Welcome to the 2016 UK Biobank Newsletter. You have received this Newsletter because you are a participant in UK Biobank. Thank you for contributing to this exciting and pioneering study. You can follow UK Biobank in more detail by visiting our website.

UK BIOLAB UNDERTAKES THE WORLD’S LARGEST IMAGING STUDY - AND WE NEED YOUR HELP TO MAKE IT A SUCCESS

UK Biobank’s imaging study is being rolled out across the country. This will give most UK Biobank participants the chance to participate in this exciting project.

Two new imaging centres are currently being developed – one in Reading and the other in Newcastle-upon-Tyne – to support the centre in Stockport, which has seen more than 10,000 participants scanned.

The centres will create the world’s biggest collection of scans of internal organs which will transform health research and the way scientists study a wide range of diseases.

The £43m project is funded by the Wellcome Trust, Medical Research Council and British Heart Foundation.

Mr Michael Hurst from Sheffield became the 10,000th UK Biobank participant to take part in our imaging study at Cheadle, Stockport. Mr Hurst is pictured with his wife, Gillian, and imaging centre staff.

Are your contact details up-to-date?

UK Biobank would like to stay in touch with you so that we can inform you of advances in research, but also ask you to help further.

If we don’t have your most up-to-date contact details, please use the enclosed form to let us know, or call our Participant Resource Centre on 0800 0 276 276 (free from most phones) 8am-7pm Monday-Saturday.

An email address is particularly valuable to us, since it allows us to maintain contact cheaply and easily, allowing us to spend more on improving the resource.

Cathie Sudlow, Professor of Neurology and Clinical Epidemiology at the University of Edinburgh, and UK Biobank’s Chief Scientist, said:

“What makes this study truly transformational is the opportunity to combine the rich imaging data with the wealth of other information already available or being collected from participants.”

Meanwhile, hundreds of scientists are already using the rich information provided by participants on their health, lifestyle and wellbeing. Many researchers have already published their results, and many more will do so in the coming year. You can find out who is using the resource and what they are doing on our web site.

www.ukbiobank.ac.uk
**IMAGING – A BIG STUDY TO TRANSFORM OUR UNDERSTANDING**

The UK Biobank imaging study has been developed by a large number of experts working together, and we are grateful to them all.

Professor Stephen Smith, of the Oxford University Centre for Functional MRI of the Brain, leads the brain imaging component of the study.

“The data are incredibly rich,” he said. “We have one kind of image that tells us about brain anatomy, another that tells us about complex patterns of brain activity, and yet another that tells us about the brain’s ‘wiring.’”

**Imaging: what’s involved?**

- Magnetic Resonance Imaging (MRI) of the heart chamber diameter, the volume of blood flow, and how the heart changes as it pumps blood around the body, thickness of the heart wall and the size, shape and stiffness of the thoracic aorta, the vessel that delivers blood from the heart
- MRI of the brain structure and function, volumes of grey matter and the mapping of major brain connections
- Low energy X ray of bone density, osteoarthritic change in the spine, hip and knee, fractures in the spine, and fat distribution throughout the body
- Ultrasound of the carotid arteries that run either side of the neck, taking blood to the brain
- MRI measures of abdominal fat including in the liver and pancreas

**Imaging: how can you help?**

UK Biobank participants are crucial to the success of this imaging project. Invites are already on their way to some of you – but it will take many years to work our way through 500,000 participants.

Attending may mean a longer journey than when you joined the project. We are sorry for the inconvenience. Scanning assessment centres are very expensive to build, and it is just not possible to re-locate them in a large number of centres. You will not receive feedback from the scan, but if a potentially serious abnormality is spotted during the procedure then we will tell you and your doctor.

Professor Paul Matthews, Head of the Division of Brain Sciences at Imperial College London, chairs the group of academic experts who have been supporting UK Biobank to create this additional resource. He said:

“One of the crucial questions we can start to answer is, what happens in the brain years before dementia, stroke or other disorders are diagnosed? Can we understand it and find new ways to treat or prevent the onset? Scientists will also be better able to discover how brain diseases such as depression, stroke or Alzheimer’s disease are affected by our genes, environments and lifestyles.”

**Imaging: Learning about fat distribution**

With increasing evidence to suggest that fat distribution, rather than the amount of fat, is important for determining an individual’s risk of future disease. Abdominal MRI provides an exciting opportunity to examine the predictive importance of particular fat depots and the relative distribution of fat for the development of disease. Using images collected during the UK Biobank scans, scientists can examine the volumes and quantity of external and visceral fat. Scientists can investigate the effects of fat around the liver, pancreas and the skeletal muscle and look at the volumes of kidneys and lungs.
**Imaging: suppose we spot a health problem?**

UK Biobank has given considerable thought to the way in which it handles so called ‘incidental findings’ – when potentially serious health abnormalities like a tumour or aneurysm are spotted in someone who has volunteered to be scanned.

Imaging is not a health check and our scanning staff are not looking for health abnormalities. When they do arise, most apparent observations turn out to be non-serious. Informing participants may lead to unnecessary worry and further costly, invasive and unnecessary investigations (which may themselves have risks). UK Biobank has investigated how participants and their GPs feel about being advised of an incidental finding. There is, of course, a level of anxiety from participants. GPs worry about unnecessary follow-up which diverts time and money from other work.

UK Biobank’s policy on incidental findings is that if a potentially serious abnormality is spotted by a radiographer (scanning technician) during the imaging visit it is referred to a radiologist (a doctor who specialises in reporting and interpreting imaging scans). If the radiologist agrees that the finding is potentially serious, the information is fed back to the participant and their GP. So far about 2% of participants have had an abnormality that a radiologist agrees is potentially serious. About one in three of these people turn out to have something clinically serious and two out of three turn out to be non-serious.

Professor Cathie Sudlow, UK Biobank Chief Scientist, said: “Our imaging assessment is designed to collect vital information for health research. It is not a health check. We are grateful to those participants who have already been scanned – and hope many others will take part in this exciting project.”

**Linking to health information opens up new research opportunities**

A key feature of UK Biobank is to follow your health over many years to find out what happens to you. This allows scientists to compare lives and genetics to find out why some people get certain illnesses and others do not.

UK Biobank does this by linking to existing health records, such as those from general practice (GP), hospitals and those collected centrally (cancer and death statistics for instances). The links are made electronically, so that individual privacy is preserved. Only information that does not identify participants is provided to researchers.

So far, we have linked to the GP records of about 200,000 UK Biobank participants. Links to the rest will be made over the coming year. Illnesses and prescriptions are given precise codes by GPs, and it is this coded data that will form the bulk of the information provided.

UK Biobank senior epidemiologist, Professor Naomi Allen, explained: “Information about what sends us to see the doctor opens up potential for research into conditions that, up until now, have been overlooked.”

There is much more information about how we link to health records, and the information we make available to researchers, on our website: www.ukbiobank.ac.uk If you have any questions, please do make contact with us (see the back page for more information).

**Genetic power aids research**

Our genes control the way our cells work – and account for our similarities and differences, including our susceptibility to disease and how we might respond to treatment. UK Biobank has obtained huge amounts of genetic information from samples of blood provided by you when you joined the project – and there is enormous excitement from researchers around the world in using it for health research. Genetic information from UK Biobank is particularly valuable, since researchers use it alongside a wide range of other information you have kindly provided about your health and well-being. Genetic studies using UK Biobank data are already advancing health research and very many more are planned for the future.
UK BIOBANK ANNUAL CONFERENCE 2016

UK Biobank has held its first Annual Meeting. It took place at the Queen Elizabeth II Conference Centre, in London, where 400 scientists and participants gathered to hear about UK Biobank achievements – and to discuss plans for the future.

If you would like to hear about next year’s events, email us at: ukbiobank@ukbiobank.ac.uk and we will send you more details when they become available, or call the Participant Resource Centre on 0800 0 276 276 8am-7pm Monday-Saturday, free from most phones (or 02920 765597). We will also send you an invite to any local events we organise.

Being part of UK Biobank

Six UK Biobank participants discuss their involvement with the project with Fergus Walsh, BBC Medical Correspondent, centre. Fergus, a UK Biobank participant, kindly agreed to tease out expectations and interests from the small group.

Resources, expertise, enthusiasm and energy

The eyes may be the window to the soul – but they are also a short cut to information about our general health, researchers told the UK Biobank Annual Meeting. Around 130,000 participants undertook eye measures as part of their UK Biobank assessment.

The scans and photos allow analysis of the optic nerve and blood vessels at the back of the eye, providing a measure of blood vessel fitness throughout the body. The thickness of the retina can predict risk of cognitive decline, and observation of the retinal vessels can allow doctors to estimate the risk of heart attacks and strokes. “Eyes are a very important indicator for the rest of the body. There is no systemic disease that does not have an impact in the eyes,” explained Professor Paul Foster from Moorfields Eye Hospital, who leads the UK Biobank Vision and Sight Consortium.

The researchers have worked with industry to reduce from two hours to two minutes the amount of time it takes to analyse the eye pictures. The resource has brought together eye experts from across the country. “To analyse all of this data it has been necessary to pool resources, expertise, enthusiasm and energy from all academic eye centres in the UK,” says Professor Foster. The Eye Consortium has 72 members from 22 groups in the UK. Visit: http://www.ukbiobankeyeconsortium.org.uk/
Baroness Helene Hayman recently took over the role of Chair of the UK Biobank Ethics & Governance Council (EGC). Her predecessor, Professor Roger Brownsword, stepped down in December 2015, after his four-year appointment came to an end.

Baroness Hayman addressed the UK Biobank Annual Meeting. “The EGC was set up as an independent group of people who could come together from a variety of different backgrounds so that we could act as an independent sounding board on (some of these) issues of governance. We are there to provide that extra level of assurance to participants and the public and to look at some of these in principle questions, just one step removed from Biobank itself. We try to maintain the balance of challenging and asking difficult questions of UK Biobank while being fundamentally committed to the success of the project,” she said.

The EGC ensures UK Biobank’s compliance with its Ethics & Governance Framework (EGF), a document that sets out how it should behave.

You can find out more about the UK Biobank Ethics & Governance Council, here: http://egcukbiobank.org.uk/

Turning data into knowledge

UK Biobank’s goal is to turn participants’ samples and data into useful, usable information for scientists as quickly as possible. Nowhere is this more evident than with the huge amounts of activity data collected over the past two years.

More than 100,000 participants have worn activity monitors for a week; and this in itself is a fantastic achievement, with more than half of you who were asked, willing to have a go.

The monitors took 100 measures over three axes (up, down and sideways) every second for a week.

“That is really a lot of data!” Dr Soren Brage, from Cambridge University, told the Annual Meeting.

Dr Brage is part of a team making sense of it. “With UK Biobank we have entered into a new era of physical activity study. It has never been done on this scale” he said.

The activity data will help with a wide range of studies, including those looking at sleep and sleep patterns, depression, and the link between activity and chronic diseases of older age.

Big is beautiful

As a stand-alone resource, UK Biobank is big, allowing for a wide range of studies to tease out the causes of disease. Its power to examine even rare diseases intensifies considerably when its data are used along with other large studies.

A new US study, called the Precision Medicine Initiative (PMI), for instance, will recruit 1,000,000 participants to provide a further boost to research. Dr Francis S. Collins, Director, National Institutes of Health (NIH), USA, says it will work closely with UK Biobank: “International partnerships will be especially critical so that we can all learn as much as possible from the similarities and differences from longitudinal studies that are emerging across the world,” he said. He acknowledged UK Biobank’s leading role in this revolution in health research.
Professor John Gallacher from Oxford University, who leads the Dementias Platform UK, told the Annual Meeting that the information provided by UK Biobank participants was putting the UK at the heart of the global efforts to defeat these diseases. In undertaking reaction time tests during your assessments and online afterwards, pairs tests and trail-making tasks, participants have helped create an incredibly rich resource with which to tackle dementia and the related illnesses.

UK Biobank has already contributed to significant discoveries about mental health, Professor Daniel Smith from Glasgow University told the audience.

“A difficult to understated the importance of mental health in the UK and globally and it is fantastic that it is so well represented in this UK Biobank study,” said Professor Smith.

He believed that the addition of genetics information, the results of a large number of blood analyses currently under way and the brain imaging will enrich the research possibilities even more.

Key achievements over the past 10 years

• 500,000 people aged 40-69 joined the study
• 20,000 participants fully assessed for a second time
• 10,000 participants scanned – with plans to image another 90,000 full steam ahead
• Genotyping of all 500,000 participants
• 100,000 participants have worn activity monitors for a week
• 3,000 scientists (and growing) registered to use the resource from 18 countries

• Over 200,000 participants have undertaken web-based questionnaires on diet, mental health, work life and cognitive function
• 100 scientific papers published in specialist journals and more on their way
• Hundreds of top researchers from a wide range of disciplines working together to improve the resource for scientists everywhere
• Following of participants’ long-term health electronically through GP records, hospital statistics and other national statistics (such as cancer, diabetes and death) established