

# The UK Biobank

A study of genes,  
environment and health



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# EU/Canada/UK Biobank/P3G Workshop

**-First Planning Meeting, London, February 2003**

*UK Biobank, Genome EU twin, Estonian Genome Project, Cartagene*

**-First Workshop Montreal, July 2003**

**-Second Workshop, Manchester, December 2003**



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**-OECD organisation for Economic Co-operation & Development:**

**Biotechnology Unit Initiatives**

**Biological Resource Centres: Working Party 2001 - 2003**

**Implementation 2004 - 2008**

**Human Genetic Databases: privacy & security issues - February 2004  
Workshop, Tokyo.**



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## OECD Biological Resource Centres: Underpinning the Future of Life Sciences and Biotechnology Report: 2001

- Defines the rationale for BRCs
- Importance of links to Functional Genomics
- Highlights the need for Technology Development
- Emphasises long-term sustainability
- Quality Management - both resources and data
- Harmonisation of Access procedures
- Provide the basis for a global network



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## OECD BRC Initiative

Report to Council of Science & Technology Policy Ministers January 2004  
Implementation Plan 2004 - 2008

## Secretariat/Board of Management

- National BRC network
- Accreditation system
- Global BRC network - international linkage
- Co-ordinate & harmonise standards
- BRC Generic Standard
- Domain standards

Report: [www.oecd.org](http://www.oecd.org)



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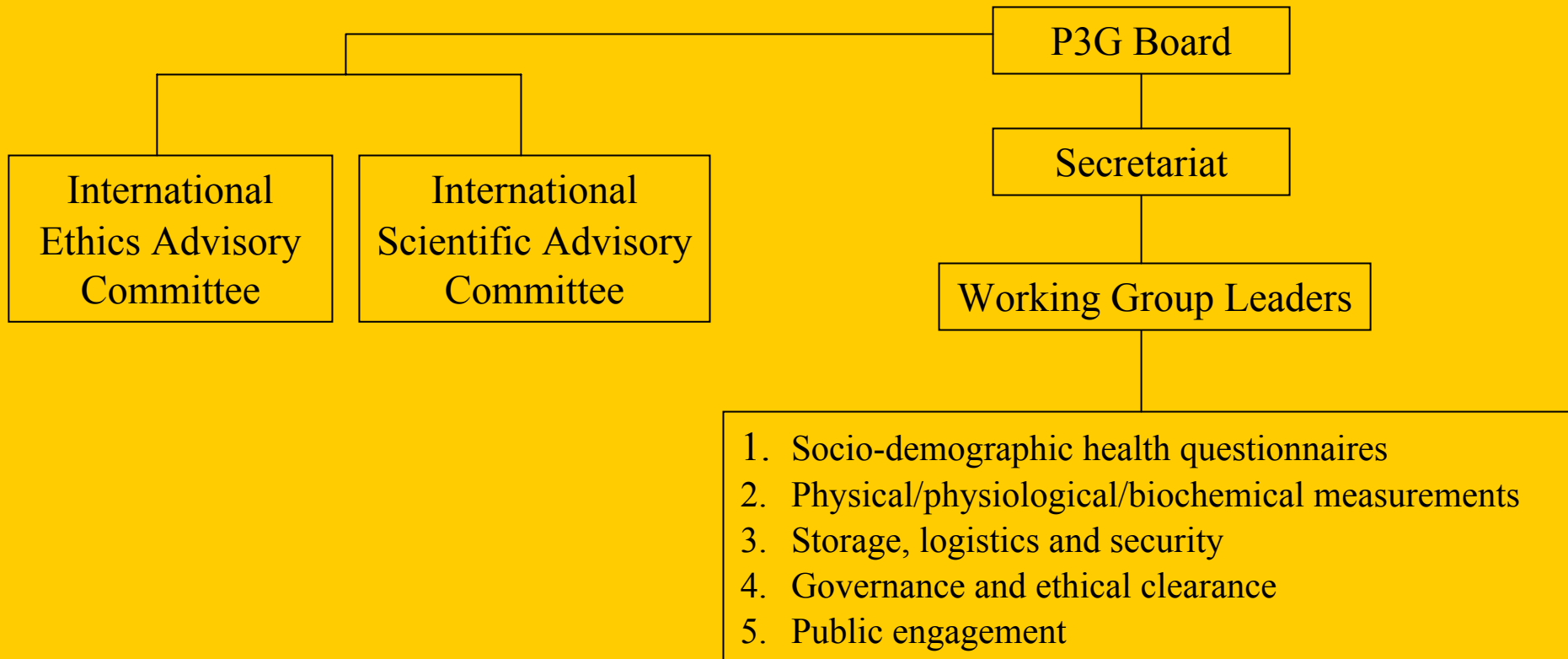
## The overall objectives of the consortium are:

- To connect the international leading public population genomics projects for the creation of an open, public and accessible common genomics dataset
- To provide necessary coordination, harmonization and standardization so that sharing genomics data, where possible, will foster international collaboration, advance science and maximise public health benefits
- To develop common understanding of the socio-ethical and legal issues
- To foster a deeper understanding of the relative contribution of genetic and non-genetic determinants to health and disease, as well as,
- To transfer this knowledge to the international community so as to optimise benefits for public healthcare worldwide.



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The proposed governance structure is as follows:



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## July 2003 Montreal Workshop topics

- Socio-economic health questionnaires
- Physical/physiological/biochemical measurement
- Storage/logistics/security
- Governance and Ethical clearance
- Public engagement



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## P3G: The Database 'Vision'

- **Access to a larger, more comprehensive dataset through a single portal**

**Caveats:** 'Open' resource versus 'restricted' resource  
Phenotypic/genotypic information  
Consent issues  
Commercial access/IPR

- **Clearing house mechanism, single approach, single proposal**

- **Each database would need 'core' information created to a common standard/validated**

- **Each database could have its own unique/bespoke approach beyond the 'core'**

- **The Researcher has a period of exclusive access, then information is returned to enhance the database(s).**



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## P3G: The Database 'Vision' - Implications

- Biobanks will need to maintain a level of control over their own data
- Control of genotyping - sample provision, technology applied, standardisation
- Genotyping capacity - standardisation and validated facilities
- Archiving and curation of data
- Virtual disseminated network - not a single database
- Patient/volunteer phenotypic information - medical records/continuous measures
- Technical Committees/Work packages/Audit



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## Advantages in Participation

- Greater utility, higher profile for projects
- Increased power
- Increased opportunity for more sophisticated analyses across populations
- Creation of a standard set of 'core' data
- Potential for an international standard in terms of data, analysis and ethical/social frameworks
- Maximise potential for funding, nationally and internationally
- Potential for co-ordination of mutually beneficial projects in technology and software development.



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## Areas of Mutual Interest, Montreal, July 2003

- Harmonisation (if not standardisation) of all personal data collections common to different projects so that there are some common nodes for identity in the medical, demographic and social data collected from participants.
- Maximum standardisation in the list of common biological phenotypes collected by each partner as well as agreement on methods and quality control for these texts.
- Compatible genotype databanks and common nomenclature of levels of identifiability of data and genomic variations.
- Compatible phenotype databanks and common nomenclature of levels of indentifiability of data and phenotypic variations.



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## Areas of Mutual Interest, Montreal, July 2003

- Coordination of access to each others' databanks while protecting confidentiality subject to ethical review and governance.
- Development of security measures for the protection of genetic data and banks in accordance with the highest international standards.
- Coordinated development of bioinformatics for compatible data mining and for clarity on ownership/copyright issues.
- Sharing of approaches to public engagement, governance and intellectual property issues.



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## Areas of Mutual Interest, Montreal, July 2003

- Exchange of experts and young researchers in many human and social scientific disciplines in addition to biology, public health and genetics.
- Support for the transfer of knowledge and technology to other developed or developing countries.
- International leadership in the ethics of genetic research involving populations.
- Comparative evaluation and validation of research results and/or hypotheses on health and disease.



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## Examples of Existing Collaborative Networks

**OECD:** GBIF (Global Biotechnology Information Forum) Secretariat, Denmark  
[www.gbif.org](http://www.gbif.org)

**EU:** CABRI (Common Access Biotechnology Resources & Information)  
[www.cabri.org](http://www.cabri.org)

**EBRCN (European BRC Network)**

[www.ebrcn.org](http://www.ebrcn.org)

- Resources
- Phenotype information
- SOPs
- Quality Policy
- Quality standards - guidelines
- 28 catalogues: BRCs in UK, Netherlands, France, Germany, Belgium, Italy



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