Ethical Committee Perspective

Responsible Data Sharing Across Borders

Nordic Expert meeting

5 March 2013, Stockholm
Research Ethics Committees

• Review all research protocols
• Ensure that research is carried out ethically
• Protect the research participants from harm
  – Ensure that nothing happens to the research subject without her valid consent and protect vulnerable groups
Current situation

• Informed consent and autonomy
  – Informed about particular research

• It is front loaded
  – “All of the research uses must be anticipated when the informed consent form is written and most of the oversight takes place before the research commences”

• “One researcher, one project, one jurisdiction”
Other types of consents

• Broad consent (biobanks)
  – Has become standard for Biobank recruitment
  – Participants consent at the time of collection rather than to a specific project

• Open consent (genome sequencing)
  – Participants must be aware that the data can and will likely be accessed, shared and linked to other sets of information
  – Individuals potentially identifiable
  – Principle of veracity
“To develop a research governance structures that can enable data flows through networks in an ethical and lawful way, we need to radically re-think the way that we organize, structure and conceptualise international research governance”
– Jane Kaye (2011)
Dynamic consent

• Dynamic consent
  – Uses the information technology to involve participants and enable them to give consent to the use of their samples over a long period of time
  – Engage participants over time
Social trust in Nordic Countries

- Registries and biobanks are a goldmine for research but so is willingness to participate and trust in research.
- People in the Nordic Countries are more informed about biobanks than in other parts of Europe.
- Governance and infrastructure is the key to good science.
• Our ambition should be to build a outstanding framework where ethical concerns are not seen as obstacles but important part of doing good science
The Nordic Committee on Bioethics

• To discuss and analyze issues in bioethics in order to achieve greater awareness, promote common understanding, improve policy making and present internationally a Nordic perspective on bioethical challenges
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