



Biobanks need publicity

Most Europeans haven't heard of their nation's repositories of human blood and tissue samples. Promote them, say **George Gaskell** and **Herbert Gottweis**, or they could fail.

In the late 1990s, the company deCODE Genetics in Reykjavik sought to pool medical and genealogical records with genetic data for the entire Icelandic population — with the intention of marketing the database to scientists. The project quickly came under fire as critics found holes in the company's plans for encrypting data, and in the rules that would govern access, patient consent and data ownership. The firm eventually moved ahead, but filed for bankruptcy in 2009.

All sorts of stumbling blocks — not least the global financial crisis — contributed to the company's demise. A key factor was that by 2003, some 20,000 Icelanders, many of whom had concerns about privacy, had opted out of the database¹.

Biobanks — collections of blood or

tissue samples, often combined with medical, genealogical and lifestyle information — are a powerful tool in the study of complex diseases. In general, tens of thousands of samples are needed to detect associations between genetic factors and a particular disease, so their effectiveness depends on enrolling enough people². Also, biobanks need donors who are prepared to give broad consent to have their samples used in a wide variety of research, because it would be hugely costly and technically onerous to draw up 'narrow' consent forms for each research project.

It is alarming then that two-thirds of Europeans recently surveyed have never heard of biobanks. This was a finding of our research based on the 2010 Eurobarometer on biotechnology³, which canvassed 15,600 people from 32 countries on the issue, and on

focus groups conducted in seven countries⁴.

Our data provide strong evidence that people are more likely to embrace the idea of biobank research if they are aware of the existence and purposes of the resources. We find that fewer than 2% have actively sought information about biobanks or have discussed them with others frequently. Crucially, only 10% of those who have never heard of biobanks say they would definitely participate, compared with 28% of those who have taken an active interest. And the 'actively interested' are more likely to endorse broad consent — 33% compared with 20% of those unaware of biobanks.

Europe has been at the forefront of the biobank movement. The Biobanking and Biomolecular Resources Research Infrastructure (BBMRI), for instance, launched

EUROPE'S BIOBANKS

The Biobanking and Biomolecular Resources Research Infrastructure includes in excess of 280 organizations (mainly biobanks) in more than 30 countries.



in 2007 to enhance cooperation, now involves 270 organizations from 33 countries. The expansion of biobanks in Europe (see 'Europe's biobanks') and elsewhere will deliver little, however, unless potential donors know enough to trust the organizations and the researchers who use them.

TRUST AND CONSENT

The results of our survey suggest that attitudes vary widely across Europe. Some of these differences offer clues as to how public acceptance could be improved.

In northern Europe, people are relatively well informed (80% have heard of biobanks in Iceland for instance, 75% in Sweden and 65% in Norway)³. People in these countries are also more willing to be donors and to give broad consent (see 'National attitudes'). These positive attitudes correspond to strong trust in government, good welfare systems and long traditions of biological samples in these countries. Finland, for example, began research dedicated to establishing national health risk factors in the 1950s⁴. DNA samples have been collected since the 1980s in various projects — such as the Helsinki Sudden Death Study, launched to study the lifestyle and genetic factors predisposing certain Finnish men to this condition.

France, Germany and the United Kingdom form another cluster. Here, people have less trust in the government, moderate awareness of biobanks, show moderate willingness to participate and prefer narrow consent agreements. One participant in a UK focus group summed up a common concern when he asked, "Do I trust what you're going to do with these samples?". People from these countries also think that biobanks should offer benefits to donors: information about cholesterol levels and other health risks, for example.

Austria and Greece form a third cluster, characterized by the lowest levels of willingness to participate: only 5% of Austrians and 4% of Greeks say they would 'definitely

contribute samples. These people are the most concerned about privacy and about what their genetic data might be used for. Greece also had the highest number of people selecting 'narrow consent'.

In our focus groups, Greek participants explained that they don't trust their country's political system and therefore worry that the data would fall into the wrong hands — the police, insurance companies and the government. In Austria, caution about biobanks might reflect a lack of enthusiasm for technologies in general and for genetic technologies in particular³.

So how might public perception be improved? Counter-intuitively, one way to generate interest in and knowledge about biobanks seems to be controversy. Today, the best informed and most enthusiastic public in Europe is in Iceland, which surely has something to do with the deCODE Genetics furore. Similarly, Estonians are relatively positive about biobank research. This is despite heated debates over the public-private partnership proposed to underpin the Estonian Genome Project, leading to the biobank's near collapse in 2003.

SHAPING ATTITUDES

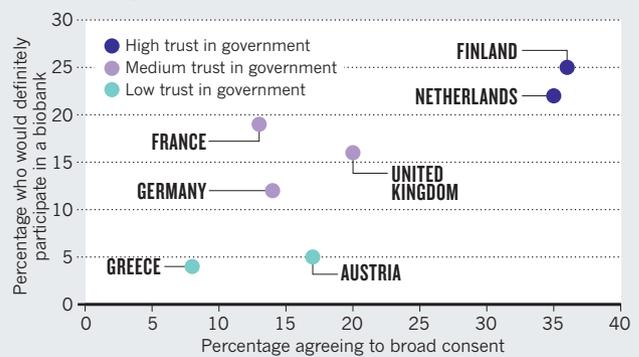
So, biobank organizers should not resist engaging in public discussion for fear that it may be critical. Controversies don't seem to lead people to reject the idea of biobank research per se. Instead they facilitate the spread of information, and improve understanding and sharing of views on what is appropriate and acceptable use of samples.

Researchers have little influence over patterns of trust in government, but they can shape attitudes to a particular biotechnology. They can, for instance: adopt clear regulations and guidelines for research; make goals and funding priorities transparent; and listen to the public and respond to its concerns. Such issues are common to much genomics research⁶.

Online communication tools such as

NATIONAL ATTITUDES

The number of people who would be prepared to participate in biobank research varies greatly by country, owing in part to the trust the citizens place in their government.



Facebook should be harnessed to reach doctors, teachers, journalists and minority-group representatives. Efforts could be made to encourage existing donors to spread the message through their social networks.

Science communication must go beyond the simple dissemination of basic information. What is needed is a dialogue with the public, to explain the purposes of biobanks and how they operate, and to give people an opportunity to voice their concerns and conditions for their support and participation. The involvement of the public in forums representing patients' perspectives in the BBMRI project, or in online public consultations and public meetings as planned for the pre-recruitment phase of a Tasmanian biobank in Australia, offer promising models. Such activities need funding, but the cost is trivial compared with the many millions of dollars needed to establish and maintain a biobank.

We will only see the benefits of the estimated US\$1 billion already spent on establishing biobanks worldwide if the general public is actively brought into the picture. ■

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