

Balancing the Local and the Universal in Maintaining Ethical Access to a Genomics Biobank

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Oppositions in data sharing

- Open access v bureaucracy/ownership
- Standardisation v local arrangements
- Public good v protection of data subject autonomy
- Broad consent v restrictive access agreements
- Platforms/consortia v repositories/studies

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- UK Bio
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Biostatistics (2010), 11, 4, pp. 661–673
doi:10.1093/biostatistics/kxq035
Advance Access publication on June 3, 2010

On inferring presence of an individual in a mixture: a Bayesian approach

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SUMMARY

Homer *and others* (2008. Resolving individuals contributing trace amounts of DNA to highly complex mixtures using high-density SNP genotyping microarrays. *PLoS Genetics* 4, e1000167) recently showed that, given allele frequency data for a large number of single nucleotide polymorphisms in a sample together with corresponding population “reference” frequencies, by typing an individual’s DNA sample at the same set of loci it can be inferred whether or not the individual was a member of the sample. This observation has been responsible for precautionary removal of large amounts of summary data from public access. This and further work on the problem has followed a frequentist approach. This paper sets out a Bayesian analysis of this problem which clarifies the role of the reference frequencies and allows incorporation of prior probabilities of the individual’s membership in the sample.

Downloaded from <http://biostatistics.oxfordjournals.org/> at Edinburgh

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Openness continued...

- Global Alliance for Genomics and Health
 - Harmonisation, setting universal standards for governance (Knoppers et al 2014) (Birney et al 2017)
- RCUK Concordat on Open Research Data (2016)
 - All data
- The FAIR Guiding Principles for scientific data management and stewardship (2016)
 - Findable, Accessible, Interoperable and Reusable (Wilkinson et al 2016)

Broad Consent v Managed access

- Toronto Statement acknowledges ‘access may be restricted’ in circumstances where detailed genomic or clinical data pose a risk of deidentification of individuals research subjects (Toronto Statement 2009)
- Consent ‘is not a panacea...robust governance is essential for the ethical conduct of research’ (WT Expert Advisory Group on Data Access 2015).
- RCUK Principle 5 reasons for not sharing: commercial interests and again the privacy and confidentiality of research subjects - (RCUK 2016)

The Scottish Place



- Expert Working Groups and the GS Executive Committee
- Access Committee
 - Scientific merit
 - Governance
 - Data/Material
 - Sustainability
- Co-authorship, which is stated in the data and materials transfer agreement and the GS Authorship & Acknowledgement Policy

Sustainability and governance

- Adequate acknowledgement of those involved in maintaining the study - authorship
- Cost recovery through access fees helping to maintain the governance and curation of the GS resource
- Original researchers ability to fulfil commitments given 'moral distance' between new and original contexts for data use and sharing (Bull, Roberts and Parker 2015)
- Implications of requests for data to be housed on platforms such as MRC Dementias Platform UK (<http://www.dementiasplatform.uk/>)?
 - Creating 'tremendous consent challenges' (Caulfield et al 2008)



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Catherine Heeney, Shona M. Kerr
doi: <https://doi.org/10.1101/157024>

This article is a preprint and has not been peer-reviewed [what does this mean?].

Abstract

Info/History

Metrics

Preview PDF

Abstract

Issues of balancing data accessibility with ethical considerations and governance of a genomics research biobank, Generation Scotland, are explored within the evolving policy landscape of the past ten years. During this time data sharing and open data access have become increasingly important topics in biomedical research. Decisions around data access are influenced by local arrangements for governance and practices such as linkage to health records, and the global through policies for biobanking and the sharing of data with large-scale biomedical research data resources and consortia. Methods: We use a literature review of policy relevant documents which apply to the conduct of biobanks in two areas: support for open access and the protection of data subjects and researchers managing a bioresource. We present examples of decision making within a biobank based upon observations of the Generation Scotland Access Committee. We reflect upon how the drive towards open access raises ethical

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Posted August 16, 2017.

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