



## Biobank: who'd bank on it?

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Over 5 years ago leading minds within the Wellcome Trust and the Medical Research Council (MRC) realised that charting the entire genome of one human would do nothing to improve health. They argued that the real meaning and significance of genes could only be unravelled by also studying their owners' behaviours and environments to determine which combinations conferred resilience and which resulted in disease. And so the idea of the UK Biobank was born.

It is truly a bold concept — to enrol 1% of the United Kingdom's population, or around 3% of people in the target age-group 45–69 years, into a massive cohort study in which genetic material is held for all participants. With 500 000 participants, the UK Biobank cohort stands to be 50% larger than the set of men originally screened for the Multiple Risk Factor Intervention Trial in the United States, twice the size of the cohort for the combined US Nurses Health Studies, 12 times bigger than that of the study of smoking in British doctors, and 100 times larger than that of the famous Framingham Heart Study. Indeed, the driving force behind UK Biobank is a desire to have adequate statistical power to study gene–environment interactions for individual types of cancer, bearing in mind that, in the UK, all types of breast cancer combined account for about 4% of all deaths in women, and all types of lung cancer collectively cause about 7% of deaths in men. Despite this, there is not yet any commitment to go beyond “risk factorology” to answer questions of public health importance. For example, Biobank would be an invaluable opportunity to explore the relationship between individual characteristics and either the contextual influences on health, such as the physical and social nature of one's neighbourhood, or the impact of health and social policy programs.

Between them, Wellcome, the MRC and the UK Department of Health have made £61 million available to UK Biobank. But, 1000 days into the project, not a single participant had been enrolled, even into a pilot study. Instead, time and energy has been consumed in:

- creating UK Biobank Limited as a private company, limited by guarantee, and as a registered charity;
- having consortia of universities (mainly their medical schools) bid to be regional collaborating centres, and then drafting and redrafting contracts for them to provide “research services” to the private company;
- recruiting a Chief Executive Officer, a Chief Scientific Officer, a Chief Operating Officer, a Director of Operations (Laboratory), a Director of Clinical Operations, a Head of Communications, and a Chief Information Officer;
- commissioning a market research company to report on attitudes of people in later middle age to inform a Communications and Consultation Strategy;

- developing an Ethics and Governance Framework, compliance with which is to be overseen by an Ethics and Governance Council, whose members will be recommended to the funders by an appointments committee;
- writing an Intellectual Property and Access Policy; and
- asking a marketing agency to develop a logo and brand.

There have also been protracted debates about which behavioural, lifestyle and environmental factors to document, and whether the collaborating centres that enrol participants should have any preferential access to the data and samples held by UK Biobank, let alone a share in their formal ownership. As yet, there has been very little consideration as to how endpoints of interest will be identified and validated. Sir Humphrey Appleby would be proud!

On the subject of public image, perhaps it is the picture of a happy granny riding a moped without a helmet, shown in the original documents with general information about the project, that crystallises a suspicion that people with world-class expertise in the “molecules of life” do not necessarily have a strong grasp of public health and the skills required to enrol and follow up very large numbers of intact, free-living humans.

Also interesting is the stark contrast between UK Biobank and Australia's

Risk Factor Prevalence Study. The latter was initiated by a non-government organisation, the National Heart Foundation (NHF), which succeeded in completing three large, population-based surveys of risk factors for cardiovascular disease, mainly in Australia's capital cities, during the 1980s.<sup>1</sup> Enrolment involved completion of a questionnaire, a brief physical examination, collection of a blood sample and sometimes a dietary survey, directly equivalent to what participation in UK Biobank is likely to involve. The survey centres had their costs covered, as is proposed for the UK project, but, unlike UK Biobank, their leaders made up the main committee overseeing the study and directed the principal analyses and their publication, initially under the aegis of the NHF alone, and in the last survey in collaboration with the Australian Institute of Health and Welfare. Each survey took about a year to plan, a year to complete and two further years to publish. Covering slightly under 0.1% of Australia's population, the Risk Factor Prevalence Study was an order of magnitude less ambitious than UK Biobank, but it constitutes a model of energy, trust, efficiency and goodwill that the Brits are struggling to emulate.

It was not always thus, for Richard Doll and Richard Peto (and colleagues) recently published the 50-year results from their study of British doctors, a project whose outstanding achievements include a follow-up that is 99% complete.<sup>2</sup> UK Biobank, by contrast, seems baffled by its own complexity, stranded in a

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## POSTCARD FROM THE UK

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**Competing interests:** Two of us (KJ and DPW) are members of Regional Collaborating Centres of UK Biobank and are bound by confidentiality agreements that preclude disclosure of certain documents relating to the project. However, the information in this article is all on UK Biobank's website: [www.biobank.ac.uk](http://www.biobank.ac.uk)

1 National Heart Foundation and Australian Institute of Health and Welfare. Risk Factor Prevalence Study – Survey No. 3, 1989. Canberra: NHF, 1991.

2 Doll R, Peto R, Boreham J, Sutherland I. Mortality in relation to smoking: 50 years' observations on male British doctors. *BMJ* 2004; 328: 1519. □