

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

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Viewpoint
Scientists and Sharing
HGP and it's 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

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