Ethical, legal and social aspects: Data Sharing and Open Access

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Viewpoint
Scientists and Sharing HGP and its legacy
A novel set of issues?
A difficult problem
Reflections
Discussion
My perspective

• Legal, financial and technical infrastructures do not fully explain practice
• Networks of actors, biobanks and norms
• The wider context/environment
• UK GGD Project, EU and Spanish Networks
Key questions

• How do scientists determine who gets access to data?
• What motivations do scientists have for sharing and not sharing?
• Is Open Access a continuation of Data Sharing or something completely new?
• What are the implications for scientists and the wider community?
Incentives and disincentives to sharing

- **Resources**
  - Money
  - Data/samples
  - Ideas

- **Interests**
  - Adequate recognition of effort
  - Relationship to career structure
  - Opportunity and actual costs
Ethical motivations

• The greater good
  – Benefits to scientific community
  – Benefits to health
  – Advance of human knowledge

• Protection of original context
  – Scientific
  – Socio/ethical
  – Stewardship
From Data Sharing to Open Access

• Human Genome Project (2003)
• A new zeitgeist
• More Data
  – Collection, storage, funding, use etc
• ´Community Resources´ (WT 2003)
The changing relationship of the scientist to her data

- Hypothesis driven data collection and use
- Case by case decisions by scientists regarding sharing
- Bound to a specific ethical, social and scientific context
- Reusable data
- No further input into decisions on sharing
- Data on the web available to all
Is there something new about Open Access?

- Negotiations
- Networks
- Relationships
- Context
- Control in collectors’ hands
- Stewardship
- One off agreements
- Repositories
- Formal applications
- Reusability
- Control in hands of repository
- ?
The problem of privacy within an Open Access model

• Aggregated anonymised data (Homer et al 2008)
• Iterative comparison between datasets (Gitschier 2009)
• Inference from available data to withheld data (Nyholt et al 2009)
• Shared traits in populations (Greenbaum et al 2008)
New Problems/Old Solutions

• Data Protection: the model of the single identifiable subject
• Consent and confidentiality
• Anonymity and inference
• What are the potential consequences of this?
Reflections

• Consensus on use of data was maintained by alignment of interests
• ‘Data’ in Biobanks have traditionally been created within specific contexts
• Open Access model must take account of former practices and rationales
• Ethical and Practical issues require innovative solutions
