

Bank on It

Britain Constructs a Universal Genetic Database

Long-term, large-scale medical research projects, like the Framingham Heart Study, used to have a certain unglamorous appeal. With plodding earnestness, researchers meticulously gathered information that, like bricks and mortar, they built up over the years in the hope of future medical breakthroughs. Today, however, such studies are marketed to the public in a tone of high adventure more appropriate for proposed climbs of Mt. Everest than mundane scientific research. The public is promised enormous benefits, little individual risk, and a generally warm and fuzzy feeling of having made a contribution to scientific advancement.

This, at least, is the buzz surrounding U.K. Biobank, a joint project of the Medical Research Council, the Wellcome Trust, and the British Department of Health that eventually will bank voluntarily-given genetic samples from half a million Britons, ages 45-69, along with information about their lifestyles and health histories, in the hope of becoming “the world’s biggest resource for the study of the role of nature and nurture in health and disease,” as the Biobank website describes. (Not everyone is treating Biobank with awe, of course. The British newspaper *The Guardian* dubbed it “a kind of museum of middle-aged mankind.”)

Biobank’s purpose is “to undertake biomedical research in the public interest,”

and supporters of the project liken it to previous eras’ need for donated corpses for medical research. “Now what medical science really needs is data, and the data are what the participants are contributing,” John Newton, the director of the project, told *The Guardian*. “And of course a blood sample.”

It is that blood sample that has sparked concerns among privacy advocates, however. Watchdog group GeneWatch U.K. has raised a number of concerns about Biobank, even publishing a report, “Giving Your Genes to Biobank U.K.: Questions to Ask,” that offers detailed analyses of some potential problems with the project. GeneWatch notes that Biobank might not be the best use of public money; that Biobank “could be used for research that is morally questionable,” such as finding the genetic causes of criminal behavior or homosexuality; and that it might be used by employers or insurance companies to discriminate against people. The group wants the British government to enact stricter genetic discrimination laws and tougher monitoring and enforcement regulations for the project.

Civil liberties advocates are also concerned that Biobank might lead to a larger genetic database of all British citizens, something law enforcement has been arguing for since Britain created the world’s first DNA database more than a decade ago. As *The Guardian* reported in September, the chair-

man of Britain's Police Superintendents Association recently called for the existing criminal database "to be extended to everyone in the country," arguing that "a compulsory database would enable the police to solve crimes more quickly, and prevent them from happening." The database currently contains more than two million genetic profiles and, as *The Economist* noted this summer, "the police can already access genetic information collected for medical purposes without an individual's consent, so long as a court agrees that it is in the public interest."

The question of compulsory DNA sampling of every U.K. citizen emerged as a contentious issue this summer as well, when the government raised the possibility of the National Health Service gathering and storing the genetic profile of every child at birth. The recommendation was made in a government white paper, called "Our Inheritance, Our Future—Realizing the Potential of Genetics in the NHS," which was released in June. It also argued for increased research funding for genetics; wider screening of disease; and assurances that "by 2004–2005, all pregnant women are offered antenatal screening for Down's syndrome and then counseled by midwives to help them make an informed choice." Supporters of the white paper

argued that such universal testing would be a boon to public health. "Increasing understanding of genetics will bring more accurate diagnosis, more personalized prediction of risk, new gene-based drugs and therapies and better targeted prevention and treatment," John Reid, the Secretary of State for Health, told the *Financial Times*.

The response of the U.K. Human Genetics Commission, Britain's advisory body on genetics issues, was not quite so positive. Citing the risk of genetic discrimination, Baroness Helena Kennedy, the Commission's chair, asked, "How can we give confidence to the public that their genetic information will be maintained with the right kind of safeguards?" According to *The Observer*, she also noted, "profiling could be misleading since environmental and other factors could change the prognosis."

Whatever the U.K. decides to do, the United States should pay close attention. Although Britain has a different civil liberties tradition than the U.S. and a more fully developed state regulatory framework for assessing genetic technologies, the British are, like us, attempting to make sense of a rapidly developing area of science. Where cool Britannia goes, we might—or might not—want to follow.