

**INTERNATIONAL DATA SHARING CONFERENCE 2010, OXFORD
PROVISIONAL PROGRAMME**

| MONDAY 20 SEPTEMBER 2010 | | | |
|--|---|--|--|
| 0930 - 0950 | Coffee and Workshops Registration | | |
| 0950 - 1230 | <table border="1" style="width: 100%;"> <tr> <td align="center"> <p><u>ETHICS WORKSHOP</u></p> <p>Dr Paula Boddington in association with Procardis</p> </td> <td align="center"> <p><u>WORKSHOP (invitation only)</u> 'Patient-Centric Initiatives in Health and Biomedical Research' in association with EnCoRe</p> <p>Contact liam.curren@dphpc.ox.ac.uk for more details</p> </td> </tr> </table> | <p><u>ETHICS WORKSHOP</u></p> <p>Dr Paula Boddington in association with Procardis</p> | <p><u>WORKSHOP (invitation only)</u> 'Patient-Centric Initiatives in Health and Biomedical Research' in association with EnCoRe</p> <p>Contact liam.curren@dphpc.ox.ac.uk for more details</p> |
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| 1230 - 1330 | Workshop Lunches | | |
| 1300 - 1400 | Conference Registration & Refreshments | | |
| 1400 - 1415 | <p>WELCOME <u>Dr Jane Kaye</u> <i>Director, HeLEX, Centre for Health, Law and Emerging Technologies, University of Oxford</i></p> | | |
| 1415 - 1600 | <p>OPENING PLENARY <u>Dr Jennifer Harris</u> <i>Senior Researcher, Norwegian Institute of Public Health, Oslo, Norway</i></p> <p><u>Prof Raj Ramesar</u> <i>Director, MRC Human Genetics Research Unit, University of Cape Town, South Africa</i></p> | | |
| 1545 -1615 | Afternoon Refreshments | | |
| 1615 - 1700 | <p><u>Prof Martin Bobrow</u> <i>Emeritus Professor of Medical Genetics, University of Cambridge</i></p> | | |
| 1700 - 1800 | <p>PANEL SESSION <i>Q&A session with opening plenary panel</i></p> | | |
| 1830 - 2000 | <p>Welcome Finger Buffet and Drinks Mordan Hall, St Hugh's College, Oxford</p> | | |
| 2000 - 2300 | St Hugh's College Bar open in the Rachel Trickett Building | | |

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| TUESDAY 21 SEPTEMBER 2010 | |
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| 0800 - 0900 | Breakfast for those staying at St Hugh's |
| 0900 - 1030 | <p>PLENARY NEW DILEMMAS AND NEW RESPONSES</p> <p><u>Dr David Cox</u> <i>Chief Scientific Officer, Target Generation Unit, Pfizer, USA</i></p> <p><u>Prof Bartha Maria Knoppers</u> <i>McGill University, Canada</i></p> <p><u>Prof Ellen Wright Clayton</u> <i>Rosalind E. Franklin Professor of Genetics and Health, Vanderbilt University, USA</i></p> <p>Chair: <u>Dr Jerome Singh</u> (TBC) <i>Head of Ethics and Health Law at the Center for the AIDS Programme of Research in South Africa (CAPRISA)</i></p> |
| 1030 - 1100 | Morning Refreshments |
| 1100 - 1230 | <p>ABSTRACTS <i>These will run in three parallel sessions.</i></p> |
| | <p><i>Session 1 Sharing data across different milieu</i></p> |
| | <p><i>Session 2 Data sharing perspectives from initiatives in the UK, USA and Australia</i></p> |
| | <p><i>Session 3 'Open source' models for the translation of research results</i></p> |
| | <p><u>Amy McGuire</u> <i>Genomic Data Sharing: Ethics, Policy, and Participant Perspectives</i></p> |
| <p><u>Dawn Field & Susanna-Assunta Sansone</u></p> | |
| <p><u>Donna M Gitter</u></p> | |
| <p><u>Isabelle Budin Ljøsne</u></p> | |
| <p><u>Holly K Tabor</u> <i>An analysis of current studies in dbGaP that involve children</i></p> | |
| <p><u>Matteo Macilotti</u></p> | |
| <p>TBC</p> | |
| <p><u>Vicky Xafis</u> <i>Ethical, legal and social considerations in administrative health data linkage in Australia</i></p> | |
| <p><u>Nick Anderson</u></p> | |

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| 1230 - 14.00 | LUNCH Poster Presentations | | |
| | STATIONS (10 min talk + 10 min discussion) | | |
| 1400 - 14.20 | Station 1 <u>Ralph Schroeder & Eric Meyer</u> Governance & Data Sharing | Station 2 <u>Jantina de Vries</u> <i>Ethnic stigmatisation in genomics: investigating the importance of including local investigators in data sharing decisions in genomics research in Africa</i> | Station 3 <u>Gus Hosein & Aaron Martin</u> <i>e-Health systems in developing countries and emergency situations</i> |
| 5 min | MOVE STATION | | |
| 1425 - 1445 | Station 1 repeat <u>Ralph Schroeder & Eric Meyer</u> | Station 2 repeat <u>Jantina de Vries</u> | Station 3 repeat <u>Gus Hosein & Aaron Martin</u> |
| 5 min | CHANGE OF STATION PRESENTERS | | |
| 1450 - 1510 | Station 4 <u>National Information Governance Board</u> <i>Facilitating medical research whilst respecting patient confidentiality: What are the principles for the legal and ethical disclosure of patient information for research? From historical custom and practice to lawful and current best practice.</i> | Station 5 <u>EnCoRe Project</u> <i>Ensuring Consent and Revocation: a research project, being undertaken by UK industry and academia, to give individuals more control over their personal information. A discussion of work to date with the Oxford Radcliffe Biobank.</i> | Station 6 <u>Aaron Kolski-Andreaco - The Journal of Visualized Experiments (JoVE)</u> |
| 5 min | MOVE STATION | | |
| 1515 - 1535 | Station 4 repeat <u>National Information Governance Board</u> | Station 5 repeat <u>EnCoRe Project</u> | Station 6 repeat <u>Aaron Kolski-Andreaco - The Journal of Visualized Experiments (JoVE)</u> |
| 1535 - 1600 | Afternoon Refreshments | | |

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| <p>1600 - 1730</p> | <p align="center">PLENARY IDENTIFIABILITY: WHAT SHOULD WE BE PROMISING?</p> <p align="center"><u>Dr Brad Malin</u> <i>Assistant Professor, Dept of Biomedical Informatics, School of Medicine, Vanderbilt University, USA</i></p> <p align="center"><u>Prof Jane Gitschier</u> <i>Professor of Medicine and Pediatrics, University of California, San Francisco, USA</i></p> <p align="center"><u>Stephanie Malia Fullerton</u> <i>Assistant Professor of Bioethics and Humanities, School of Medicine, University of Washington, USA</i></p> |
| <p>1730 - 1900</p> | <p align="center">SUMMING UP BY FACILITATORS <u>Roger Brownsword</u>, <u>Paul Burton</u>, <u>Tim Caulfield</u>, <u>Barbara Koenig</u>, <u>Amy McGuire</u> and <u>Eric Meslin</u></p> |
| <p>1930</p> | <p align="center">DINNER AND ENTERTAINMENT Poets in Residence St Hugh's Dining Hall</p> |
| <p>Open until midnight</p> | <p align="center">St Hugh's College Bar open in the Rachel Trickett Building</p> |

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| WEDNESDAY 22 SEPTEMBER 2010 | | | | | | | | | | | | | |
|---|---|---|---|-----------|---|---|---|--|-----|---|---|--|---|
| 0800 - 0900 | Breakfast for those staying at St Hugh's | | | | | | | | | | | | |
| 0900 - 1030 | <p>PLENARY: SHOULD WE FEEDBACK INDIVIDUAL RESULTS TO PARTICIPANTS?</p> <p><u>Dr Matt Hurles</u> <i>Wellcome Trust Sanger Centre, UK</i></p> <p><u>Dr Anne Cambon-Thomsen</u> <i>Inserm, Toulouse, France</i></p> <p><u>Sharon Terry</u> <i>President and CEO, Genetic Alliance, USA</i></p> | | | | | | | | | | | | |
| 1030 - 1100 | Morning Refreshments | | | | | | | | | | | | |
| 1100 - 1230 | <p>ABSTRACTS <i>These will run in three parallel sessions.</i></p> | | | | | | | | | | | | |
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| | STATIONS <i>(10 min talk + 10 min discussion)</i> | | |
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| 1330 - 1350 | Station 1 TBC | Station 2 Kieran O'Doherty <i>How will human microbiome research affect ethical conundrums in data sharing?</i> | Station 3 Barbara Koenig <i>The NIH eMERGE Consortium: an American model for integrating bioethics into leading-edge genomic research</i> |
| 5 min | MOVE STATION | | |
| 1355 - 1415 | Station 1 repeat TBC | Station 2 repeat Kieran O'Doherty | Station 3 repeat Barbara Koenig |
| 5 min | CHANGE OF STATION PRESENTERS | | |
| 1420 - 1440 | Station 4 Kelly A Edwards <i>What are the justifications for data sharing policies, and how are decisions to share made?</i> | Station 5 Deborah Mascalzoni <i>The Virtual Patient</i> | Station 6 Anthony Brookes |
| 5 min | MOVE STATION | | |
| 1445 - 1505 | Station 4 repeat Kelly A Edwards | Station 5 repeat Deborah Mascalzoni | Station 6 repeat Anthony Brookes |
| 1505 - 1600 | CLOSING PLENARY: MOVING FORWARD Led by: Roger Brownsword , Paul Burton , Tim Caulfield , Barbara Koenig , Amy McGuire and Eric Meslin | | |
| 1600 | CONFERENCE CLOSES | | |