



Launch of the Nuffield Council on Bioethics report

The collection, linking and use of data in biomedical research and health care: ethical issues

Tuesday 3 February 2015

One Great George Street Westminster SW1P 3AA

Programme

14.00 **Registration – tea and coffee available for guests**

14.30 **Welcome**

Jonathan Montgomery, Chair of the Nuffield Council on Bioethics

14.35 **Introduction and overview**

Presentations by members of the Working Party:

Martin Richards, Chair of the Working Party and Emeritus Professor of Family Research, University of Cambridge

Jane Kaye, member of the Working Party, Director of the Centre for Law, Health and Emerging Technologies (HeLEX), University of Oxford

Anneke Lucassen, member of the Working Party, Professor of Clinical Genetics and Honorary Consultant Clinical Geneticist, University of Southampton Cancer Sciences Division and the Wessex Clinical Genetics Service.

15.10 **Session 1: Data initiatives in health care systems**

Speaker: **Paul Matthews**, member of the Working Party and Head of the Division of Brain Sciences, Imperial College London

Responders to comment on the report:

Justin Keen, Professor of Health Politics, University of Leeds

Tony Calland, Joint Vice Chair, Confidentiality Advisory Group - Health Research Authority

15.40 **Tea and coffee**

16.00 **Session 2: Data initiatives in biomedical research**

Speaker: **Susan Wallace**, member of the Working Party and Lecturer of Population and Public Health Sciences, Department of Health Sciences, University of Leicester

Responders to comment on the report:

Anna Middleton, Senior Staff Scientist, Wellcome Trust Sanger Institute

Ronan Lyons, Director, Farr Institute Centre for Improvement in Population Health through E-records Research (CIPHER)

16.30 **Panel discussion and Q&A**

Chair: Jonathan Montgomery, Chair of the Nuffield Council on Bioethics

Panellists: members of the Working Party.

17.15 **Thanks and close, followed by drinks reception**

Jonathan Montgomery, Chair of the Nuffield Council on Bioethics

Background to the report

The use of new technologies that greatly facilitate the collection, storing and linking of data has become increasingly important to biomedical research and healthcare, as well as to many of the conveniences of contemporary life. However, new uses of health and biological data relating to distinguishable individuals also holds potentially far-reaching implications for privacy, interpersonal relationships and the relations between individuals and society. This report considers the ethical questions raised by these developments, and makes a range of recommendations for ethically sound governance and design of data initiatives.

The report was produced by an expert Working Party. In coming to its conclusions, the Working Party invited contributions from a wide range of people including an open consultation that ran from October 2013 to January 2014.

More information about this project is available at www.nuffieldbioethics.org/project/biological-health-data/