

GENETIC DATABASES AND PUBLIC ATTITUDES: A COMPARISON OF ICELAND, ESTONIA AND THE UK

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Abstract. The paper discusses the public perceptions of population based genetic databases in the three countries where these plans have been most fully developed – UK, Iceland and Estonia. Drawing on various qualitative and quantitative studies, the article discusses how differences in the context of introducing the idea, in terms of previous experience with gene technology and general attitudes towards science and technology sphere, have influenced the nature and volume of concerns in respect to gene banks among the general public, as well as the very design of the projects. It is suggested that in all three cases, the most significant aspect of the public's attitude to genetic databases – and a crucial factor in the eventual success or failure of the projects – will rest on a perception of the trustworthiness of the professionals and institutions involved in setting up and operating the databases.

Keywords: public attitudes towards science and technology, genetic research, genetic databases, Icelandic Health Sector Database, Estonian Genome Project, UK Biobank

1. Introduction

This paper reports the initial findings, from three countries, of a comparative study of public attitudes to, and perceptions of population based genetic databases in those countries. Database projects are now being planned and set up in many countries throughout the world. These databases vary to the extent that they combine genetic information with medical information of large populations and, in some cases, genealogical records. The researchers from three countries currently involved in such projects – Iceland, Estonia and the United Kingdom – are partners in an EC funded research project to investigate the Ethical, Legal and Social Aspects of Genetic Databases (ELSAGEN). It is widely recognised that a key challenge posed by the operation of population based databases containing genetic information is to find ways of protecting the interests and concerns of individuals, whilst at the same time creating opportunities for more information to

be made available to medical research. In this sense genetic information emerges as a key political issue, in discussions about its ethical, legal and social aspects, because it straddles the boundary between the individual concerns of the donor, or patient, and the wider social concerns of citizens. One of the research aims of the ELSAGEN project is to provide more information and a better understanding of these concerns.

In presenting our findings concerning public attitudes in the three countries, where database projects are prepared or already being implemented, we begin by comparing the very different political, economic and social context in which they are being set up and by considering what factors, in the presentation of these projects to the nation's public, might have affected their reception. We have also taken account of all the information available to us relating to people's general attitude to science and technology in each country. This article then begins to draw links between the particular social contexts of introducing the projects and the actual working principles of the data banks, with respect to the involvement of the public as donors and as beneficiaries. This, to some extent, could be seen as our baseline but in order to address the research aims referred to above we also drew on more detailed studies about public attitudes to genetic information, and we undertook our own empirical investigations based on surveys and focus groups.

The following comparative review discusses the public views on the nature of participation (voluntary or presumed), as well as the anonymity of data gathered (issues associated with privacy and the possibility for feedback). We also bring together comparative research that allows us to draw conclusions about how to interpret those results that refer to general levels of public trust in the ability of scientists and institutions to regulate the operation of the database projects.

2. Comparing the context

The database projects will be described in detail in section 3 but we begin by comparing and contrasting the national contexts in more general terms and by examining existing evidence relating to general attitudes to science and technology in each case.

Iceland is a small country with a very small population (280,000 people) even compared with Estonia (1,370,000), but Icelanders are proud to be seen as a rapidly developing technologically motivated society with exceptionally high levels of literacy and per capita income. Surveys have revealed that a relatively high proportion of the Icelandic people (84%) think that more emphasis on the development of technology would be good (Halman 2001). On the other hand, the UK public (a culturally diverse population in excess of 58,000,000) has a complex and chequered relationship with science, and with the technological development that has marked its progress into the twenty-first century. Repeated surveys and other evidence reveal a well-entrenched feeling of scepticism in the British public towards government regulation and scientific advice. For instance, a recent government report by the House of Lords (2000) refers to a public lack of con-

confidence in science associated with industries such as biotechnology and information technology and to areas where scientific research is not being directed towards a perceived public benefit. The report concluded that: 'science's relationship with UK society is under strain' (House of Lords 2000:13) and suggested that this response could be a backlash to situations arising from recent publicly debated crises such as BSE and, latterly, to the controversy about the introduction of GM foods into UK markets. It should be noted that these surveys have revealed that medical applications of biotechnology have been more positively perceived than agricultural applications (GMOs). However, further reflection suggests that this is not entirely because of the expectation of personal benefits. Compared with other areas of scientific research and development, the social and legal regulation of medical research and the nature of risk assessment procedures in this area were felt to be more trustworthy. This is an important insight for our comparative review that we will return to later.

As a member of the European Union the UK has been subject of many large-scale comparative surveys by 'Eurobarometer', in particular on public attitudes to biotechnology (in 1991, 1993, 1996, 1999, and 2002). The surveys (which require careful interpretation) reveal that, compared with their European counterparts, the British people are not technophobic although they do hold a generally suspicious attitude to some aspects of the regulation of science. Estonia has recently also come under scrutiny by the Eurobarometer – as a candidate to become a new member of the European Community (May 2004). In a recent Eurobarometer survey of public attitudes to science and technology it was found that the Estonian population hold attitudes towards science and technology similar to those of Eastern Europeans, with higher levels of optimism in this field than people in Western Europe (Candidate Countries Eurobarometer 2002). According to the survey, only 20% of Estonians consider themselves well informed about science. However, the same survey implies that the Estonians were more knowledgeable than most of their Eastern European counterparts and so it is important to note that this might not reflect the actual lack of scientific knowledge. Rather, this could reflect a greater esteem within Estonia for science and a greater respect towards "hard" scientists. We return to this when we assess the results of the current survey – which shows that for a majority, the perceived benefits provided by new scientific knowledge are valued higher than the perceived risks.

Iceland was the first of the three countries to announce a project to set up a population based medical database when, in April 1998, the company deCode genetics announced that it was going to construct a national medical database – the Health Sector Database (HSD) – by amalgamating a unique combination of DNA data (from blood samples), medical records and a genealogical database. In December 1998 the Icelandic Parliament passed a bill authorizing the construction of the National Health Sector Database. The objective of the Act was to "authorise the creation and operation of a centralised database of non-personally identifiable health data with the aim of increasing knowledge in order to improve health and health services" (Act on a Health Sector Database no. 139/1998).

During this period there was a very high level of media attention by the national and international press. Opinion polls showed that the majority of the public supported the HSD. In 1998 Gallup poll (Meirihluti 1998) concluded that 58% of Icelanders supported the database, 19% were opposed and 22% were neither for nor against. In 2000 a Gallup poll concluded that the overwhelming majority of the public was supporting the database, 81% supporting – while only 9% were opposed and 10% neither for nor against (Rúmt 2000). The planned database has been a subject for debate and discussion from the outset. Some of the discussions focused on the exclusive licensing agreement with a multi-national company – authorized by the Icelandic Parliament. In Iceland therefore, discussion about genetic research has mostly been in connection with the Health Sector Database and the form of the Act. A large number of articles have been written about HSD and its ratification by Parliament, both by Icelandic specialists as well as people from other countries. The main focus is often the issues of individual consent and privacy. However, this debate is affected by previous larger issues of privacy, e.g. Iceland's participation and entrance in *Shengen*¹, possible establishment of a biobank for the police, and surveillance in public area as well as in the workplace.

Soon afterwards, in June 1999, the UK Medical Research Council, the Wellcome Trust and the Department of Health also proposed a UK-wide population based biobank (also combining DNA data with medical records and lifestyle information – but not genealogical records), for medical research purposes. Prior to the launching of the project, and with the express purpose of informing the operation of the database, a major public consultation was undertaken (during 2000–2001) by the Government's strategic advisory body, the Human Genetics Commission (HGC) on the future uses of personal genetic information. As part of this consultation they commissioned a quantitative survey of public attitudes to human genetic information (HGC 2001). At the same time a government inquiry, by the House of Lords, (2000) was set up to examine actual and potential uses of both existing and future human genetic databases, in order to investigate the most important issues relating to their storage, protection and use. The UK Biobank partners (the Medical Research Council and Wellcome Trust) also began their own process of consultation in 2000. To this end, they carried out a programme of qualitative research to inform their guidelines and principles (the protocol) governing use and collection of data – (WT/MRC 2000). During the period of this consultation process, there was very little media attention – unlike the Icelandic project – and the surveys suggest that awareness of the planned database was extremely limited, even amongst health professionals. The main issues of concern arising from the consultation process will be discussed in greater detail later but they could be divided into two categories: first of all issues about ownership and social control of the data and then concerns relating to the individual. Many people

¹ The purpose of the Act is to promote that personal data are processed in conformity with the fundamental principles and rules governing protection of such data and the right to privacy, to ensure reliability and quality of such data and the free flow of personal data in the internal market of the European Economic Area.

were very concerned about what they saw as a need to establish public ownership of the resource. They also wanted to be sure that its research uses would be regulated by an independent body. Other concerns related to security and anonymity of the data and the possibility of police access to information and to genetic discrimination by insurance companies and employers if they were given access.

At the same time, also in 1999, the Estonian Human Genome Project (EGP) was being launched in very different circumstances. In the Estonian society, the launching of the gene bank can be viewed as really the first “gene issue”, as Estonian public to a large extent “missed out” on the previous topics that were heatedly discussed in other countries, e.g. genetically modified crops or animal cloning.² Also personal experience of the various applications of gene technology among lay persons is rather low and application of human genetic research, e.g. prenatal genetic testing is yet not widespread. At that time there had been very little public consultation or research into public attitudes towards genetics or genetics-based research and no general awareness of the existence of various DNA sample banks, although a few already exist. At an individual level the practice of asking for informed consent for various medical researches has been introduced only quite recently.³ In spite of this, as we have already mentioned, it was felt that genetic scientists enjoyed a high status in the Estonian society and at international level, due to the recognition of their scientific achievements. At least on the political level, the idea of a population-based gene bank was received with high level of enthusiasm, and the initiator of the project, Andres Metspalu, was named the “Person of the Year” by an influential journal in 1999.

3. Comparing the different features of the database projects

The planned Icelandic Health Sector Database is part of a larger Icelandic Biogenetic Project that contains three databases (Figure 1).

First there is the Health Sector Database, which contains health data from medical records. Then there is a database that contains genetic information, and thirdly there is a database with genealogical information. Each of these three databases is subject to different legal provisions. The Health Sector Database itself is subject to Health Sector Database Act, No. 139/1998. The genetic database is covered by the Act on Biobanks and the Patients Rights Act, the Data Protection Act and other legislation, and the Data Protection Act covers the genealogy database (Hreinsson 2002).

² The first debate over allowing the import of genetically modified fodder appeared in the press in summer 2003.

³ Only recently, it was public news that the medical researchers are very much annoyed about the new data protection law that orders them to ask for consent from every patient whose medical history (e.g. from the cancer hospital) they use for research.

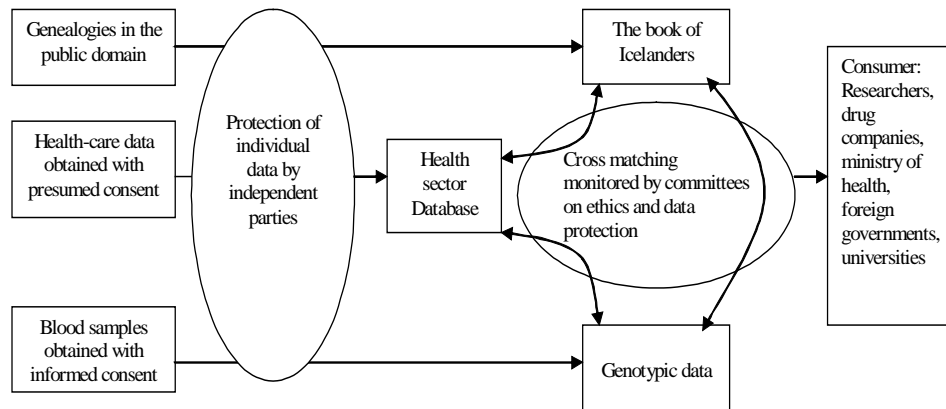


Fig. 1. The Icelandic Biogenetic Project (Pálsson, Harðardóttir 2002)

The 'UK Biobank', as it is known⁴, will eventually contain genetic information from DNA samples, medical records and lifestyle information of 500,000 volunteers aged between 45–69. The project to create a national resource for medical research has been promoted by the funders⁵ as a vital resource for the study of common diseases like heart disease, cancer and diabetes, which will affect people later in life. The data contained in the collection will arise from a number of sources yet to be collected from – blood samples and purpose-specific questionnaires; the existing and future medical records. UK Biobank has been claimed, by the organisers, as the world's largest study of the role of nature and nurture in health and disease. No specific legislation, or Acts of Parliament have been asked for but it has been made clear that the data arising from the collection of samples, from medical records and from other 'lifestyle' information, will be 'anonymised'⁶ and treated in accordance with the provisions of the Data Protection Act (1998). Current arrangements are for regional centres across the UK to recruit volunteers (each to be asked for their informed consent) and to collect samples and information for storage in a central bank. The co-ordinated centre will be set up as a non-profit making body 'UK Biobank Ltd' as the legal custodian of the data and samples.

The declared objectives of the Estonian Genome Project (EGP) are "to establish a database of health and genetic data of the Estonian people that enables more exact and efficient diagnoses of illnesses, improvement of treatment and determination of

⁴ In 2002 UK Biobank was given the necessary initial funding (45M pounds) to go ahead by a consortium comprising: Wellcome Trust, the Medical Research Council and the Department of Health.

⁵ The Wellcome Trust biomedical research charity, the Medical Research Council (MRC) and the Department of Health (DoH).

⁶ Samples will have the personal identifiers removed for all research purposes, but the anonymisation process will be reversible in order to maintain links with the donor's ongoing medical history.

risks of the development of an illness in the future.”⁷ The gene bank is to be used only for scientific research, research into and treatment of illnesses of gene donors, public health research and statistical purposes. In December 2000, after only a short discussion, the Human Genes Research Act was approved by the Parliament that delineates the main provisions for the projects. The database consists of phenotype (health data) and genotype (blood samples) information of all the Estonian inhabitants. The actual collection of data is carried out by a family doctor, who is paid “per head”. In contrast to the Icelandic database, it is based on voluntary participation and requires an informed (though open) consent of the donor. The confidentiality of gene donor regarding health data and genetic data is achieved through a complicated coding system. The “Gene Act” outlaws any discrimination on the basis of genetic information. However, the gene donors are granted the right to receive personalised information about their genetic data.

Ownership of the Estonian Genome Project is complicated. EGP was initially introduced as a private initiative and founded by the non-profit making Estonian Genome Foundation in January 1999. Soon however, support by the state was gained and in 2001 the Estonian Genome Project Foundation was founded by the government. Since then the situation has become even more complex with the introduction of a public limited company E-Geen (owned by individuals) and a US based venture capital company E-Geen International Corporation. These companies are responsible for the financing and investments of the EGP. However, the state-established foundation is the official owner of the gene bank, i.e. the DNA-samples, while E-Geen has the exclusive commercial rights over the selling of genetic information to different research and commercial institutions. The Estonian scientists (and their international partners) do not have to pay for doing research on the database; however, the patents resulting from that research will remain in the ownership of the Project. The pilot project was launched in three counties in autumn 2002 with the aim of gathering 10,000 samples. By late 2003, around 5000 samples had been collected in the framework of the pilot project, which is complemented by almost the same number of samples gathered from other counties within the few month of the running of the real project, enjoying a steady, though a lower than expected increase.

4. Our research. Comparing different methods and outlining interpretive approach

In designing our approach to this comparative research several aspects were taken into account. As we point out, one of the main objectives of the ELSAGEN project, to which this empirical work contributes, has been to increase knowledge about the social aspects of genetic databases. A number of issues have been raised for further consideration: amongst the key concerns has been the need for more information about people’s attitudes to the trustworthiness of public and private

⁷ For more information, see <http://www.geenivaramu.ee/>

professional groups and institutions that may have a practical or regulatory role in the forthcoming database projects. Another concern has been about the need to understand more about people's perceptions concerning privacy, and about whether and how standards might vary in different circumstances and between different countries.

As is already evident, the contexts within each country vary enormously both in terms of cultural and economic foundations and in the set-up of the database projects. We came together to collect and share knowledge and to compare our findings but we had access to very different resources and background information. For instance, in the UK – against a background of several high-profile public debates about biotechnology issues such as animal cloning and GM food – there had already been several thorough studies into public attitudes towards genetic research including those already referred to. As a member of the European Community the UK public has also been the subject of a series of comparative surveys – unlike Iceland and (until very recently) Estonia.

The survey methods used to study public attitudes to science and genetics can be divided very broadly into quantitative survey studies and qualitative methods such as in-depth interviews and facilitated group discussions such as focus groups. It is important to realise, in interpreting the results, that each method produces a different kind of data. Quantitative studies, of the kind produced for Eurobarometer, offer important and useful information that can be used to present a picture of public opinion at a particular point in time or, as they will be in this case, to compare attitudes to similar situations in different countries. Samples are generally large and designed to produce a statistical representation of the population being studied. However, because they rely on preset 'closed' questions, unlike qualitative studies, they are not well suited to explore more complex and contingent perceptions about issues such as people's perceptions of privacy and their attitudes to the trustworthiness of the institutions involved in regulating genetic databases.

Our awareness of these issues, allied with a concern to use the available resources to best advantage, dictated our individual approach to gathering empirical evidence and subsequently influenced our interpretation of the results. With these factors in mind we undertook the following investigations in each of the three countries.

4.1. Iceland

In Iceland a nationally representative quantitative survey was carried out in November and December 2002. The sample consisted of 1500 randomly chosen Icelandic citizens from the entire country, aged 18 to 75 years who were interviewed by telephone. The reasons for choosing to conduct a telephone survey were as follows. It was felt that postal surveys would not give sufficient response rate in Iceland (where the response rate is frequently much less than 50% of the sample). Face-to-face surveys on the other hand, although reliable, would have been too expensive and not necessary while telephone survey still gives an acceptable response and a good picture of the nation.

The response rate was 68% (male 49.9%, female 50.1%) and the distribution of sample gave a good picture of the Icelandic nation.

4.2. UK

Unlike the other ELSAGEN partners, the UK researchers made extensive use of the existing quantitative and qualitative data (described above) for the initial comparison reported here. The results of a detailed survey⁸ commissioned by the UK government's human genetics advisory group (the Human Genetics Commission) were used for the survey comparisons. In addition to this the UK team undertook an additional investigation. Their aim was to use a more qualitative approach, based on focus groups to explore public perceptions of privacy in relation to genetic databases and to understand better the reasons why people felt able to place their trust in some professional groups rather than others. To this end they conducted six focus groups in various locations throughout the UK. Each group consisted of 6–8 participants with a wide range of ages. In five of the groups the socio-economic characteristics were selected for variation, but in order to address a bias towards white participants, a further group of non-white participants was recruited for a sixth discussion. These focus group discussions were tape-recorded, transcribed and then analysed systematically to inform the qualitative aspects of privacy and trust mentioned above.

4.3. Estonia

In Estonia, similarly to Iceland, no previous research existed on the public attitudes towards gene technology, or towards scientific research in general. While preparing the questionnaire, the aim was to achieve as much international comparability as possible, as well as have a deeper insight into the public opinion on the Estonian Genome Project. Yet another aim seemed necessary – within the limited space available, also gain some knowledge about the general attitude of the public towards the development of science and technology. As the “gene debate” in Estonia has been focused foremost at different aspects of the Genome Project, also the questions targeting the fears and hopes in relation to gene research and gene technology were framed with reference to the gene data bank. However, as in Estonia by the time of the survey, several contentious issues, in regards to the ownership, profit sharing and access to data were already established by often complicated arrangements outlined above, these topics were not included. A nationally representative survey was carried out in a form of face-to-face interviews with 914 respondents aged 18–74 at the end of 2002.

Though there are considerable differences in both research designs and the objects of study due to differences in the context, on a more abstract level, the comparison of the three studies allows some generalisations. First, the research allows comparison between peoples' **general attitudes** towards science and

⁸ 1,038 survey interviews with a sample of the public – weighed to the profile of all adults in the UK and supplemented with 221 supplementary interviews with Black and Asian respondents.

technology, as well as the fears and hopes related to genetic research. We can also draw conclusions about how differences in the context of introducing the idea have influenced **the nature and volume of concerns** in respect to biobanks among the general public, as well as the very **designs of the databanks**. Thirdly, one of the main focuses of the current article will be people's **trust** towards persons and institutions involved in the creation and maintenance of the gene banks.

5. The empirical evidence

5.1. Evidence of general attitudes to genetics

As for the general prospects of genetic research in medicine, at the present day, the populations in all three countries are characterised by exceptionally high expectations. According to the surveys, more than 90% of the Estonian and Icelandic population agree that gene research will provide better cures for many diseases and this optimism is shared by the UK population, though on a bit lower level of confidence (Figure 2).

Though the expectations concerning the new developments of genetic research are high in all three countries, the opinions diverge considerably with respect to what the new applications of gene research could be used for. For example, there is indeed overwhelming support for the use of genetic tests for diagnosing diseases both in the UK and Estonia (96% and 88% respectively). However, while in the UK, people are much less willing for this information to be used by parents in deciding whether children with certain disabling conditions should be born, in Estonia also this kind of application holds wide-scale support (Figure 3).

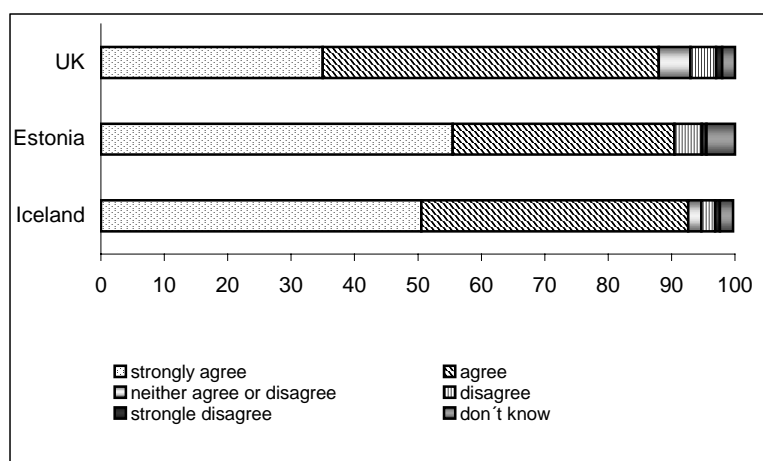


Fig. 2. Do you agree or disagree to the statement that the development of biotechnology means that many illnesses can be cured?

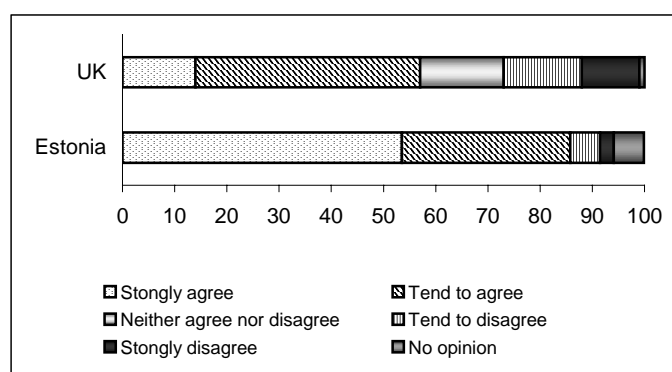


Fig. 3. Do you agree or disagree to the statement that genetic information may be used by parents to decide if children with certain disabling conditions are born?

The rather radical approach of the Estonians in these matters is further characterised by the fact that two thirds of the respondents also agree that parents with high probability of having a disabled child should be discouraged from having children at all. In this respect, Icelandic people show a considerably higher level of caution for the new applications: 94% of the respondents are in favour of prenatal testing for serious medical conditions, however, the majority would allow it only when there are clear reasons to suspect such a condition.

At the same time, the idea of using genetic information in areas other than medical research is less well accepted in all three countries. For example, the majority of the UK public feels that it would be inappropriate for the results of genetic tests to be used by insurance companies for defining their premiums or by employers to judge the suitability of present or future employees. It should be noted however, that the majority would be willing to use those tests for employees' own safety at work. Similarly, the use of such information in order to decide whether to give a health insurance is considered inappropriate by three quarters of Icelanders, while an even larger part of the population (83%) are against the use of genetic tests by employers, to decide whether a person is qualified for a job. There are no directly comparable data from Estonia. However, according to the survey, these are perceived as the most probable negative consequences of the growing use of genetic information in their society, much more probable than e.g. harmful effects on personal or social relations. Nevertheless, such concerns are seen as a problem by less than half of the respondents, while the majority declares no worries.

5.2. Support for, and concerns about, the gene bank projects

In the attitudes towards proposed population-wide genetic banks, the UK population is once again characterised by a higher level of caution. Though surveys suggest general popular support for the database, many people also

articulate concerns. Qualitative research⁹ has revealed that the anxieties focus around two main areas – that employers and insurance companies may have access to the data and that the collected data will be used for commercial purposes which, in turn, may lead to patenting and exploitation.

In Iceland, the popularity of the database appears to be high. Around three quarters of the population have expressed their support for the Health Sector Database, while 15% do not like the idea. A similar proportion of people consider that a contribution from everyone is necessary to make progress in biotechnology. Although a large majority strongly oppose the use of genetic data in insurance or employment relations, this is not perceived as an acute problem at the moment. It is significant that only 25% of the respondents report their concern over diminishing privacy.

In Estonia, the idea of the gene bank has gained remarkably strong public support, especially for its medical goals. A large majority (over 80% of the respondents) consider that the project will contribute both to the general improvement of medicine and pharmaceutical research as well as to the development of Estonian health care system. The majority also believe in the positive impact of the project on Estonia's economic development and the country's reputation in international community. All of these aspects have been emphasised in the public presentation of the project by its initiators.

One more aspect of the EGP is of great importance – 86% of the respondents also consider important the possible personal benefits of the participants from the project, i.e. the possibility to receive an individual gene card displaying a person's health risks. Indeed, among the people planning to take part in the project, the vast majority intend to apply also for it. However, though the majority of the respondents seem to be agreeing to the positive impact of the EGP, the most often mentioned fear related to the EGP is the possibility of psychological stress caused by the knowledge of one's health risks (considered probable by almost 80% of the respondents). More than half of the respondents express greater or lesser concern over the possible leakage and abuse of data by insurance companies or employers, and the use of data for unethical research.

Overall, the surveys suggest that the public's attitude towards planned gene banks in the three countries is to some extent influenced by their attitude towards genetic research in the respective countries. Though generally supported among those who have heard about it, in UK the idea of launching a gene data bank is treated with the same level of caution as all the other widely debated areas of genetic research. In Iceland and Estonia, the idea has been received with a greater level of public enthusiasm. However, at least in the case of Estonia, though with great expectations on both the wider social and on a personal level, ongoing discussions about the effects the EGP can have in future have made the population also more conscious of the sensitive issues in respect to genetic research.

⁹ In this case the evidence about concerns arose from qualitative studies: i.e. a study of about 60 people in the age group 45–69 (the age of the people to be recruited for UK Biobank), and also from 16 focus groups commissioned by Wellcome Trust and the Medical Research Council.

Furthermore, a major motivation for participation in the Estonian Genome Project seems still to be provided by the prospect for receiving a personal gene card. Data from UK research also suggests that many people in the UK would like to receive personal feedback if anything significant emerged. There is no comparable evidence about personal feedback from Iceland but, according to the survey, the majority support the general statement that contributions are necessary from everyone for progress to be made in biotechnology.

5.3. Attitudes to the issues about social control of the databases

Though previously displayed data showed that the idea of the creation of the gene data bank has been generally accepted with varying levels of support, in all three countries, public perception of some specific aspects in relation to the data banks are worth further exploration. For instance, trust is a big issue and it is believed that the final success of the project involving such delicate personal information, will be strongly influenced by the trust people have in professionals and institutions who are either directly involved in the project or will have access to the data – especially in the case of Estonia and Iceland, where it is anticipated that the whole population will be involved. Also, people's decision whether to participate or not (or, as in the Icelandic case, to opt out or not) can be affected by their satisfaction or dissatisfaction with the actual conditions of involvement.

5.3.1 Trust in the adequacy and use of information

As is evident from Figure 4, genetic scientists are considered the most trustworthy as a source of information on the workings of the gene banks by both the Estonian and Icelandic public. In the Estonian case, even more remarkably, is the high level of trust the public vested in the employees of the Estonian Genome Project (trusted by 80% of the respondents), which is higher than that of the Ethics Committee supervising the activities of the Project. People's trust towards the persons connected to the project outweighs also trust towards e.g. family doctors (70%) – the actual contact persons of the potential gene donors – and other scientists (little over 60%).

Also in Iceland, trust towards authorised scrutinising bodies – in this case, the Minister of Health, is considerably lower. An especially low level of confidence in both countries, however, characterises public attitude towards journalists (20%), although mass media constitute the actual main sources of information on the project. This could be a reflection of the presented image of the projects as being primarily a scientific undertaking and one in which scientific expertise is crucial.

However, the picture changes considerably if people are asked who they trust to **use** the information held on medical databases responsibly. Both in UK and Iceland, in this respect, the highest level of trust is vested in the family doctors (87% and 81%), followed by other health professionals (74% and 80.5%). This support, however, can be sensitive to other factors – qualitative research commissioned by

¹⁰ In the case of the Estonian survey, the answers: 'trust totally' and 'rather trust' are combined.

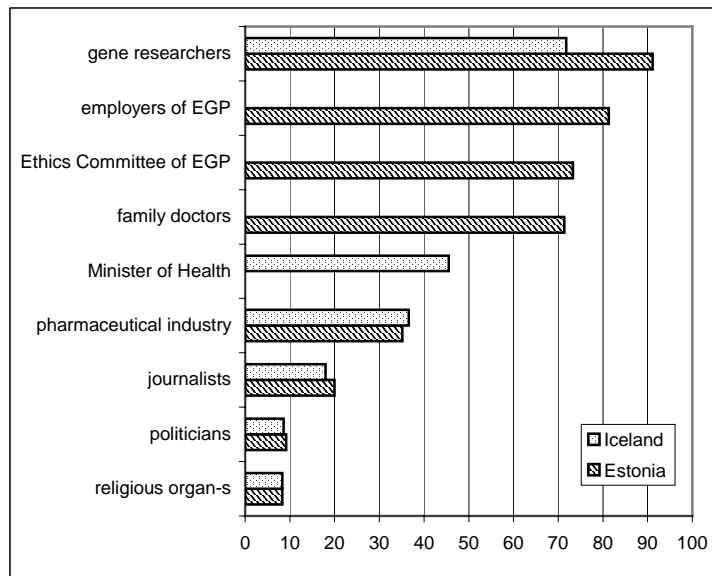


Fig. 4. Do you trust the following people's and institutions' statements about the gene bank?¹¹

the Wellcome Trust and MRC contained evidence of recent erosion of trust, within the UK in medical practitioners after a series of health-related scandals. It is interesting that, in UK, the academic scientists have a very low record (38%) of trust and many more respondents would rather trust the Police (59%) or a Government Scientific Advisory Committee (39%). In Iceland, the scientists have a better reputation in this realm (60%), followed by Police (38%) and pharmaceutical companies (32%). Insurance companies (7% and 14%) and employers (8%) naturally are mistrusted by the large majority.

5.3.2. Ownership and access to genetic databases

Other crucial issues relating to control of the databases are those of ownership and access. There is evidence from UK that over half of the population would firmly prefer such types of genetic databases to be publicly owned, and that only a small fraction (8%) would accept commercial ownership. In Estonia, the questions of ownership of the gathered genetic material, as well as access to the database are regulated by a special law (Human Genome Research Act), which rules out any possibility of access to the database by employers, insurance companies and Police. Thus, special no-questions were posed to the respondents. The overwhelmingly supportive attitude towards the project suggests general satisfaction with the established principles and confidence in the institutions directly involved

¹¹ In the case of the Estonian survey, the answers: 'trust totally' and 'rather trust' are combined.

in the workings of the project. However, the survey revealed that three quarters of the respondents would actually permit the Police access to the genome bank during criminal investigations, which is strictly prohibited under the current legislation.

5.3.3 Concerns over personal involvement

In comparing public attitudes towards the mechanisms of personal involvement, it seems important to remember that this is one of the areas where the working principles of the three data banks differ the most. In UK, people's participation is of voluntary nature. However, having once agreed to participate, it is expected that people will be asked to give broad consent to the use of their information in all research studies (The UK Biobank Ethics and Governance Framework, published October 2003). The data will be 'anonymised' and the donors will not receive any feedback (except in very exceptional cases). Participation is also voluntary in the Estonian Genome project. In signing a consent form, people will accept that they will be approached again, and also that they will allow the gene bank to ask for supplementary health information from other sources, e.g. hospitals. They still have the opportunity to sign a special form, and their data will be inserted to the data bank anonymously. The most delicate aspect, however, in the Estonian case, is the decision by the initiators of the bank to provide the gene donors with feedback. In Iceland, the gene data bank is designed as anonymous, however, the participation is devised on the principle of "assumed consent", i.e. the data will be collected from all the persons who do not officially "opt out" from the project.

Despite differences in the actual design of individual participation, in all three countries, there exists dominant public agreement that genetic information of an individual can be kept in a database only if they have declared their consent. Furthermore, in all cases, there is majority support also for idea that fresh consent should be required before new research is conducted on their existing samples, which is a concern that appears not to be addressed by the major working principles of the gene data banks in all cases. In more specific aspects, the Estonian public seems to agree to the principles established in the law. According to the survey, more than half of the potential donors are willing to give the Foundation a free hand and allow them access to other health databases; only a quarter have decided to forbid it.

6. Discussion

As we have already pointed out, the contexts into which the idea of launching a human genome data bank was introduced in the three countries, varied considerably. The UK context stands out by its longer history of public debate about the different aspects of genetic research and relatively high level of public awareness of the possible risks involved with it, although medical applications of bio-

technology are thought to be more acceptable to people than agricultural uses. The sponsors of the UK Biobank were well aware of the need to address public concerns when they launched their consultation process. Since then the idea of a population based gene bank has been given qualified acceptance. Results of the consultation process – including surveys and qualitative research – suggest that the main criteria for the acceptance of the project will be that it is a public, non-commercial initiative, and that there should be independent monitoring and legal scrutiny over the workings of the project.

In both Iceland and Estonia the introduction of the idea of a gene bank corresponds well with the dominating image of the country being or becoming an example case of a small, effective, knowledge-based economy. Populations in both countries are characterised by a high level of optimism about new applications of technology. This has perhaps fuelled expectations of public benefits of the projects and led to agreement that this will demand a contribution from each member of society. However, in Iceland, either because of the more intensive debate surrounding the data bank, or due to previous experiences, the Icelandic people seem to have more awareness of the complex ethical challenges involved in such an initiative. In this respect, the Estonians, with a legacy of a different social experience, seem much less concerned with the possible moral or ethical limits to the use of new technologies.

We have also noted how differences in the design of the projects reflect, or perhaps respond to, these different public concerns. For instance, whilst in the UK and Iceland the gene banks are being very carefully designed to protect anonymity and to avoid the complex ethical issues associated with the use of personal information the EGP has made a radical decision to provide gene donors with feedback. From a short-term marketing perspective this seems to have been a smart strategy, the vast majority of the potential donors consider the possibility of acquiring a personal gene card a major personal benefit from the project and indeed intend to apply for it. However, at the moment, it lacks a feasible complementary strategy for counselling or treating the so-created “presymptomatic patients”.

In respect of public acceptance and motivation to participate in these projects, however, the ability of the initiators and developers of the project to create the feeling of trust and confidence in the potential donors play the crucial role. With the information we have we can compare people’s level of trust in two ways: at one level we gained insights into whether people trusted the general aims of the project; at another level we asked specifically about who people would trust to act responsibly in regulating the operation of the databases. Our analysis gives reason to suggest that the public trust depends both on the previous reputation of the involved institutions, as well as the concrete presentation of the project. Further qualitative research and analysis of UK evidence that rated trust in academic scientists low – and industrial scientists even lower – revealed some of the reasons why the gene scientists are mistrusted. The UK public place their confidence in professionals and institutions that are demonstrably independent of commercial and vested interests and concerned primarily with medical research for the public

benefit. In Estonia, however, where the gene scientists enjoy especially high level of reputation as the cornerstones of the Estonian path towards high-tech economy, their involvement is a major guarantor of the rightful aims of the project, and the question of public and private interests involved in the project have no greater relevance.

We have compared survey information about the public acceptance of these projects, but our evidence can say very little about why people would choose to become donors. However, we note that, in all three countries, the level of personal agency in managing the fate of the contributed DNA sample and health information seems an important factor. Here, people seem to be inclined to the established traditions in medical research, i.e. they remain firmly committed to the requirement of informed consent and to the need for renewed consent for each new research use. In the case of gene banks, which are designed as long-term multiple-use data sets, such strict limitations could be viewed as an obstacle. Nevertheless, people appear to be able to balance personal interests against the wider social benefit of medical research and to make concessions when they trust the operators to work towards those principles. This is evident from the Estonian case, where, though wanting to be informed of each case their data or sample are used, people are willing to give a free hand to the representatives of the gene bank to ask for further information from other medical institutions – actually a major source of possible breach of the privacy of data.

An interesting aspect that is unveiled in the course of the analysis, is the perceived relationship between people's perceptions of the wider public risks and benefits (the common good) and personal risks and benefits deriving from the project. In this respect, the Icelanders seem to stand out with their commitment to the general benefit of the project and the view that everybody has an obligation to contribute to the development of this science. This could be the reason why the initiators dared to design the project on the principle of assumed consent. Also in Estonia the Estonian Genome Project has played on a popular image of a national undertaking, thus appealing for people's moral obligation to maintain solidarity and to contribute to the common cause. For the majority, however, it appears that the possibility of being granted a personal gene card provides at least equally attractive reason for participation although there is some concern about the risks this may entail.

In conclusion, our findings at this stage suggest that the idea of launching population-based genetic data banks has gained qualified acceptance in all three cases, although the degree of caution varies according to circumstances. We have pointed out that these variations in the public's attitudes are reflected to some extent in the design of the projects – where only in the case of EGP the unprecedented decision has been made to provide the donors with personal feedback. People's main personal concerns relate not only to the need for adequate protection of their anonymity, but also to their desire for personal agency in maintaining some control over the fate of their donation. However, we have also noted an overall willingness to balance the perceived personal risks against a

wider social benefit – even in the UK where potential donors are more cautious about the risk of personal and wider social discrimination. Overall we suggest that the most significant aspect of the public’s attitude to genetic databases – and a crucial factor in the eventual success or failure of the projects – will rest on a perception of the trustworthiness of the professionals and institutions involved in setting up and operating the databases for the public good.

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