

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 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

Lifestyle, medical history, sociodemographic, etc.

Cognitive function and hearing tests



Physical measures



Environmental measures



Urinary biomarkers



Genetic data (150,000)



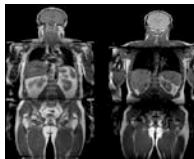
Web-based questionnaire data (~200,000)



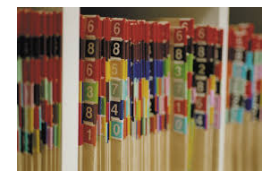
Physical activity monitor (100,000)



Imaging (15,000 + counting)



Health outcome data



2017

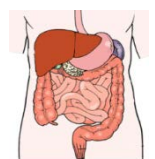


Genotyping & imputation
(n=500,000)

Online mental health questionnaire
(n=139,000)

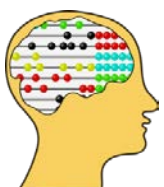


2018



Online IBS questionnaire
(n=152,000)

Death, cancer & HES update
(n=500,000)

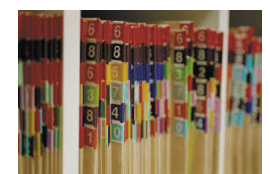


New cognitive function tests
(n=10,000)

Biochemistry
(n=500,000)

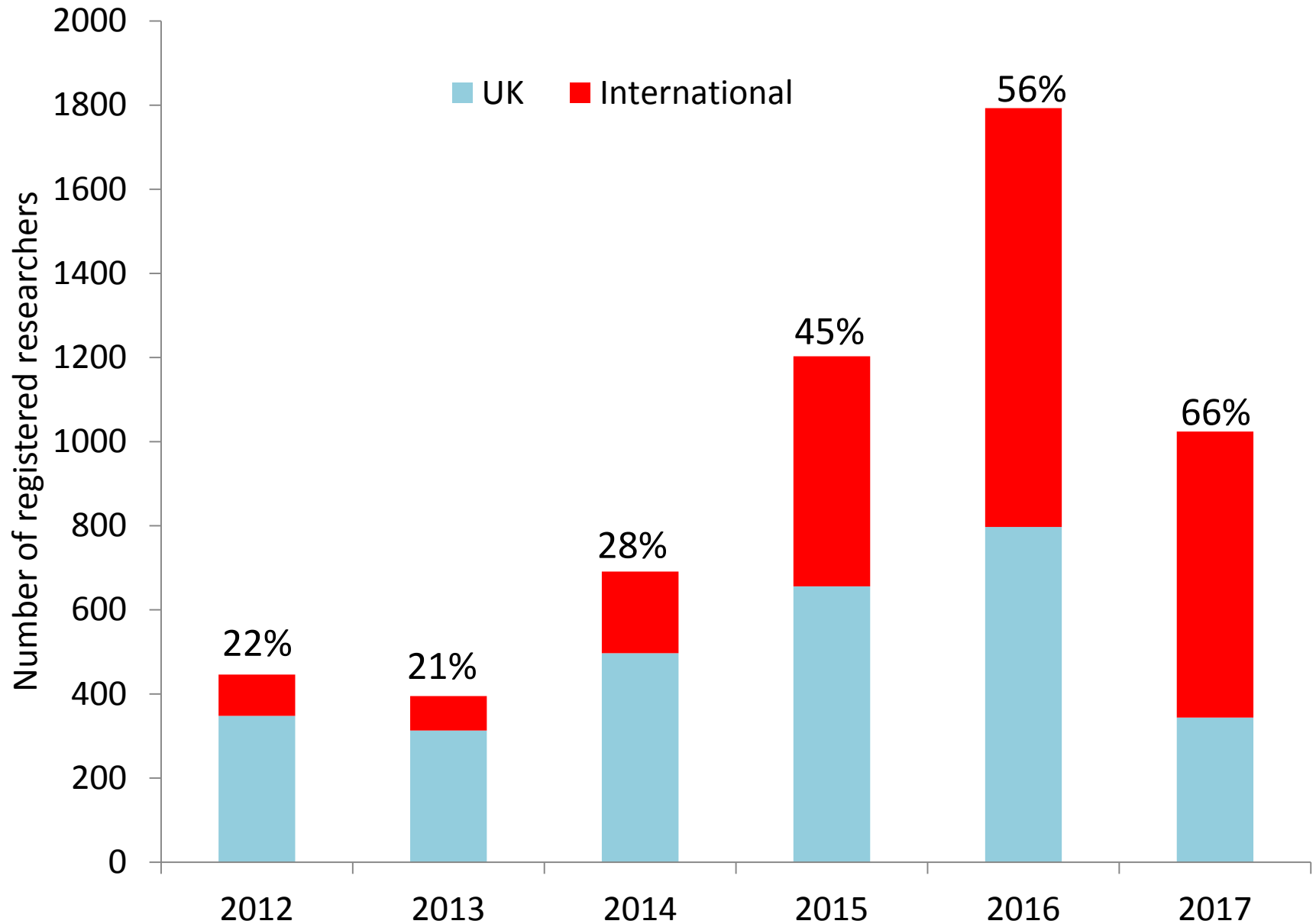


Primary care
(n=170,000)



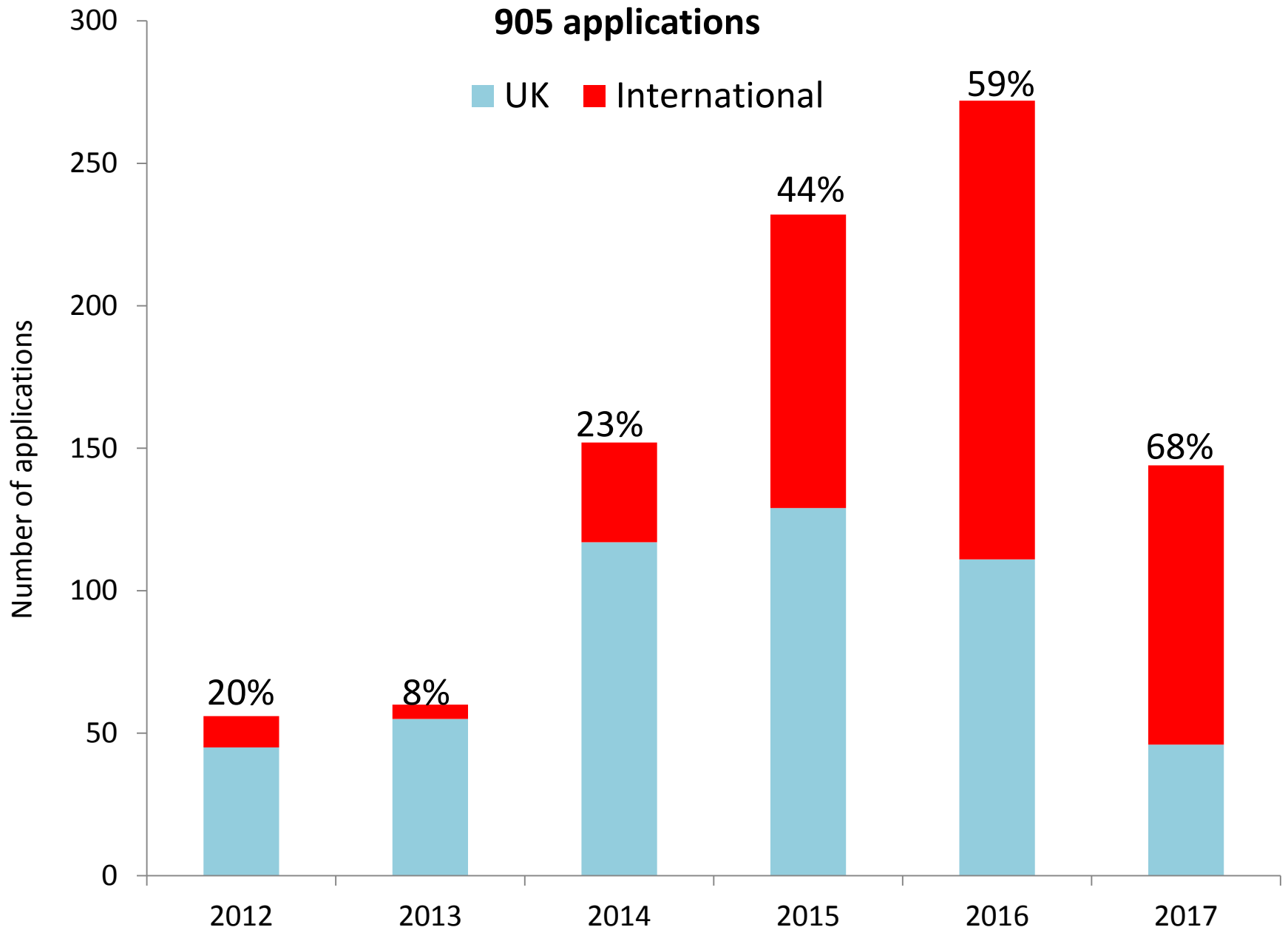
- Opened for access March 2012
- 5,000 approved registrations
- 900 applications submitted
 - 450 projects underway
- 200 publications
 - Projects cover a broad range of topics
 - See www.ukbiobank.ac.uk/approved-research for summaries

5,000 registered researchers



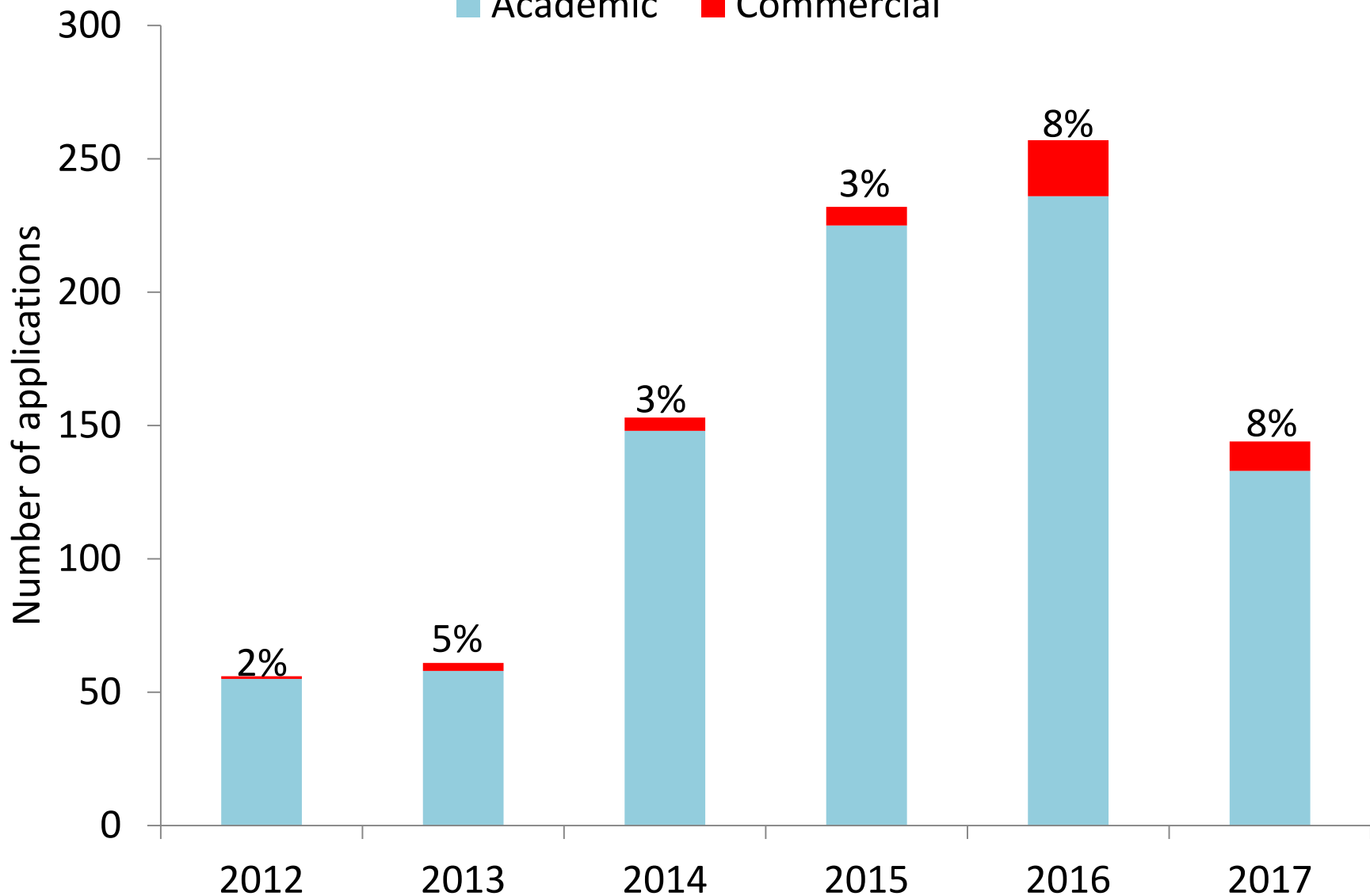
Number of researchers worldwide

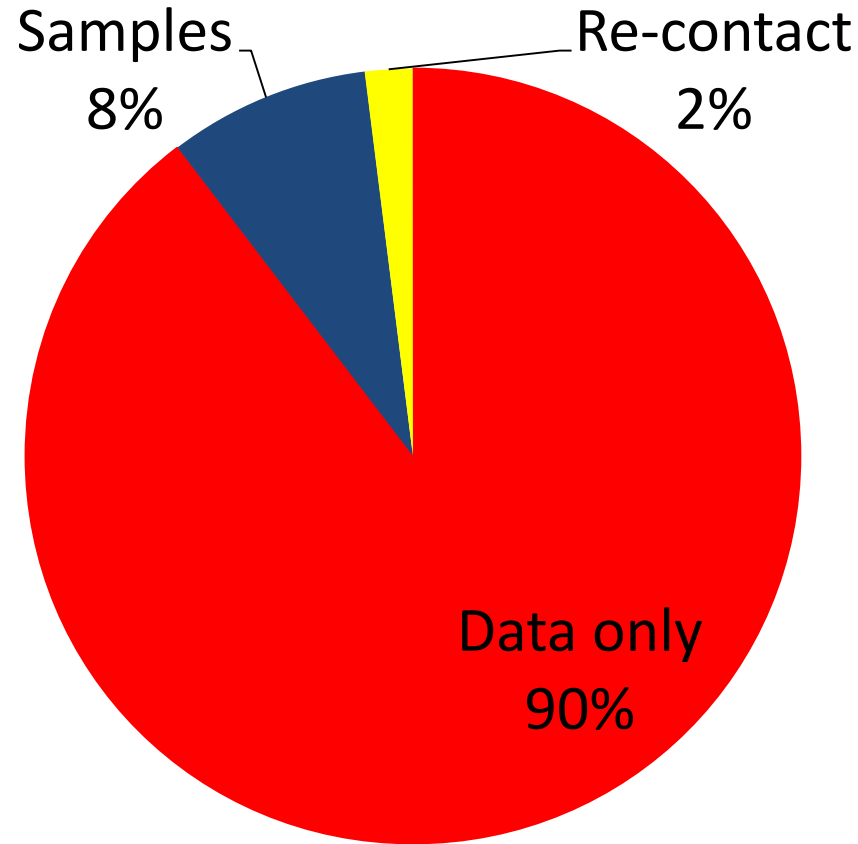




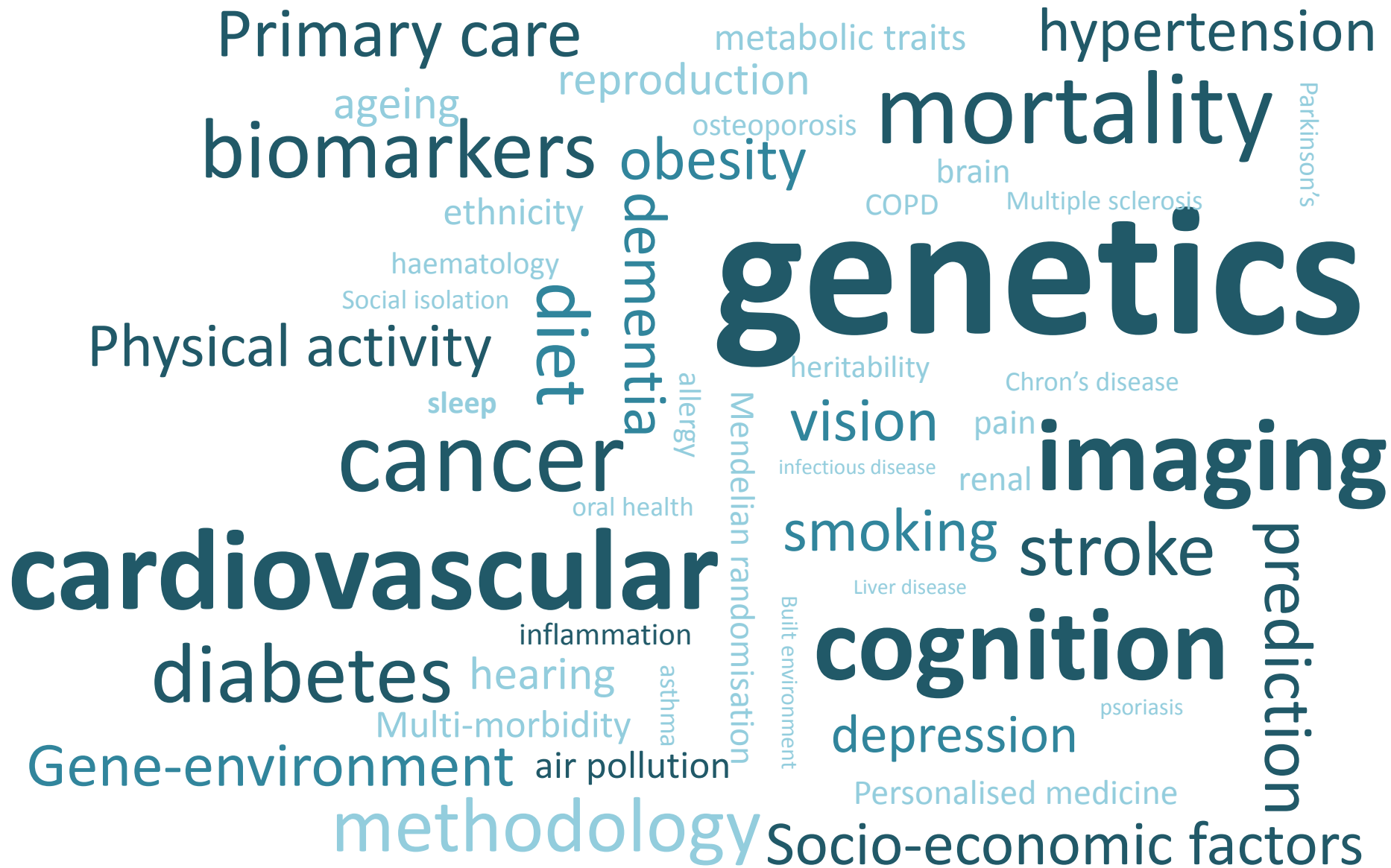
905 applications

■ Academic ■ Commercial

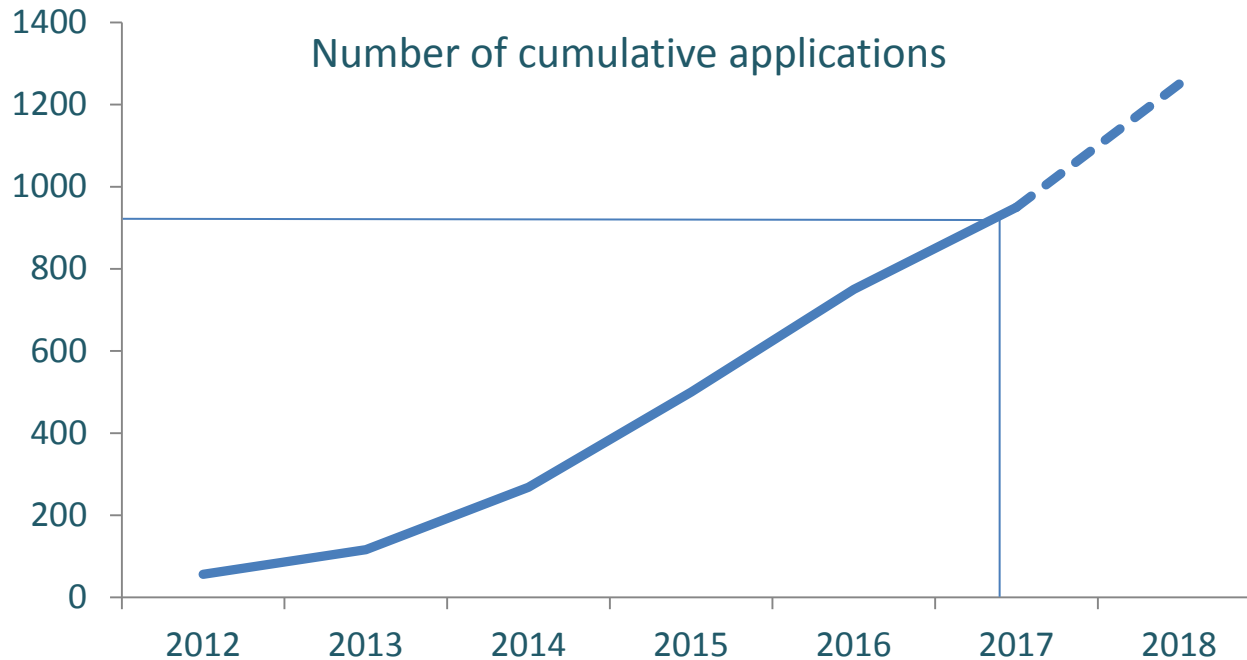




- Low threshold to release data
- More stringent criteria to access biological samples and to re-contact participants

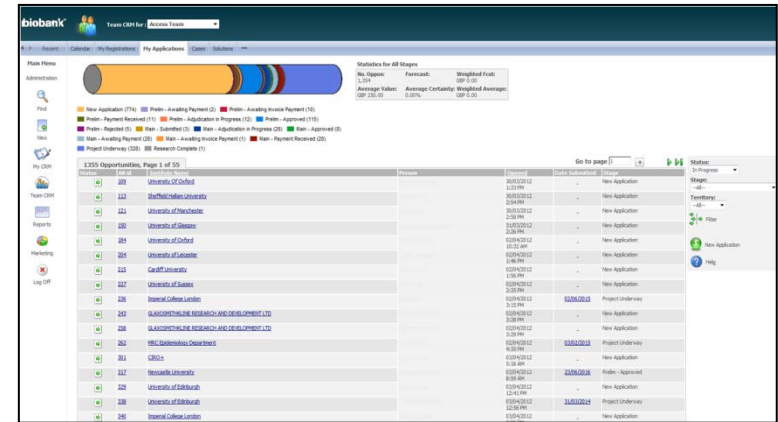


- Requests to use UK Biobank are expected to continue to increase



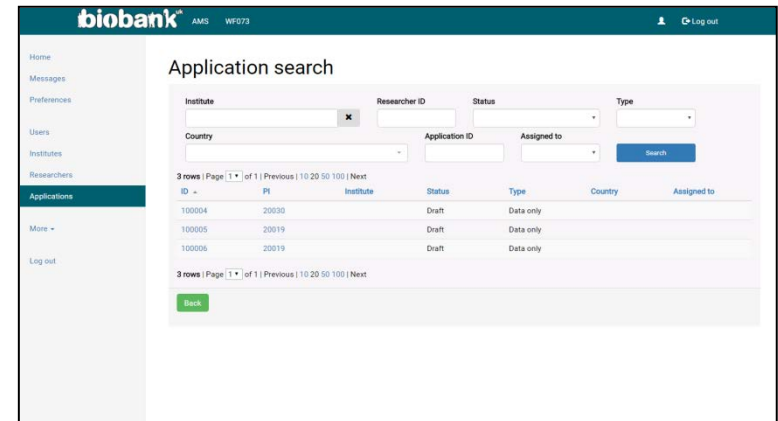
- We want to make it easier and quicker to access data...
- Whilst maintaining rigorous review of sample and re-contact requests

- 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



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

- 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



Future system: custom-built, easy to use

- **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