardiff University, UK  <b>Commentator: Dr. Andrew Smart</b>, Bath Spa University, UK</p>		
10.45 - 11.15	<b>Morning Refreshments – Ruth Deech Foyer</b>		
	<b>Tsuzuki Lecture Theatre</b>	<b>Seminar Room 7</b>	<b>Seminar Room 8</b>
11.15- 12.45	<b>SESSION 1</b> <b>Governing Bodies</b>  <b>Chair: Prof. Susan Leigh Star</b>	<b>SESSION 2</b> <b>The Challenges of Informed Consent</b>  <b>Chair: Prof. Tim Caulfield</b>	<b>SESSION 3</b> <b>Engaging Participants</b>  <b>Chair: Dr. Beverley McNamara</b>
11.15 – 11.45	<p>The governance structures for biobanks are still evolving. This session explores whether existing mechanisms are appropriate and considers the new bodies that have been established. How does this reconfigure the relationships between different gatekeepers?</p> <p style="text-align: center;"><b><i>Potential conflicts in governance mechanisms used in population biobanks</i></b>  Susan Wallace, Université de Montréal, Canada</p>	<p>Informed consent is regarded as a fundamental requirement for medical research. However, biobanks challenge the notion of broad consent and other models which have been proposed. Is informed consent necessary in all situations?</p> <p style="text-align: center;"><b><i>Understanding of Features of a Genetic Registry Study: Implications for Informed Consent</i></b>  Arlene M Davis &amp; R. Jean Cadigan, University of North Carolina, USA</p>	<p>Donors of samples and data are essential for research, but what are their motivations for taking part, and how can we incorporate these insights into building models of governance?</p> <p style="text-align: center;"><b><i>Why do people take part in biobank research? Accounts from participants</i></b>  Carolyn Tarrant <i>et al.</i>, University of Leicester, UK</p>
11.45 – 12.15	<p style="text-align: center;"><b><i>Fair Health Information Practices and the Role of Research Ethics Committees</i></b>  Trudo Lemmens, University of Toronto, Canada</p>	<p style="text-align: center;"><b><i>Patients' dissent in Swedish biobanks: A rare phenomenon</i></b>  Linus Johnsson <i>et al.</i>, Centre for Bioethics at Karolinska Institutet and Uppsala University, Sweden</p>	<p style="text-align: center;"><b><i>Deliberation and representation: diverse purposes and practices in exploring views about genetic databases</i></b>  Gill Haddow, University of Edinburgh, Scotland</p>

12.15. – 12.45	<b><i>The role of the Ethics and Governance Council of UK Biobank</i></b> Martin Richards <i>et al.</i> Ethics and Governance Council, UK	<b><i>Developing an appropriate consent model for biobanks: In defence of 'broad' consent</i></b> Margaret Otlowski, University of Tasmania, Australia	<b><i>The use of stored biological samples from children for genetic research: What do guidelines say?</i></b> Kristien Hens, Katholieke Universiteit Leuven, Belgium
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12.45 - 14.00	<b>LUNCH – College Dining Hall</b>		
	<b>Tsuzuki Lecture Theatre</b>	<b>Seminar Room 7</b>	<b>Seminar Room 8</b>
14.00 – 15.45	<b>SESSION 4 The Public Interest Chair: Dr. Mark Stranger</b>	<b>SESSION 5 Consent or Governance? Chair: Prof. Mike Burgess</b>	<b>SESSION 6 Genetic Privacy Chair: Dr. Trudo Lemmens</b>
	The public interest is often used as a justification for certain activities. What is the relationship between the individual and society when the 'public interest' justification is used in biobanking?	Considering the challenges of obtaining informed consent, could we rely instead on governance mechanisms? What models are currently being used and could be used in the future?	What are the principles that we should consider in order to protect privacy in biobanks? What protections do we find in law? How are these applied in practice?
14.00 – 14.30	<b><i>Volunteerism, research ethics and the United Kingdom's National DNA Database</i></b>  Caitlin M Connors & Aaron Martin, LSE, UK	<b><i>Informed Consent</i></b>  Lukas Gundermann, Unabhängiges Landeszentrum für Datenschutz (ULD), Germany	<b><i>Protecting Privacy and Trust</i></b>  Salvor Nordal, University of Iceland, Iceland
14.30 – 15.15	<b><i>The use of medical records for research – an empirical study</i></b>  Lindsey Brown <i>et al.</i> , University of Oxford, UK	<b><i>Alternative consent approaches to biobanking in the new regulation of biomedical research in Spain</i></b>  Antonio Casado da Rocha University of the Basque Country, Spain	<b><i>Privacy Interests in biobanking: a preliminary view on a European Perspective</i></b>  David Townend <i>et al.</i> , University of Sheffield, UK
15.15 - 15.45	<b><i>Community engagement, confidence and accountability: critical underpinnings for biobanking</i></b>  David Weisbrot, President of the Australian Law Reform Commission	<b><i>The Need for Stewardship: Moving beyond consent to principled decision making</i></b>  Kelly Fryer-Edwards <i>et al.</i> , University of Washington, USA	<b><i>Ensuring Participants Confidentiality in Bio-repositories</i></b>  Atieh Zarabzadeh <i>et al.</i> Trinity College, Dublin, Eire
15.45 - 16.15	<b>Afternoon Refreshments – Ruth Deech Foyer</b>		
	<b>Tsuzuki Lecture Theatre &amp; Seminar Room 7</b>		
16.15 - 17.45	<b>PLENARY III – Regulatory Models and Benefit Sharing</b>  This plenary will discuss the issue of governance as it relates to benefit sharing. If we are serious about benefit sharing, what regulatory models should we put in place for biobanks? In particular, how		

	<p>should regulatory regimes be designed to maximise the public good? If we are not content to leave it to 'market forces' and the 'trickle down effect' how might we best build mechanisms into the governance of biobanks that will help lead to the equitable distribution of benefits to all stakeholders in the local, national and global contexts?</p> <p style="text-align: center;"><b>Speakers:</b></p> <p style="text-align: center;"><b>Asst. Prof. David Winickoff</b>, University of California, Berkeley, USA  <b>Prof. Michael Parker</b>, The Ethox Centre, University of Oxford, UK  <i>Commentator: Prof. Graeme Laurie</i>, University Of Edinburgh, Scotland, UK</p> <p style="text-align: center;"><b>CLOSE OF DAY</b></p>
19.30	<p><b>GALA DINNER – ST. CROSS COLLEGE</b></p> <p><b>Please meet at the Porter's Lodge at 19.20 for the short walk to St Cross College</b></p>

	<b>THURSDAY 26<sup>th</sup> June 2008</b>		
8.00 – 9.00	<b>Light Breakfast – College Dining Room</b>		
	<b>Tsuzuki Lecture Theatre &amp; Seminar Room 7</b>		
9.00 - 10.30	<p style="text-align: center;"><b>PLENARY IV - Global Governance</b></p> <p>The regulation of biobanking is carried out at a national level, even though DNA samples and personal information are shared across national borders as part of global research activity. As we move towards the sharing and networking of resources, what kinds of regulation and procedures need to be standardised? What global structures are needed to facilitate this process that exists outside of the national frameworks?</p> <p style="text-align: center;"><b>Speakers:</b></p> <p style="text-align: center;"><b>Prof. Bartha Maria Knoppers</b> – University of Montreal, Quebec, Canada  <b>Dr. Jane Kaye</b>- Ethox Centre, University of Oxford, UK  Commentator: <b>Prof. Don Chalmers</b>, University of Tasmania, Australia</p>		
10.30 - 11.00	<b>Morning Refreshments - Ruth Deech Foyer</b>		
	<b>Tsuzuki Lecture Theatre</b>	<b>Seminar Room 7</b>	<b>Upper Common Room</b>
11:00 - 12:30	<b>SESSION 7</b> <b>Promoting Data-sharing</b> Chair: <b>Asst. Prof. Dianne Nicol</b>	<b>SESSION 8</b> <b>Incorporating Participant Perspectives</b> Chair: <b>Prof. Margaret Otlowski</b>	<b>SESSION 9</b> <b>Commercial Involvement in Biobanks</b> Chair: <b>Naomi Hawkins</b>
11.00 – 11.30	<p>Sharing samples and data between researchers in the same project who may be based in different institutions and countries, raises many issues. The purpose of this session is to discuss these issues and how they have been addressed.</p> <p style="text-align: center;"><b><i>Ethical and Governance Issues in Human Fetal Tissue Bio-banking.</i></b></p>	<p>Biobank participants' perspectives on sharing the benefits from biobanks vary across the world. What methods have been used to obtain the views of participants? Have participants' views been translated into policy? How should they be translated into policy and governance?</p> <p style="text-align: center;"><b><i>Deliberative mini-publics: Deriving Public advice on the Governance of biobanks</i></b></p>	<p>Research is increasingly about partnerships between publicly-funded institutions and companies. How does this effect donors' involvement in biobanks and the governance structures that should be developed?</p> <p style="text-align: center;"><b><i>Public Perceptions of Commercial Biobank Research</i></b></p>

11.30 – 12.00	<p>Simon Woods, Policy, Ethics &amp; Life Sciences Research Institute (PEALS), Newcastle University, UK</p> <p><b>An Interinstitutional Genetic Databanking Policy Perspective: The United States CTSA Initiative</b></p> <p>Nicholas Anderson <i>et al.</i>, University of Washington, USA</p>	<p>Michael Burgess, University of British Columbia, Canada</p> <p><b>The tools of engagement: Public participation strategies used in Western Australian biobank research</b></p> <p>Beverley McNamara, University of Western Australia, Australia</p>	<p>Morten Andreassen, University of Copenhagen, Denmark</p> <p><b>Public Biobank and Commercial Interests – A Korean Perspective</b></p> <p>Jeong-Ro Yoon, Korean Advanced Institute of Science and Technology, Korea</p>
12.00 – 12.30	<p><b>A new proposal to help researchers in the respect of legal requirements for the exchange of human biological material</b></p> <p>Emmanuelle Rial-Sebagg <i>et al.</i>, INSERM, Toulouse, France</p>	<p><b>Participation in commercial biobank research: ensuring morally acceptable constraints</b></p> <p>Bjorn Myskja, Norwegian University of Science and Technology, Norway</p>	<p><b>Commerce, confidence and commitment: How can biobanks meet all three objectives?</b></p> <p>Graeme Laurie, University of Edinburgh, Scotland</p>
12:30-13.30	<b>LUNCH – College Dining Room</b>		
	<b>Tsuzuki Lecture Theatre</b>	<b>Seminar Room 7</b>	<b>Upper Common Room</b>
13.30-15:00	<p><b>SESSION 10</b></p> <p><b>How do you implement benefit-sharing?</b> Chair: <b>Asst. Prof. David Winickoff</b></p>	<p><b>SESSION 11</b></p> <p><b>What should be the principles for determining access to biobanks?</b> Chair: <b>Mylène Deschênes</b></p>	<p><b>SESSION 12</b></p> <p><b>Global Governance</b> Chair: <b>Prof. Bartha Knoppers</b></p>
13.30 - 14.00	<p>If we agree that there should be benefit-sharing how should this be implemented in practice? What are the governance structures that are needed to support this?</p> <p><b>Biobanking Benefits and Public Interest: On the Road to Better Governance?</b></p> <p>Nadja K. Kanellopoulou, University of Edinburgh, Scotland</p>	<p>Biobanks are established as resources to be used by many researchers for many different research projects into the future. On what basis should access to biobanks be decided?</p> <p><b>Negotiating consensus around the use of biobanks</b></p> <p>Catherine Heeney, University Of Oxford, UK</p>	<p>Governance models differ between biobanks across the world, which has implications for the development of data-sharing regimes at a global level. This session explores some of these challenges and possible ways forward.</p> <p><b>Comparing different models: what are the common factors for success or failure in biobanks.</b></p> <p>Herbert Gottweis, University of Vienna, Austria</p>
14.00 – 14.30	<p><b>Transforming ethical principles of benefit sharing into national legislation: a case study of the Taiwan biobank</b></p> <p>Kuan-hsun Chen, UCLA, USA</p>	<p><b>Fair access in principle and practice</b></p> <p>Martin Yuille, University of Manchester, UK</p>	<p><b>The governance of biobanks in Japan – How the country is struggling and working towards global cooperation.</b></p> <p>Kazuto Kato <i>et al.</i>, Institute for Research in Humanities and Graduate School of Biostudies,</p>

14.30 – 15.00	<b><i>Best Practice Models for Benefit Sharing in Biobanking</i></b>  Dianne Nicol, University of Tasmania, Australia	<b><i>Access to Information and Tissue Stored in Biobanks</i></b>  Loane Skene, University of Melbourne, Australia	Japan  <b><i>Towards ethical governance and sharing of genetic data in Asia and the Pacific</i></b>  Darryl Macer, Regional Unit for Social & Human Sciences in Asia & the Pacific, UNESCO Bangkok
15:00- 15:30	<b>Afternoon Refreshments – Ruth Deech Foyer</b>		
<b>Tsuzuki Lecture Theatre &amp; Seminar Room 7</b>			
15:30- 17.00	<b>CLOSING PLENARY</b> <b>Reflections – Disciplinary and regional challenges in the context of multidisciplinary research and globalisation</b> Prof. Don Chalmers, University of Tasmania, Australia Dr. Anne Cambon-Thomsen, INSERM, France Dr Ousman Nyan, University of Gambia Dr Tohru Masui, National Institute of Bio-medical Innovation, Osaka, Japan  <b>Commentator : Prof. Alastair Campbell, National University of Singapore</b>		
17.00	<b>CONFERENCE CLOSES</b>		