Ethical Concerns in e-Science Projects

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Motivation

• Privacy of information
• Access to medical data
• Use of medical data as test data
• Securing ethical approval in a multi-site project
• Designing technology to ‘fit’ organisational purposes
• Ownership of data

Plan for Session

16.10 Introduction
   Marina Jirotka, University of Oxford
16.20 - 17.40 Presentations (15 mins + 5 mins questions each)
16.20 e-Science and ethical issues: a comparison with randomised clinical trials
   Steve Harris, University of Oxford
16.40 Ethical issues in e-Science: The View From Clinical Genetics
   Jonathan Berg, University of Dundee
17.00 De-identifying the EHR: building a resource for research
   Dipak Kalra, University College London
17.20 Making sense of the guidelines on sharing personal data
   Richard Ashcroft, Imperial College London
17.40 General Issues
   Marina Jirotka
17.45 Open Discussion
18.10 Close

Objectives

• Catalogue of ethical problems
• Set of best practices and solutions
• Proposed guidelines and procedures
• Implications for future e-Science projects
  – project design and proposal writing
• Implications for policy
  – ethical committees, NHS and government policy

Issues

• Use of retrospective data - implied consent insufficient
• Use of personal data
  – Plan for prospective collection of informed consent
• Anonymisation strategies
  – Implications for future use of system
• Ethical design must be inherent in database
• Gaining ethical approval - MREC and LREC
• Global considerations - multi-national projects?