



biobank^{uk}

Improving the health of future generations
UK BIOBANK PARTICIPANT NEWSLETTER FEBRUARY 2012

UK BIOBANK – READY FOR RESEARCH

UK Biobank has now set out in detail how scientists will be able to use the Resource for research that is intended to improve the health of future generations.

Its Access Procedures were recently launched (www.ukbiobank.ac.uk), and scientists will soon be able to apply for data and for analyses of samples.

Access to the Resource meets the commitments that UK Biobank gave to participants when they joined the project. The overriding principles are the privacy of the participants and ensuring best use is made of the Resource for improving health.

Key points

- ◆ Scientists will need to be approved to use the Resource for health-related research that is in the public good;
- ◆ Stringent measures are in place to ensure that participants are not identified;
- ◆ Scientists using the Resource will be obliged to share their results with UK Biobank so that advances can be built on by others.

Researchers from both the UK and overseas, and from both academia and industry, will be able to use UK Biobank. *“This is an open access resource, which means if scientists anywhere in the world think it can help with their health research, then we would encourage them to apply to use it,”* said UK Biobank Principal Investigator, Professor Sir Rory Collins.

“If the research is in the public interest, then we would expect it to be approved. The intention is that UK Biobank is used as extensively as possible to tackle the widest range of illnesses that cause pain, disability and death.”



Distinguished scientists from the US, Australia, Canada, Europe and the UK come together every year to provide advice to UK Biobank. Members of the International Scientific Advisory Board are photographed after their November 2011 meeting at Oxford University. Photo: John Cairns Photography, Oxford

Please stay in touch

UK Biobank would like to keep participants informed of results, as they emerge, and other developments within the project – such as notifying you of ways in which you may be able to help further.

If you have a new email address please do let us know. Keeping in touch with participants by email is a fraction of the postal cost and means money we save can be spent on improving the Resource instead.

It is easy to up-date your contact details by visiting the UK Biobank website (www.ukbiobank.ac.uk) and clicking through to the *Update Your Details* link on the top right hand corner of the page.

If you do not have email, please make sure we have your current postal address. You can tell us of any changes by using the reply envelope enclosed with this newsletter, or by calling 0800 0 276 276 (8am-7pm Monday-Saturday).



Many thanks to all UK Biobank participants for your help and support of this unique health project over the past year. We are very grateful to you.

www.ukbiobank.ac.uk

Thank you for taking the time and trouble to participate in UK Biobank



Taken a look at our new website yet? Please do; we'd love to know what you think. If you have any thoughts about the sorts of information on UK Biobank's progress that you would like to read about—do let us know. You can email me at Andrew.trehearne@ukbiobank.ac.uk or give me a call on 01865 743960. I look forward to hearing from you.

Andrew Trehearne, Newsletter Editor.

PS—Please don't forget to update your contact details via our website, if you can. Otherwise, call our free phone Participant Resource Centre on 0800 0 276 276 (8am-7pm Monday-Saturday).

www.ukbiobank.ac.uk



Please help strengthen the Resource further

The UK Biobank Resource will open for use to scientists shortly. We're now turning our attention to collecting further information from participants that will add scientific value to this unique resource.

Measuring physical activity

Physical activity is known to affect health. But, until now, it's been hard to assess reliably how much people really do, even from detailed activity questionnaires (though they help). Advances in technology are making this possible. A wrist-worn monitor (an "accelerometer") about the size of a watch could soon transform our understanding. It will record accurate information about the duration, frequency and intensity of all kinds of activity (even during sport, including swimming).

Later this year, UK Biobank will start writing to invite participants to wear one of these robust water-proof devices continuously for a week. We plan to make the process as simple as possible. The device will turn itself on and off automatically. After wearing the device for a week, participants will just need to return it in the stamped addressed envelope provided. Only information that does not identify participants will be provided to researchers.

Please do look out for your invitation to participate. (Note that as we'll be only able to assess about 600 people per week, your invitation may not come this year.)

Accelerometer: it may be small, but it's able to store lots of important information.



A second assessment in some participants

A proportion of participants from the north and north east of England are going to be invited back later this year and early next year for a repeat assessment. This will be conducted at the UK Biobank coordinating centre in Stockport, where a bespoke assessment centre has been built with all of the key equipment in place. Some participants may be asked to travel further than for their original visits, but travel expenses can be reimbursed (and tours of the coordinating centre's automated laboratories and sample archive will be available).

Repeating the assessment in about 20,000 participants will allow UK Biobank to take account of variation in answers and measurements collected at the first assessment. This will add a lot of value to the Resource for researchers. So, if you are invited to attend, we would be most grateful if you would do so. (As far fewer people need to be re-assessed than for the first assessment, the visits will be less pressured.)

Online questionnaires

The fourth – and final – UK Biobank online diet questionnaire is currently underway. Many thanks to all those people who have participated so far – more than 400,000 questionnaires have been returned. The questionnaire allows UK Biobank to better understand how food intake varies, and will allow the project to maximise the nutritional information available to scientists.

Questionnaires about work and residential history are planned.

What is UK Biobank?

UK Biobank is one of the most detailed studies of its kind. Its goal is to help doctors improve treatments and better prevent a wide range of illnesses that strike in middle age, such as heart disease, stroke, diabetes, cancer, dementia, depression, arthritis, kidney, eye, joint, back and bone disorders.

Why is taking part so important?

Without your help, this vital Resource would not be possible. Knowing what illnesses participants do and do not develop will allow scientists to compare a wide range of differences in genes, lifestyles and environmental exposures to identify causes and suggest new ways to tackle common illnesses of middle and old age.



Processing samples

SCIENTIFIC ACCESS TO THE UK BIOBANK RESOURCE

UK Biobank's Access Procedures which govern how scientists use the UK Biobank Resource are based on key principles set out in the UK Biobank Ethics & Governance Framework – a public document that details how UK Biobank is managed.

An Access Sub-Committee of the UK Biobank Board will oversee the access process. It will be able to call on ethicists, legal experts, other scientists, the independent UK Biobank Ethics & Governance Council and participants as it is considered necessary.

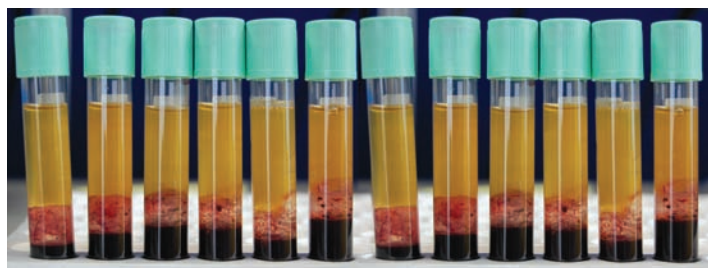
Health research requests to use samples of blood, urine and saliva collected from participants, or to re-contact them, will undergo a more rigorous review than those seeking data only.

Professor Collins said: *"Use of the resource is an investment in the resource because the results of all analyses will be put back into UK Biobank, bringing benefit to the research of other scientists."*

A list of research uses of the Resource will be published, as these are approved, on the UK Biobank website. A Showcase of data – providing summary information only – collected from participants, will be available on the UK Biobank website from the Spring.

You can read the Access Procedures at www.ukbiobank.ac.uk or call our Participant Resource Centre on **0800 0 276 276** for a printed copy.

UK Biobank Board member, Tara Camm, pictured right, a lawyer with significant experience in the biomedical sciences, will chair UK Biobank's Access Sub-Committee. Tara is a trustee of the Nuffield Trust, and currently General Counsel and Company Secretary for Plan International, a development organisation focused on children. She was involved in the early days of planning for UK Biobank, especially in helping to develop the Ethics & Governance Framework which guides its conduct.



Follow-up: how are we doing?

More than 500,000 people have joined UK Biobank and provided detailed information on their health and lifestyle, creating the foundations of a life-long resource to help scientists understand why some people get illnesses and others do not. Now the long-term follow-up of participants' health through a wide range of different health record systems, regularly used for health research, is underway.

Admissions to hospital

In England, a national statistical 'data warehouse' contains over 200 million coded records about people's stays in hospital. There are similar national systems in Scotland and Wales. Data on diagnoses made and the procedures carried out during hospital admissions in England, Scotland and Wales are expected to be included in the UK Biobank Resource during 2012.

Cancer

The UK has one of the most comprehensive cancer registration systems in the world. A system for regularly updating UK Biobank with information about those participants who have developed cancer will come into effect in 2012.

Primary care records

These provide information about diagnoses, treatments (such as prescriptions) and previous histories and patterns of illnesses in coded format. Systems for linking to primary care (general practice) records are well underway in Scotland and Wales and are now being developed in England as well.

Other records

UK Biobank also hopes to link to disease registers (such as those for diabetes, heart disease and kidney disease) and to other health-related records systems (such as dental and occupational health records) in order to extend the range of health-related exposures and health outcomes that can be studied. Automatic notification of deaths to UK Biobank is a priority. These data are already being received for England and Wales and data from Scotland will be available soon. It can take several months for this sensitive information to work through to UK Biobank's records. As well as being part of the information needed by researchers, it is useful in helping UK Biobank avoid contacting people who have died (although due to the delays in reporting, it may not always prevent this from happening).

Information provided to approved scientists will not identify participants.

Stroke expert's new role as UK Biobank Chief Scientist

Dr Cathie Sudlow, a clinician and scientist with a particular interest in understanding the causes and prevention of strokes, has joined UK Biobank as Chief Scientist and Senior Epidemiologist. Dr Sudlow is Clinical Reader and Honorary Consultant Neurologist at the University of Edinburgh, and continues to look after patients with strokes and other neurological disorders. She holds a number of key positions within stroke research, including chair of the British Association of Stroke Physicians scientific committee, and membership of the International Stroke Genetics Consortium. Cathie's role will include overseeing UK Biobank's linkages to health records and working with expert groups to ensure that these records are combined in the best way for health-related research on a range of different conditions. She also looks forward to developing new ideas for improving the Resource to make it more useful to the health researchers.



And welcome to UK Biobank's newest senior researcher



Dr Naomi Allen, who has played an important role in the UK's Million Women Study, has also recently joined UK Biobank. Dr Allen is a Senior Epidemiologist at Oxford University and she will use her experience to develop enhancements that improve the

outcomes of research using the Resource, including analysis of data from the diet web questionnaire. The Million Women Study is itself a landmark health project. It is investigating the factors that affect health in women aged 50 and over, including use of HRT, diet, childbirth and family history of disease. Scientists are now starting to use that resource to investigate the causes of a wide range of cancers, heart disease, fractures and other conditions.

www.millionwomenstudy.org/introduction/



Rory Collins, the scientist who leads UK Biobank, has been knighted for his Services to Science. Sir Rory is UK Biobank Principal Investigator and British Heart Foundation Professor of Medicine at Oxford University.

HELPING OTHERS

As a global leader in biobanking, UK Biobank is passing on its expertise to other scientists undertaking similar projects around the world.



Experts, including those most recently from Germany, Japan and China, have been in contact to find out 'how Biobank does it'. The establishment of other biobanks will strengthen UK Biobank as a health resource, providing more information for health scientists to study.

UK Biobank Executive Director Dr Tim Peakman, pictured, was recently seconded to help Australian researchers to establish an equivalent facility for children's health.

UK Biobank has also established UK Biocentre, a wholly-owned subsidiary of UK Biobank, to provide skills and storage facilities to other health projects. Spare freezer capacity is now helping the Leukaemia and Lymphoma Research charity. It is using UK Biocentre space, and know-how, to store samples from its latest childhood leukaemia study. Any profits from UK Biocentre will be gift-aided back to UK Biobank so that they can be used to make the Resource even more useful for researchers.

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UK Biobank, 1-2 Spectrum Way, Adswold, Stockport, SK3 0SA
www.ukbiobank.ac.uk ukbiobank@ukbiobank.ac.uk
UK Biobank Participant Resource Centre
free phone 0800 0 276 276

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