Access to UK Biobank: progress so far

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Open access resource, available for bona fide researchers to conduct health-related research this is in the public interest

Available for use by academia and commercial companies, both in the UK and abroad

No preferential or exclusive access to the resource

Costs are based on a cost-recovery model

Researchers are obliged to return their results to UK Biobank so they can be shared with others
Research scope

• Research applications can:
  • be broad - do not need to focus on specific risk factors or health outcomes
  • involve a range of genotypes/phenotypes (i.e. GWAS/PheWAS)
  • be purely methodological

The main consideration is that the scope of the research project can be objectively defined, i.e. the intended research goals are clear
Data available in the resource

- Lifestyle, medical history, sociodemographic, etc.
- Cognitive function and hearing tests
- Physical measures
- Environmental measures
- Urinary biomarkers
- Genetic data (150,000)
- Web-based questionnaire data (~200,000)
- Physical activity monitor (100,000)
- Imaging (15,000 + counting)
- Health outcome data
Access to UK Biobank so far

• Opened for access March 2012
• 5,000 approved registrations
• 900 applications submitted
  – 450 projects underway
• 200 publications
  – Projects cover a broad range of topics
  – See www.ukbiobank.ac.uk/approved-research for summaries
Number of registered researchers

5,000 registered researchers

Year | UK (%) | International (%) |
--- | --- | --- |
2012 | 22% | 28% |
2013 | 21% | 28% |
2014 | 21% | 28% |
2015 | 45% | 28% |
2016 | 56% | 28% |
2017 | 66% | 28% |
Number of researchers worldwide

- Canada: 1368
- United States: 2724
- United Kingdom: 577
- China: 118
- Brazil: 14
- Australia: 197
Applications: UK and abroad

905 applications

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<tr>
<th>Year</th>
<th>UK</th>
<th>International</th>
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Applications: academia and commercial

905 applications

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Total applications: 905
Submitted applications split by type

- **Data only**: 90%
- **Samples**: 8%
- **Re-contact**: 2%

- Low threshold to release data
- More stringent criteria to access biological samples and to re-contact participants
What research is being done?

- Genetics
- Obesity
- Cancer
- Cardiovascular mortality
- Vision
- Physical activity
- Imaging
- Sleep
- Smoking
- Dementia
- Diet
- Metabolic traits
- Heritability
- Inflammation
- Depression
- Osteoporosis
- COPD
- Multiple sclerosis
- Chronic’s disease
- Hypertension
- Stroke
- Diabetes
- Ageing
- Asthma
- Ethnicity
- Reproduction
- Metabolic traits
- Social isolation
- Socio-economic factors
- Multi-morbidity
- Built environment
- Psoriasis
- Personalised medicine
- Brain
- Pain
- Liver disease
- Renal
- Reproduction
- Haematology
- Allergy
- Primary care
- Metabolism
- Methodology
- Mendelian randomisation
Streamlining the access process

- Requests to use UK Biobank are expected to continue to increase

- We want to make it easier and quicker to access data...

- Whilst maintaining rigorous review of sample and re-contact requests
Streamlining the access process

• Existing access system built on a customised “CRM” platform
  – quick to develop but not flexible

• Has worked well but new system is needed to cope with demand

• New custom-built system
  (developed in collaboration with University of Oxford)

• Aim to simplify management, increase capacity, speed up application process and provide improved reporting capability

Existing system: uses SAGE-CRM, not user-friendly

Future system: custom-built, easy to use
Access System: key changes

- Improved user interface – easy to use
- Single registration – no longer per application and supports multiple affiliations
- Single application form – quicker and easier to access data
- Messaging within the Access portal – single view of all communications
- Simplified MTA process – removing need for addendums if scope changes
- Enhanced reporting – providing full transparency of the Access process
- Management of projects underway – easier to request data refreshes
- Researcher home page – provides authenticated access into Data Showcase

Available late Summer 2017