

Monday 21 September 2009

UK BIOBANK COMES TO CROYDON

A major UK medical research initiative kicks off in Croydon this week (24 September 2009) as part of a nationwide battle against a wide range of serious and life-threatening illnesses.

UK Biobank hopes that many of the 40-69 year-olds currently being invited by letter in the Croydon area to take part in the ambitious project will rise to the challenge to improve the health of future generations.

The ambitious project expects to recruit about 500 people a week from the surrounding area over the next six months, and with their permission will follow their health for the next 30 years or more.

As the project matures, it will become an unparalleled treasure chest of vital information on a range of diseases including cancer, heart disease, diabetes, stroke, dementia, depression, arthritis, osteoporosis, skin and lung disorders and many other life-threatening and debilitating conditions.

The project has the support of leading medical health charities such as Cancer Research UK, British Heart Foundation, Diabetes UK, British Lung Foundation and the Arthritis Research Campaign and is a joint effort between scientists and doctors at 22 UK universities.

Dr Tim Sprosen, UK Biobank Chief Scientist, hopes that local people will want to participate. He said: "This is a fantastic opportunity to put something back, and to do something very positive for future generations."

More than 360,000 people have now joined UK Biobank in other cities across the UK (including Manchester, Stoke, Leeds, Newcastle, Edinburgh, Glasgow, Hounslow and Liverpool).

UK Biobank is funded by the Wellcome Trust charity and the Medical Research Council, Department of Health, Scottish Government, Welsh Assembly Government and the Northwest Regional Development Agency. It is hosted by the University of Manchester.

Dr Tim Sprosen added: "It is exciting to be involved with such a large and important project that we hope, in years to come, will lead to better prevention and treatment strategies for a wide range of life-threatening and debilitating diseases.

"I am very grateful to all those people who have so far agreed to join UK Biobank and I hope that many more will find the time to come along and be part of this project.

“The long-term nature of the project means it is unlikely most participants will directly benefit from participating. However, there is a tremendous feel-good factor in taking part and knowing that you are contributing to the better health for all in future generations.”

In building this resource, UK Biobank asks participants to attend an assessment of about two hours at Norfolk House, Wellesley Road, Croydon, CR0 1LH (next to the Travelodge hotel), next to a tram stop and close to bus and rail networks.

Participants provide information on their current health and lifestyles and have a number of measurements taken, such as blood pressure, weight, lung function and bone density. Participants leave with a list of personal health-related measurements and some indication of how they compare to standard values. UK Biobank also asks for a small donation of blood and urine and, with participants' permission, it will track their health over the next 30 years and more.

The information will help to untangle the complex interplay of nature (that is, genes) and nurture (such as lifestyle) and provide insight into why some people get particular diseases and others do not – paving the way for prevention and better treatments.

Professor Rory Collins, UK Biobank's Principal Investigator, said: “This is a fantastic opportunity to do something very positive for future generations. I can't think of a better way to spend time than attending our assessment centre and knowing that your altruistic act will have a direct impact on people's health in the future.”

Participation is voluntary and by invitation only; most people aged 40-69 living within about a 15-20 mile radius of Croydon will be asked if they wish to take part in the months ahead. Participants can withdraw at any time should they wish to do so.

UK Biobank has secured approval from a number of ethics and regulatory groups in relation to its research remit, recruitment process and the storage of blood and urine samples and access to participants' medical records, with their consent, over many years.

UK Biobank is governed by an Ethics & Governance Framework and its activities are monitored by an independent Ethics & Governance Council to help look after the public interest. The Council is chaired by Graeme Laurie, Professor of Medical Jurisprudence at the University of Edinburgh.

Web link: www.ukbiobank.ac.uk

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1. People who receive letters asking them to participate in UK Biobank will be offered an appointment time and date. However, if the timing is inconvenient they can easily change this by calling 0800 0 276 276, Monday to Saturday, 8am-7pm. Participants will be able to confirm their appointment and find out more about the project by visiting UK Biobank's web site: www.ukbiobank.ac.uk
2. A full list of measurements that will be provided at the end of the UK Biobank assessment visit, a location map for the assessment centre and other background information can be found on our web site: www.ukbiobank.ac.uk
3. UK Biobank is one of the biggest prospective epidemiological research studies ever undertaken and will certainly be the richest in terms of the information collected on participants. Following people's health – rather than relying on them to remember what they did in the past – is a powerful way of learning about the causes of disease. Indeed, a similar British study launched by the eminent scientist Sir Richard Doll more than 50 years ago provided the crucial evidence that smoking was a major cause of lung cancer and heart disease; a finding that has saved many millions of lives worldwide.
4. UK Biobank is governed by an Ethics and Governance Framework and its activities are monitored by an independent Ethics and Governance Council to help look after the public interest. The Council is chaired by Graeme Laurie, Professor of Medical Jurisprudence at the University of Edinburgh. Website: www.egcukbiobank.org.uk Further information from Barry Taylor barry.taylor@bristol.ac.uk 0117 928 8867 or 07748 337172.
5. The idea of establishing a large national blood-based cohort was first proposed in 1999, with a provisional decision to support it made by the funders in 2002. So, there had been nearly seven years of consultation and meticulous planning for UK Biobank before an initial start-up phase in the Manchester area got underway in March 2006. This three-month 'pilot' to refine procedures led to the now-approved final protocol, which will be further enhanced as the project proceeds. Over the course of the 3-4 year recruitment period, there will be around 35 assessment centres in England, Scotland and Wales. The centres will be located in areas where there are about 150,000 men and women aged 40-69 living within about 10 miles' radius (or the equivalent in travelling time for congested places like London). Each centre will be optimally located for public transport links, easy parking and access, including for disabled people. They will be staffed by trained nurses and other healthcare professionals. People in the target population will be mailed invitations to participate. No one will be pressured to take part and participants are free to withdraw at any time. All of these procedures have been carefully tested in the pilot phase, and found to be very acceptable by participants. The single baseline assessment visit takes about 90 minutes and involves a computer touch-screen questionnaire, a short interview, some standard measurements, and small samples of blood (equivalent to about 3 tablespoons) and urine. Information about participants' subsequent health will be obtained, with their permission, from medical and other health-related records.

Stringent security systems will be in place to protect participants' privacy. The project, which complies with the Data Protection Act and other relevant legislation, is subject to ongoing review by an independent Ethics & Governance Council and an International Scientific Advisory Board, as well as by the NHS North West Multi-centre Research Ethics Committee.

6. The recruitment phase for UK Biobank is jointly funded by the MRC and the Wellcome Trust at £28m each. The DH is providing an additional £5m and the Scottish Government and the Northwest Regional Development Agency have added an additional £0.5m to the total.
7. The **Medical Research Council** is dedicated to improving human health through excellent science. It invests on behalf of the UK taxpayer. Its work ranges from molecular level science to public health research, carried out in universities, hospitals and a network of its own units and institutes. The MRC liaises with the Health Departments, the National Health Service and industry to take account of the public's needs. The results have led to some of the most significant discoveries in medical science and benefited the health and wealth of millions of people in the UK and around the world.
8. The **Wellcome Trust** is the largest charity in the UK and the second largest medical research charity in the world. It funds innovative biomedical research, in the UK and internationally, spending around £500 million each year to support the brightest scientists with the best ideas. The Wellcome Trust supports public debate about biomedical research and its impact on health and wellbeing. Website: www.wellcome.ac.uk
9. The **Department of Health's** budget for health research for 2006-07 is £753m. Of this, £50m is allocated for capital funding; the rest is allocated to research through a portfolio of national research programmes. The funding supports clinical research in the NHS, research commissioned for policy development, and the NHS costs incurred in supporting research funded by other bodies such as the Research Councils and charities. Some funding is provided to increase capacity to undertake research, and to underpin the UK Clinical Research Collaboration and priority disease research networks.
10. The **Scottish Government** is the devolved government for Scotland. It is responsible for most of the issues of day-to-day concern to the people of Scotland, including health, education, justice, rural affairs, and transport. It manages an annual budget of more than £27 billion in the financial year 2005-2006 which is due to rise to over £30 billion in 2007-2008.
11. The **Northwest Regional Development Agency** (NWDA) leads the economic development and regeneration of England's Northwest and is responsible for supporting business growth and encouraging investment; matching skills provision to employer needs; creating the conditions for economic growth; connecting the region through effective transport and communication infrastructure; promoting the region's outstanding quality of life.