

Wednesday 21st March 2007

MANCHESTER FIRST FOR UK BIOBANK

A multi-million pound visionary medical project that will recruit 500,000 people across Britain to help find out much more about curing many life threatening and debilitating diseases gets underway in Manchester today (Wednesday). UK Biobank will recruit people aged 40-69 and track their health over the course of the next 30 years or more.

In the first phase of a four-year recruitment process, about 10,000 letters asking people to take part in UK Biobank will arrive on residents' door mats today and over the course of the next few days.

Tens of thousands more invitations will be sent throughout the course of the year to people across Manchester, asking them to join this exciting project. A successful pilot study to check the feasibility of this huge undertaking took place in Altrincham (south Manchester) last year.

Hosted by the University of Manchester, UK Biobank is one of the biggest and most detailed public health research initiatives of our time. It will provide a valuable resource for research into a wide range of diseases including cancer, heart disease, diabetes, dementia, mental illness, Parkinson's disease, joint and dental disease and many other life-threatening and debilitating conditions.

Researchers, including some of the most eminent scientists from around the world, believe that UK Biobank will be an extraordinarily important resource for scientists for many years to come. It will help doctors and other medical researchers to develop a better understanding of the causes of many common diseases and to improve their prevention and treatment.

People in Manchester who agree to take part in UK Biobank will attend a 90 minute assessment at a special centre in Hulme, south Manchester. They will be asked to allow UK Biobank to follow them through routine health records over many years. The assessment centre will open in April.

Participants will be asked about their current health and lifestyle and will have a number of measurements taken, such as blood pressure, weight, lung function and bone density (1). They will also be asked to give small samples of blood and urine. Though not a health check, participants will leave with a list of personal health-related measurements and some indication of how they compare to standard values.

Dr Tim Peakman, UK Biobank Executive Director, based at the charity's headquarters in Stockport, said: "We can't do this without people's help. Though UK Biobank may not directly benefit those who take part it will help our children and our children's children to live longer, healthier lives. A willingness to help others in this altruistic way will, I hope, be a powerful motivation for many people to take part.

"At the assessment centre we will obtain the consent of people who want to join UK Biobank and collect what we call baseline information about their health and wellbeing. Along with the blood and urine samples, this will provide important data for scientists of the future when they are trying to work out what causes some people, and not others, to develop a particular disease.

"The UK Biobank resource will help untangle the complex interplay of nature (that is, genes) and nurture (such as lifestyle) in the development of many different diseases. Its goal is not to focus on genes alone, which may be better done through other sorts of study."

Around 15 million blood and urine samples will eventually be stored for decades in specially designed laboratories near Manchester, at temperatures down to about -200°C.

UK Biobank is not just for the fit and healthy. "It is important that we involve the whole population. So if people who are not in good health receive an invitation to take part we would very much welcome them as participants in this remarkable health project," said Dr Peakman.

Rory Collins, British Heart Foundation Professor of Medicine and Epidemiology at Oxford University, and UK Biobank's Principal Investigator, said: "UK Biobank is a project of which the whole of Britain can truly be proud. We are talking to lots of British scientists about the ways this resource can help their research and, internationally, advising others who want to set up similar projects in their own countries.

"Health research has taken enormous strides in the past decade and we know a lot about how our bodies work, but we need to find out more. In setting up UK Biobank for researchers in the future - those who may only be in primary or junior school now or not even born - we are establishing the blood-based resource to do just that, and making a significant contribution to improving the health of future generations."

Health Minister Lord Hunt said: "This vital project is only possible because of the unique role that the National Health Service plays in our lives, providing comprehensive health care for people throughout the UK. I urge all those who are invited to participate in UK Biobank to do so and be part of a project that will help future generations lead lives free of disease."

Laura Roberts, Manchester PCT's Chief Executive, and a co-signatory on the letters going out, described UK Biobank as a visionary and exciting project which has enormous implications for the future health of the whole population. "I would encourage all Manchester people who receive an invitation to take part. Manchester has some of the most challenging health problems in the country and therefore the most potential to benefit from the vital information we could get from this research."

Mike Farrar, Chief Executive of NHS North West said: "NHS North West fully supports the work of UK Biobank and its role in improving the health of people living in the region. This medical project highlights some of the excellent initiatives that are taking place to transform public health."

UK Biobank will recruit in Manchester for about one year. People who receive letters asking them to participate 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

Taking part in UK Biobank is entirely voluntary and participants will be able to withdraw at any time should they wish to do so.

Recruitment is by invitation only, though most people aged 40-69 who live within a five to ten mile radius of the Manchester assessment centre can expect to receive an invitation to join in the months ahead. The opportunity to take part in this unique project will be made available to people in other areas of the country as assessment centres are rolled out over the next few months across Britain.

UK Biobank is funded by the Wellcome Trust, the Medical Research Council, the Department of Health, the Scottish Executive and the Northwest Regional Development Agency. It is hosted by the University of Manchester, has the support of the National Health Service (NHS) and is a collaborative effort between 22 UK universities. It 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 over many years.

Web link: www.ukbiobank.ac.uk

Ends

Notes for Editors

1. 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
2. When the Manchester assessment centre opens in April it will be possible to offer you the chance to talk to participants and tour the assessment, processing and storage facilities.
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
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 Executive and the Northwest Regional Development Agency have each 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 Executive** 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** (NWRDA) 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.