

## UK BIOBANK PARTICIPANT NEWSLETTER MARCH 2013

Improving the health of future generations

Hello and welcome to your 3rd annual UK Biobank Newsletter. You have received this Newsletter because you have agreed to participate in UK Biobank. We are very grateful for your continued support of this exciting health resource.

### A great year for UK Biobank

Much has happened in the past year.

- A summary of the health information collected so far, and a system that allows scientists to register to access UK Biobank have been put on the UK Biobank website;
- The first meetings of the [UK Biobank Access Sub-Committee](#), which approves applications to use the resource, have taken place;
- 20,000 participants who live in the north-west are attending a repeat assessment;
- A series of on-line diet questionnaires have been completed, with 400,000 responses.

Having spent four years collecting information at the baseline assessment visit from 500,000 participants, the UK Biobank resource opened to scientists in March 2012. Currently more than 400 researchers have registered with it. The first research projects have been approved, and scientists are now using the anonymised, detailed information provided by participants to improve health. Other exciting developments include:

- The first data on cancer and deaths are now being channelled into UK Biobank. Linkage to other health records is making good progress;
- Almost £10 million of new funding has been provided for UK Biobank to undertake a feasibility study to image 100,000 participants using sophisticated scanning equipment;

- An additional £10 million has been provided for UK Biobank to measure a wide range of important substances in blood samples from all of the participants;
- 50,000 participants will have their genes analysed in the first study of its kind to investigate lung diseases like chronic bronchitis and emphysema.

### **Please stay in touch**

UK Biobank becomes of more use to scientists the older it gets and the more information it collects. We will keep participants informed about results and other developments - such as how you may be able to help further, and plans to make the resource of even more value to health researchers. You can find out how the resource is being used by clicking on the '[Approved research](#)' button at the top of the UK Biobank website homepage.

Allowing us to keep in touch with you by email is the easiest and cheapest way of maintaining contact. Emails cost just a fraction of postal costs and the money we save can be spent on improving the resource. If you are new to email, or have recently changed your email address, please do let us know by clicking through to the '[Update your details](#)' section of our website.

If you do not have email, please make sure we have your correct home address. You can tell us of any changes by using the reply envelope enclosed with this Newsletter, or by calling 0800 0 276 276 (free from most landlines, 8am-7pm Monday-Saturday), or 02920 765597.

Thank you for supporting UK Biobank. Your help is very much appreciated.

[www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk)

The UK Biobank website is a great way to follow the latest news emerging from this world-leading health resource. In the past year we have added several new links:

- [Data Showcase](#) – showing a summary of most of the information collected from UK Biobank assessments and afterwards.
- [Register & apply](#) – an online system allowing scientists to register with UK Biobank.
- [Approved research](#) – an up-to-date summary of scientists using the resource.

If there is anything you would particularly like to read about, please let me know.

You can email me at <mailto:Andrew.trehearne@ukbiobank.ac.uk> or give me a call on 01865 743960. I look forward to hearing from you.

Andrew Trehearne, Newsletter Editor.

### **Did you know? Google alerts**

If you have access to the internet, you can follow UK Biobank's progress in two ways:

Regularly check our website at: [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk)

Set an 'alert' for UK Biobank which will automatically send you up-dates and other mentions of the project as they appear online. Follow instructions at:

[www.google.com/alerts](http://www.google.com/alerts)

### **UK Biobank welcomes imaging funding**

UK Biobank is delighted that £9.6 million has been provided by the UK Medical Research Council (MRC) for a large-scale feasibility study which, if successful, will allow detailed imaging assessments of 100,000 UK Biobank participants over the next few years.

This more detailed characterisation of participants will allow scientists to develop an even greater understanding of the causes of a wide range of different diseases (including dementia) and of ways to prevent and treat them.

The study will involve:

- Magnetic resonance imaging (MRI) of the brain, heart and abdomen;

- Low power X-ray imaging of bones and joints;
- Ultrasound of neck arteries.

The feasibility phase is scheduled to start later in 2013, and will continue for at least one year, at a dedicated regional UK Biobank imaging centre. People living closest will be invited first. (The cost of setting up such a centre means it is not possible to establish one in every location in which UK Biobank undertook its original assessments – but people will be invited to the closest centre).

Please do look out for more information later this year. The scanning of volunteer participants will provide a huge amount of additional and important data for health researchers.

Professor Paul Matthews, Head of the Division of Brain Sciences, Imperial College, London, who led the team of experts that developed the imaging plans, said:

“This enhancement represents large-scale science and pioneering 21st Century population research that promises to produce novel insights into risk factors for the later life diseases that are an increasing challenge for the NHS.”

The proposed pilot study aims to include 8,000 participants, which, in itself, is the biggest study of this kind ever undertaken. The assessment is likely to take about 3 hours. Participants will be able to choose an appointment time that suits them, having completed a pre-visit assessment on the telephone to ensure they are able to be scanned (e.g. unfortunately some people with some metal implants will need to be excluded). More information will be posted on the UK Biobank website as it becomes available.

### **Healthy Minds Initiative**

Your mind is perhaps your most valuable asset. This Spring, UK Biobank plans to launch its Healthy Minds initiative which focuses on cognitive and emotional health. As a first step it will invite participants to complete a series of short cognitive tests online. Some of these tests were done when participants joined the study whilst others will be new. The tests have been specifically selected to help scientists understand the likely causes of dementia, and all are quick, interesting and enjoyable to do. UK Biobank intends to repeat these tests periodically so that it can find out why some people's

cognitive health changes more than other people's, as this will help understand how to prevent dementia in the future.

Dr John Gallacher, who helped design the tests says: "The prospect of preventing dementia is really exciting. Helping UK Biobank to achieve this goal is a great investment in all our futures."

### **Genetic analysis**

UK Biobank was established to allow health scientists to study the complex interaction of genes, lifestyle and environment to answer questions about the causes of a wide range of common illnesses.

Genes are contained within DNA, which is the inherited material found in most cells. There are about 22,000 genes, which are little packets of information that tell the cell how to behave. The vast majority of genes are the same in all of us, but tiny differences account for many of our own personal characteristics. Differences in genes also play a role in the likelihood of us developing disease.

Exciting advances in genetic research are having a big impact on the way DNA, and genes in particular, is studied. Analysing genes is getting cheaper and it can be done ever more quickly and in greater detail. It is also becoming apparent that not only genes, but also the bits between genes on DNA, may well be relevant to disease.

UK Biobank will be at the forefront of applying sophisticated genetic knowledge to health studies:

- Some scientists will study participants with known health problems. They will want to know if these people have the same damaged DNA and if they share common lifestyles.
- It is also possible for researchers to read the entire genetic codes of participants - all 22,000 genes and the 3 billion letters that are the building blocks that make them - to uncover genetic susceptibility to disease.

It is very unlikely that scientists would be able to identify participants from the anonymised genetic data provided to them. Nonetheless, UK Biobank will rigorously enforce its agreements with scientists that they should not try to do this. Reassuringly,

other on-going studies have had no problems in this respect. As with other aspects of this study, no individual results will be provided to participants, but the research findings will be made public.

UK Biobank promises to keep participants informed of developments. What is possible and what could be possible are the subject of dialogue between UK Biobank, its independent Ethics & Governance Council, scientists and participants. Updates will be posted on our website at: [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk). Please do get in touch if you have questions.

### **Hearing problems highlighted**

Manchester scientists are using data from the UK Biobank resource to help with studies about hearing loss. Dr Piers Dawes and Professor Kevin Munro, from the School of Psychological Sciences at the University of Manchester and Manchester Biomedical Research Centre will examine anonymised data from all UK Biobank participants.

The work will provide unique insight into the prevalence of hearing problems. The team will examine the risk factors for hearing disability, including noise exposure, cardiovascular disease, diet, exercise, smoking, alcohol intake, medications and brain function. They will also examine how hearing loss, along with visual impairment, affects quality of life.

The Manchester team is collaborating with other leading scientists in the UK and US: Professors David Moore and Heather Fortnum at the Institute of Hearing Research, Nottingham; Professor Adrian Davis, Royal Free Hampstead NHS Trust, London; Professor Mark Lutman, University of Southampton Institute of Sound and Vibration Research, and Dr Karen Cruickshanks, University of Wisconsin and Professor Larry Humes, Indiana University, in the US.

Hearing loss is a common problem. There are around 10 million people with hearing loss in the UK and this is forecast to increase to 14.5 million by 2031. Around 25% of participants who joined UK Biobank reported difficulties with hearing, which can have a profound impact on emotional, social and physical well-being.

Hearing loss receives relatively little research attention (in 2010, £1.34 research money spent per person affected, compared to £14.31 for vision and £49.71 for cardiovascular research).

Dr Dawes said: “Almost everyone will experience hearing loss as they grow older; it is a big problem and will get worse. UK Biobank offers a fantastic opportunity to explore the causes of hearing loss.”

### **Studying physical activity – look out for your invite to help!**

UK Biobank hopes many thousands of participants will join it in a huge study to find out how physical activity influences health.

Participants will have the chance to wear an activity monitor for a week in the coming year. Requests to help are being staggered and invitations will be by email.

The wrist-worn monitor is designed to be kept on 24 hours a day, whether working or sleeping, having a bath or shower, or playing sport. It does not matter how active participants usually are, or if they are more or less active than usual during the week the monitor is worn. Wearing the monitor will supplement the questionnaire information participants provided at their assessment.

Participants will first be asked to indicate if they are happy to wear an activity monitor. If they are, then they will be mailed one. The packet fits through a standard letterbox, so there will be no need to wait in.

Participants are asked to put the monitor on as soon as it arrives. The activity monitor turns itself on and off automatically. After 7 days all that needs to be done is to mail the device back in the pre-paid envelope provided.

### **How it works**

The activity monitor is a high-tech wrist worn sensor. It monitors when the wearer moves and stops. It means the intensity of movement can be linked to energy consumption.

The monitor is not designed to measure heart rate (changes in which can be accounted for by a variety of other events, such as fear) so it does not measure

'fitness'. But it will help researchers understand the amount of energy people use, allowing for important comparisons to be made between different sorts of people.

At the heart of each monitor sits a tiny machine called a Micro-electro-mechanical-system. No wider than a single human hair, it is able to measure changes in the rate of velocity in three directions - up and down, side to side and forwards and backwards.

The device is primed and ready to go upon receipt. So participants will need to put it on as soon as they can - because it will turn itself off after seven days.

The activity monitor measures three directions of movement, and each can be plotted on a chart, building up a picture of movement throughout the day.

Scientists will analyse the graphs created from the data and be able to calculate movement for a wide range of activities. However, they do not necessarily want to know what type of activity is being undertaken - they just need a sense of the pattern and intensity of movement.

Statistical techniques are used to relate movement to energy expenditure and energy expenditure to disease. For instance, at the most basic level, it will be possible to study people with chronic heart disease - or who go on to develop chronic heart disease - and see how that is related to activity.

These techniques have been validated in other studies, to show they are reliable and produce scientifically useful information.

However, with increasing computer power and more intensive modelling, it is easy to see how particular activities generate their own patterns or footprints. This may allow for more detailed analyses in the future.

Sophisticated programmes can distinguish between rowing and walking, or running and swimming, and would even pick out the high frequency bounces of a bike rattling along a road.

The activity monitor cannot track location and it does not contain any information that could identify participants. A special code on each device is matched with each participant's ID number and the key to this code is known only to a small number of



UK Biobank staff. Personal details and data about health and lifestyle are stored separately. Other security mechanisms are also used to protect privacy.

The activity monitor has been developed by the Digital Interaction Group at Culture Lab, Newcastle University, led by Professor Patrick Olivier.

If you receive an activity monitor please do not forget to return it to us - preferably in the return envelope provided (we can send you another envelope if you lose it).

### **Stroke, diabetes, chronic pain, lung disease, mental health: scientists studying a wide range of diseases register with UK Biobank**

More than 400 scientists have registered with UK Biobank and are gearing up to use this pioneering health resource. Of these, the majority are from the UK, with around 20% coming from overseas.

Of 59 research teams who had submitted research applications up to mid January 2013, 58 were funded by health charities and universities – and one is from industry. Forty-eight of these are from the UK and 11 are from overseas (predominantly Europe and North America).

The applications span a wide range of diseases, from visual and hearing impairment to diseases such as stroke, heart and lung disease, diabetes, eye diseases, as well as chronic pain and mental and dental health, and the links between smoking, alcohol, obesity and physical activity to illness.

Many more research proposals are expected in the months and years ahead. UK Biobank will become increasingly valuable as it follows-up participants' health over the very long-term – up to 30 years and more. Linking to a wide range of health and health-related records will add yet further to the usefulness of the resource.

UK Biobank opened to researchers in March 2012, having obtained detailed information about the lives, health and wellbeing of its 500,000 participants. Only information that does not identify participants will be provided to researchers.

## Linkage update

UK Biobank is making considerable progress in linking health and health-related data to UK Biobank participant records. The links will allow participants' health to be followed over many years – though information that might identify participants will not be provided to scientists.

Information about new cases of cancer is now regularly being received by UK Biobank. Details on deceased participants are also updated regularly. UK Biobank is also linking to information about stays in hospital.

## Helping researchers

UK Biobank is monitoring how many times it asks participants to help with new research.

The project does not wish to over-burden participants. But it also believes that many participants may be happy to help with follow up questionnaires, attending repeat assessments and enhancements to the project.

Scientists may also make requests to re-contact participants for their own studies (though UK Biobank will ask participants for their permission to do this).

If you have any questions or suggestions about the way in which UK Biobank stays in contact with you please email <mailto:ukbiobank@ukbiobank.ac.uk>, visit our website feedback form at [www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk) or call us on free phone (from most land lines) 0800 0 276 276 8am-7pm Monday-Saturday or 02920-765597.

## Accessing the UK Biobank resource

Any bona fide scientist undertaking health research for the public good is able to register to access the UK Biobank resource. Applications are checked to ensure they meet UK Biobank's criteria and then data, or the results of tests on blood, urine and saliva, will be released to them.

Scientists are obliged to give their results back to UK Biobank, and so provide more up-to-date information for other researchers to use.

Summaries of the data available can be viewed via UK Biobank's online Data Showcase. Information on recent deaths and cases of cancer has just been added, as has data from recent web-based diet questionnaires.

Scientists wishing to register can do so by visiting the UK Biobank Resource Access Management System. UK Biobank is also creating key research disease groups, so that they can formulate plans of how best to use the data from the study.

### **Further funding to undertake analysis of blood samples**

The Medical Research Council, Wellcome Trust, British Heart Foundation and Diabetes UK have provided a further £10 million to UK Biobank – to allow some analysis of blood samples to take place.

Experts have helped UK Biobank draw up a list of the most useful blood tests which will be of interest to a wide range of researchers. They include biomarkers which are a strong risk factor for disease (e.g. cholesterol for heart disease); early diagnostic markers of disease and biomarkers that can help characterise liver and kidney function (e.g. liver enzymes as markers for liver function, creatinine and protein for kidney function). As with other aspects of the project there is no feedback of individual results to participants.

“This is a fantastic commitment by the funders to UK Biobank,” says Professor Rory Collins, UK Biobank Principal Investigator. “It means that the scientists themselves will not have to find the funding to do these commonly requested and useful tests, which will make UK Biobank an even more attractive resource to use.”

Researchers requiring the answers to other analyses will still be able to apply to have these done. The results will be put back into the resource for other scientists to use.

### **Coming back for more**

UK Biobank has embarked on a new phase of the project – by seeing 20,000 participants for a second assessment.

The process has started in Manchester, where the first participants were recruited six years ago. Participants from a much wider area, including parts of Sheffield, Liverpool and Leeds have been asked if they would consider returning.

Up-dated measurements on a small proportion of participants will enable scientists to analyse the association between these measures and disease risk more accurately. UK Biobank will undertake similar repeat assessments in other parts of the country over time.

“We do understand that we may ask participants to travel further. We are happy to provide travel expenses and have been very pleased by the up-take so far,” says Paul Downey, UK Biobank’s Chief Operating Officer. “Thanks to all those people for helping.”

### **UK Biobank supports major study into lung disease**

Researchers using the UK Biobank resource are conducting the largest ever study of the genetics of lung disease. The main aims are to discover what influences lung health and why smoking harms the lungs of some people more than others.

This major study is funded by the Medical Research Council. It is being undertaken by scientists from the Universities of Nottingham, Leicester, Oxford, Glasgow and St George’s, University of London, and Imperial College, London. The researchers hope to find out why some people are genetically more prone to develop lung disease, particularly chronic obstructive pulmonary disease (COPD).

COPD includes conditions such as chronic bronchitis and emphysema and is the sixth most common cause of death and disability in the UK (around 30,000 deaths per year). It affects approximately 900,000 people in the UK and costs the NHS £500m every year.

The research team will use the anonymous data from 50,000 UK Biobank participants with the best and worst measured lung function to determine genetic variants associated with susceptibility to COPD. Participants had their lung function measured and gave information about their smoking habits when they joined UK Biobank.

The project aims to discover the genes which affect lung function, and also those which may affect the chances of developing lung disease. It will also investigate whether genes play a part in the ability, or the failure, to maintain good lung health for both smokers and non-smokers.

Lead researcher and Dean of Nottingham Medical School, Professor Ian Hall, says: “We currently know very little about why there is such a wide difference in lung health even among smokers. It may have something to do with genetics so we’re extremely excited about using the unique resource of UK Biobank to test this theory. This study couldn’t be done anywhere else in the world.”

The World Health Organization (WHO) estimates that COPD is the 4th leading cause of death worldwide (after coronary heart disease, cerebro-vascular disease and acute respiratory infection) but it is predicted to move into 3rd place in the near future.

**UK Biobank, 1-2 Spectrum Way, Adswold, Stockport, SK3 0SA**

[www.ukbiobank.ac.uk](http://www.ukbiobank.ac.uk) <mailto:ukbiobank@ukbiobank.ac.uk>

UK Biobank Participant Resource Centre on 0800 0 276 276 (free from most land lines) or phone 02920 765597

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