



Parliamentary Office of
Science and Technology

UK BIOBANK

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Overview

UK Biobank

- what is it?
- how will it work?
- who is behind it?
- status
- possible benefits
- a parliamentary perspective
- potential concerns



What is Biobank?

- research database that will be used to study the causes of common diseases
- aim is to understand the contribution of genetic and environmental factors to diseases such as heart disease, stroke, cancer & diabetes
- will run for at least 10 years
- will involve 500,000 people in the UK aged 45-69 recruited via their GPs
- will collect biological, medical, lifestyle, dietary and other information as baseline measures...



Baseline measures / follow up

Participants will be asked to:

- complete a questionnaire (socio-economic status, age, sex, lifestyle, history, etc.)
- attend an interview (medical/surgical history & current medication)
- undergo a physical assessment (blood pressure, lung function, height, weight, etc.)
- give a blood sample (for genetic and other analyses)
- complete a 7 day dietary diary
- consent to follow up – e.g. on contracting certain diseases, admission to hospital, etc.



Funding and management

- £45 million (Wellcome Trust, MRC and DoH)
- will consist of a co-ordinating centre (hub) based in Manchester University
- and 6 regional centres (spokes) involving collaborations between 23 UK universities
- project will be overseen by an independent oversight body – responsible for ensuring samples/data are used responsibly and in line with the consent obtained from participants



How will it work?

- Biobank is seen as a research resource
- researchers will submit proposals for studies using Biobank
- these will be assessed by the hub
- and possibly also by the independent oversight body
- open to researchers in UK and overseas both in public and private sectors



Current status

- CEO appointed to UK Biobank in April 2003 (Dr John Newton)
- hub and spokes selected in May 2003
- interim advisory group has been meeting /consulting since February 2003 to advise on ethical/governance issues
- programme design has been informed by a series of workshops and consultations since 2002
- ethics and governance framework published in September 2003
- aim to start recruiting in 2005 after pilot studies



Possible benefits - 1

Biobank aims to improve understanding of:

- the influence of specific genes or genetic variations on the development or severity of disease
- the number of people who carry a particular genetic variation and hence are at greater or lesser risk of disease
- the way in which interactions between genes and environmental factors are involved in the cause of disease



Possible benefits - 2

This improved understanding may prove useful in:

- designing new drugs to prevent a range of chronic diseases;
- targeting drugs at those who might benefit the most
- predicting the likelihood that an individual will develop disease, so that drugs or other interventions can be used to prevent the onset of disease in those at higher risk

But these benefits may not accrue for years. In the meantime Parliament has to consider public concerns...



Parliamentary perspective

Parliamentary interest in Biobank to date has been limited to specialised scrutiny

- Commons S&T Committee has looked at Biobank as part of a wider review of medical research funding
- Lords S&T Committee has examined it as part of wider inquiry into genetic databases
- POST has published a short briefing note (July 2002) to coincide with a short Westminster debate on Biobank

Relatively little interest from constituents to date. Consultation has shown that public are generally positive

about Biobank but do have a number of concerns...



Public concerns

- consent – general or specific?
- security of data
- police/employer/insurance access to data - need for legal safeguards to protect participants
- balance between public and private interests

Also a number of wider issues that Parliament may have to consider...



Wider concerns

- design of the project (too big, too small, wrong age group, etc.)
- over-emphasis on genetics rather than on environment or lifestyle factors
- good use of public money?
- wider ethical/legal concerns over Biobank



Website

www.parliament.uk/post

