Access to UK Biobank: Streamlining the Process

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Improving the health of future generations
Principles of accessing UK Biobank

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

• Available for use by researchers from academia and commercial companies, both in the UK and overseas

• No preferential access (and limited exclusive access for data generated by researchers)

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

• Applications to access the UK Biobank resource can:
  • be broad – they do not need to focus on specific risk factors or health outcomes
  • involve a range of genotypes and/or phenotypes e.g. GWAS, PheWAS
  • be purely methodological e.g. development of methods to create derived data fields

• The main consideration is that the scope of the research project can be objectively defined i.e. the intended research goals are clear
Use of the UK Biobank Resource: Researchers

UK Biobank Approved Researcher Registrations

- **Number of approved registrations per year**
- **Cumulative number of approved registrations**

- **Year**
  - 2012
  - 2013
  - 2014
  - 2015
  - 2016
  - 2017
  - 2018
  - 2019

- **Number of approved registrations**
  - 0
  - 500
  - 1000
  - 1500
  - 2000
  - 2500
  - 3000
  - 3500
  - 4000

- **Cumulative number of approved registrations**
  - 0
  - 500
  - 1000
  - 1500
  - 2000
  - 2500
  - 3000
  - 3500
  - 4000

- **Approved researcher registrations per year**
  - Blue bars

- **Cumulative approved researcher registrations**
  - Red line
Use of the UK Biobank Resource: Applications

UK Biobank Approved Applications

- Number of approved applications per year
- Cumulative number of approved applications

Year:
- 2012
- 2013
- 2014
- 2015
- 2016
- 2017
- 2018
- 2019

Approved applications per year

Cumulative approved applications

www.ukbiobank.ac.uk
International use of the UK Biobank Resource: Locations of researchers worldwide
How do I get Access?

- Access is described in our **Access Policy** and is managed via our **Access Management System (AMS)**:
  - **Registration**: We check the identity of each researcher to confirm their bona fides as part of their approval.
  - **Application**: We assess whether the application meets the criteria of being for health-related science that is in the public interest.
  - **MTA and Payment**: there is a small cost-recovery access fee and researchers must enter into a Material Transfer Agreement (MTA) before data (and samples) are released.
How long does it take to access data?

Mean timelines from application submission to data release

Goal: 12 week turnaround time in 2020

We are currently focussed on reducing the time from application submission to data release
Where is this time typically spent?

- Application submission
- Initial payment
- Application approved
- Project started

5 weeks: Waiting for payment
9 weeks: Application processing and amendment
10 weeks: Waiting for signed MTA and main payment

Upcoming process improvements that we are making:

- Removal of initial payment (combine with main payment) – early Q3 2019
- Introduction of a standardised basket – early Q3 2019
- Improved signposting and help/support - creating tutorial videos to guide the stages of the access process including signing and returning MTAs – by end of Q4 2019
What can I do to speed up the process?

More than half of the overall processing time is in your hands!

Considerations you may wish to make:

- Pay online
- Involve your legal team early
- Be responsive to queries from the Access team
- Sign and return your MTA electronically
What impact is UK Biobank making?

There are now over 750 published research papers using the UK Biobank resource

- Please report to us all papers **2 weeks** ahead of publication
- Presentation of research at conferences should be reported
- Researchers are obliged to return their results so we can make them available to others and grow the resource
UK Biobank Website: Expect BIG changes...

Redesign and rebuild

Our aim to better lead researchers through the process:

- Simplified navigation
- More effective searching
- Presentation of key information
- More narrative architecture
- Provide alternative ways to discover & explore the resource
Meet your Access Management Team today!

Thanks!
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