

# Genetic databases

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A simple visit to the doctor in a few years' time might see you taking part in the largest research project ever conducted in the UK. The ethical and logistical challenges of this study are as complex as the scientific ones.

One of the greatest challenges in biomedical research today is to uncover the interactions between lifestyle, environment and genetic makeup that cause common diseases such as heart disease, cancer, diabetes and asthma. The 'UK Biomedical Population Collection', proposed as a joint project between the Wellcome Trust, the Medical Research Council and the Department of Health, aims to elucidate these interactions by following the lives of around half a million adults in the UK aged between 45 and 64 over a period of at least 10 years. If successful, the project could yield vital clues to disease risk factors and is likely, long-term, to lead to the development of tailor-made treatments for patients. The project is proposing to achieve these goals by collecting key medical and lifestyle information from participants. Crucially, this will include the collection of blood samples for genetic analysis. The scale of the project, and the collection of physiological, environmental and genetic data in a single place, should enable researchers not only to link diseases to common but subtle genetic variants or environmental factors separately, but also to look for interactions between genes and environment.

The establishment of such a collection is timely given the huge increase in our knowledge about the human genome. The collection will provide the samples and human genome studies will provide the genetic clues to carry out a broad spectrum of genetic epidemiological studies. And it is not just the UK that wishes to grasp this opportunity now. A similar collection, known as the Icelandic Healthcare Database, is already underway in Iceland and aims to recruit as many of the country's 270 000 inhabitants as possible. Here, the idea is to bring together the country's extensive health records, genealogical records dating back centuries and genetic data. Estonia, too, is preparing to launch a similar national database, which will recruit three-quarters of its population. And the 'Children of the 90s' study is an example of an on-going collection in the UK. Following the lives of 14 000 children born in 1991 and 1992, the study will collect data of all kinds that can be used to investigate the ways in which environmental and genetic factors influence children's health, behaviour and development.

The controversy that has accompanied the establishment of the Icelandic database gives an indication of some of the problems that the proposed UK collection will face. A major concern there has been that a commercial company is financing and running the database. No such arrangement is contemplated for the UK collection, but the issues of ownership of data and potential misuse of information by commercial organisations, for insurance or employment purposes for example, are certainly uppermost in people's minds. This was highlighted by a recent consultation exercise with a broad cross-section of the UK public, commissioned by the Wellcome Trust and the Medical Research Council. The overall attitudes of those interviewed were generally positive, but other key concerns that emerged were consent, confidentiality, and maintenance of anonymity of volunteers. Consent is an especially irksome issue and informed consent by partici-

pants as to how samples are to be used was regarded as being crucial. By contrast, the medical records of an Icelander will be included in the Icelandic database unless a person opts-out of the system. This is a far cry from informed consent, which requires an individual to be provided at the outset with adequate information about the uses to which their data will be put. Of course, informed consent is not trivial to obtain as some of the scientific questions that might be addressed in the future, using the data, cannot be envisaged at the outset. A practical solution may be to set clear boundaries for the types of use of the data – volunteers may, for example, feel differently about their data being used to study a disease rather than a characteristic such as intelligence. A further consideration is that what is regarded as ethically acceptable today may not be regarded thus in the future.

There are also major logistical challenges to collecting data on a population-wide basis, such as, ensuring the consistency and reliability of disease diagnosis. Take behavioural disorders, which might be one of the most interesting types of disease to look at, but which are notoriously difficult to diagnose. For the UK collection, the preferred route of recruitment of participants is *via* GP surgeries, but how will already over-stretched GPs cope with having to collect accurate and up-to-date information? One suggestion for alleviating this burden is to place a highly trained research nurse at each of the regional centres where data are collected.

Clearly, those behind the UK collection have plenty to consider as they begin to lay out an operational plan for the project. There is much to be learnt from the setting up of other population-based databases, and public consultation will continue and broaden. For example, the issues surrounding human genetic databases are being looked at by both a House of Lords' Science and Technology Committee Inquiry and a Human Genetics Commission Working Group. Though the project's launch is still some way off, an ethically, scientifically and organisationally robust UK collection will no doubt yield some exciting science in future years.

## Further reading

R Haraldsdottir, Fire and Fury in Iceland, Science and Public Affairs, February 2000, 12 – 13.  
A Coghlan, A wild gene chase, New Scientist, 9 December 2000, 16 – 17.  
A Abbott, Manhattan versus Reykjavik, Nature 27 July 2000, 406, 340 – 342.

## Website

[www.wellcome.ac.uk/en/1/biovenpopcol.html](http://www.wellcome.ac.uk/en/1/biovenpopcol.html)

The results of the public consultation exercise commissioned by the Wellcome Trust/Medical Research Council.

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