

## **WELLCOME TRUST BIOMEDICAL ETHICS PROGRAMME GRANTHOLDERS' MEETING 2004**

The inaugural meeting of Trust grantholders in Biomedical Ethics took place on 9 December 2004. 30 grantholders and five members of the Trust's Biomedical Ethics Funding Committee attended. The purposes of the meeting were:

- To build a greater sense of identity for the programme;
- To foster contacts within the grantholder community, and between grantholders, Trust staff and members of the Funding Committee;
- To highlight to grantholders the range of Biomedical Ethics research supported by the Trust;
- To discuss how ethics research can be applied to policy and practice, and identify some of the barriers to success;
- To give grantholders the opportunity to provide feedback on their experience of the programme, and their perspectives on how the programme could evolve.

The meeting included sessions on the following:

- Overview of recent developments in the Trust's Biomedical Ethics programme
- Presentations on Trust-funded research projects
- Poster presentations from PhD students
- Discussion of how ethics research can influence policy and practice
- Future development of the programme

### **Recent developments in the Trust's Biomedical Ethics programme**

Trust staff gave the meeting an overview of recent developments in the Biomedical Ethics programme. These include:

- A revised Statement of Purpose;
- New grants schemes (small project grants and research travel grants);
- New mechanisms to encourage the wider application of biomedical ethics research (a newsletter - the Wellcome Ethics Bulletin - and featured research findings on the website).

Further details are available on the Trust's website,  
[http://www.wellcome.ac.uk/doc\\_WTD003247.html](http://www.wellcome.ac.uk/doc_WTD003247.html)

### **Research supported by the programme**

Presentations were given on some of the research supported by the programme. Further details of these projects are available on the Trust website at:  
<http://www.wellcome.ac.uk/node4410.html>

1. "Genetic information and crime investigation: the UK National DNA Database, and forensic DNA databases in Europe"

*Mr Robin Williams, School of Applied Social Sciences, University of Durham*

DNA is increasingly being seen as the gold standard for forensic evidence. This is driving efforts by criminal justice agencies and ministries of justice to increase the coverage of existing databases, to include a wider range of individuals than convicted criminals.

On the other hand, there are increasing challenges for the governance of these databases. The growth in the size of forensic DNA collections raises questions of confidentiality of the information they contain, and the equity of their regulation. The emergence of forensic genetics raises new problems; for example, is it acceptable to analyse genetic information from individuals from whom samples have been taken without their consent (as is legal in some countries, including the UK)?

The UK's National DNA Database (NDNAD) is the largest forensic DNA database in the world and is seen as the leading resource of its type. Facing the governance challenge will require the NDNAD to broaden out discussions of its future to involve a wider range of stakeholders than at present.

[Robin Williams' presentation \(PowerPoint\)](#)

## 2. "Assessment of mental capacity"

*Professor Matthew Hotopf, Institute of Psychiatry, London*

Matthew Hotopf has carried out research comparing the "McArthur Competence Assessment Tool – Treatment (MacCAT-T)", a semi-structured interview technique, with assessments of capacity by the clinical teams in a general hospital and a psychiatric hospital in London.

The research revealed significant discrepancies between the assessments of capacity from MacCAT-T and the clinical team. In the general hospital study, only 25% of those judged to lack capacity on MacCAT-T were also judged to lack capacity by the clinical team. This raises concerns that patients may be being treated when they are compliant but lack the capacity to give informed consent.

These findings could be significant for wider issues of public policy. Two important pieces of mental health legislation are currently being debated by Parliament – the Mental Health Bill and the Mental Capacity Bill. Matthew Hotopf argued that the law on capacity would be confused if these Bills were to be enacted in their present form. Problems over assessing capacity could be exacerbated by an incoherent legal framework.

[Matthew Hotopf's presentation \(PowerPoint\)](#)

## 3. "Evaluating genetic tests: policy issues"

*Dr David Melzer, Department of Public Health, University of Cambridge*

David Melzer and colleagues are building on their research on pharmacogenetics to look at genetic testing more widely. Genetic tests for complex traits will generate probabilistic information that will be challenging to incorporate into clinical decision-making.

Previous research identified criteria for analysing whether genetic tests should be incorporated into clinical practice:

- Does the test have analytical validity - does it work in the lab?
- Does the test have clinical validity - does it work in the clinic?

- Clinical utility – does it provide a more useful approach to testing in a clinical setting than the alternatives?
- Does the test raise any ethical, legal or social concerns?

The new research will involve a number of strands, involving interviews and focus groups, analysis of the European Directive on *in vitro* devices, and comparisons with other countries such as Australia and Japan.

[David Melzer's presentation \(PowerPoint\)](#)

### *Discussion*

The presentations highlighted the range of research questions and methodologies that have been supported by the Trust programme. The meeting gave grantholders the opportunity to discuss how they might shed light on questions that had been raised by researchers from other disciplinary backgrounds. It was also clear that a variety of data was being collected that would be of interest to scholars in other fields.

### **How ethics research can influence policy and practice**

The Trust is very interested in this question and seeks to support grantholders to engage with audiences beyond their academic disciplines.

This session began with two presentations:

#### 1. "A policymaker's perspective"

*Dr David Coles, Science in Society, DG Research, European Commission*

- Ethics research is an important element of the European Sixth Framework Programme
- Policy that draws on ethics research will be more robust, more inclusive, and will have greater public acceptability;
- Researchers need to remember that policy often has to be made quickly – key messages need to be drawn out and presented clearly.

[David Coles's presentation \(PowerPoint\)](#)

#### 2. "A researcher's perspective"

*Dr Kathy Liddell, Faculty of Law, University of Cambridge*

- A perspective drawing on research interests in political philosophy, and practical experience of trying to influence policy;
- Ethics researchers can contribute to policy development by mapping the moral landscape for policymakers, identifying the ethical implications of different policy options;
- Researchers may not always be able to influence policy decisions, but they can have a useful input into the development of policy; at the same time the science policy 'landscape' can often be difficult and changing terrain for bioethics, and we need to find an appropriate anchorage point for ethics itself

[Kathy Liddell's presentation \(PowerPoint\)](#)

*Discussion*

- Policymakers need to listen to a range of views and not just the most strident voices;
- Policymakers are interested in research that combines empirical findings with analysis of the implications of different policy directions;
- Researchers may not always be able to influence policy decisions, but they can have a useful input into the development of policy;
- Communication needs to improve on both sides: policymakers need to define their problems more clearly, and researchers need to draw out how their research findings address these problems.

**Future development of the programme**

- The Research Assessment Exercise – funding bodies such as the Trust could have a role in tackling problems with assessing interdisciplinary research, and of getting credit for research communication and encouraging application of research;
- Systematic reviews – these are useful for policymakers and the Trust could consider provide grant support for them; we need to distinguish in such reviews between research *for* and research *on* biomedical ethics theory and practice;
- Integrating science and ethics – the Trust should look for opportunities to organise joint discussions of scientists and ethicists on suitable topics;
- The use of ethics research in policymaking – this was felt to be an interesting research question for which the Trust could provide support;
- The ethics of non-therapeutic applications of biomedical technologies eg forensics, insurance – more research needs to be done on these topics and how, if at all, they converge with or diverge from ‘the medical’, and this brought to the attention of policymakers and opinion formers.

**Next meeting**

The next Biomedical Ethics Grantholders' meeting is due to be held in November 2005.