

Report for PRIVILEGED project

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***Privacy and Research involving Genetic Databases and Biobanks: Attitudes
across the New Member States Region***

**New Member States region covers: Bulgaria, Czech Republic, Estonia, Hungary,
Latvia, Lithuania and Poland.**

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1. Introduction

Any attempt to talk about New Member States (NMS) region as a whole must be cautious to the fact that the extent of its homogeneity remains an open question. On the one hand, there are opinions that „[c]ountries in transition in central, eastern and southeastern Europe have similar path of development and historical background“ (Borowečki *et al.* 2005: 227). On the other hand, it is claimed that “[t]he arguably common path that these [post-communist] countries started out on branched many different directions, partly because they all started from different bases. Today countries in transition are politically and economically [...] heterogeneous.” (McKee and Fister 2004: 1355). Therefore, any generalizations must be based on solid data and results of research conducted in one country cannot be automatically extrapolated to another one or to the whole region.

The heterogeneity of the situation makes the comparison of the countries even more problematic taking into account a very limited data on privacy issues related to research involving genetic databases and bio banks available. There have been only few large-scale surveys reported that cover most of these countries and that directly touch upon the relevant issues (Eurobarometer 2005, 2006). Additionally, there are some data available from several smaller surveys in particular countries and some sources that indirectly address genetic privacy issues. However, different researches differ both in scope and methods and this constitutes a major difficulty for any attempt of fruitful meta-analysis. Therefore in this report we will concentrate on description of concrete examples from different countries that will, we hope, help to provide a glimpse at more general tendencies within the region. To get a more comprehensive picture we would need to initiate new extensive public attitude studies.

Keeping in mind these difficulties we were able to single out three general trends specific to the region of interest: (1) the level of public debate concerning genetic privacy is low; (2) balance between societal and individual interests is shifted towards societal interests; and (3) dominating images of biotechnologies are optimistic. The following exposition will provide more content to back these assumptions.

2. Public perceptions of privacy interests related to research involving genetic databases and biobanks: Estonian and Latvian national genome projects

At the time of writing this report there have been only two countries in the region – namely, Estonia and Latvia – running large-scale population biobanking projects. The Estonian Genome Project was launched in September 2002 and was the first one of this kind in the region. The project aimed at establishing a database that would include genetic and health data of the majority of the country's population to be used for research purposes. In anticipation of the Project, Estonian Human Genes Research Act was passed in less than ten months and entered into force at the beginning of 2001 (for details, see Kruuv and Nõmper 2003). Similar project was initiated a bit later in Latvia as well and, accordingly, analogous piece of legislation – Human Genome Research Act – was passed in 2002 (for details, see Pīrāgs and Grēns 2003). The Act came into force in the beginning of 2004 and the Project was launched soon afterwards.

The analysis of the public attitudes towards these projects has revealed that public debate was not intense and most often did not touch privacy issues. For example, Külliki Korts reports that „[b]efore and during the launch of the EGP [Estonian Genome Project], there was a limited debate over the [privacy] issue, but it was a debate that never reached far beyond a limited scientific community” (Korts 2004 a, 189). A similar position is taken by Tiiu Hallap who claims that “overwhelming majority of pronouncements belong[ed] to biomedical professionals. Non-specialists have made almost no comment on the database issue” (Hallap 2004:221). In a media article Michael Gross provides an emotional summary: “Estonians appear to be blissfully unaware of the side-effects that the combination of medical and genetic information could have. [...] While the ethical dilemmas surrounding genetic screening have been debated at length in Britain and other European countries, Estonian's don't seem to be aware of these problems” (Gross 2000).

One of the reasons why privacy and other ethical issues were not at the centre of public discussions could be attributed to the fact that overall atmosphere surrounding the projects was very optimistic; only positive possible outcomes were brought into attention. Participation in the national Genome Projects was portrayed in Latvian and Estonian media as a contribution towards international fame, economic strength and national pride of the country. It would be instructive to provide several examples to illustrate this point.

Piia Tammpuu claims that during the first years of the Project Estonian journalists tended to uncritically follow rhetoric and assumptions by the proponents of the Project. Possible benefits were given more attention than possible risks. (Tammpuu 2004a, 2004b, 2007).

In order to find out Estonian public opinion towards the Estonian Genome Project a national survey was conducted in 2002 within the international research project ELSAGEN (Korts 2004a, 2004b, 2007, Korts *et al.* 2004). The survey showed that Estonians were really optimistic about benefits of genetic research in general and positive effects (medical, economic and related to international image of Estonia) of the national Genome Project in particular (over 80% of the respondents). Estonians were exceptionally optimistic about possible personal benefits of being a gene donor, including hopes of getting to know their health risks (86% consider them important) (Korts 2004a: 191), which could indeed be attributed to the misconception about therapeutic benefits of

the project mentioned above. In addition to this optimism, public is less concerned with the possible ethical problems related to the use of new technologies. Only a little bit more than half of the respondents “express greater or lesser concern over possible leakage and abuse of data by insurance companies or employers, and the use of data for unethical research” (Korts *et al.* 2004:142).

Some of the studies reported above also address issues of balance between social benefits and autonomy of the individuals (Putniņa 2003, Tammpuu 2004a, 2004b, 2007, Korts 2004b). In this respect Korts provides a useful summary: “In general, in the public eye, the possible social benefits created by genetic knowledge seem to triumph over the ethical dilemmas in respect to autonomy of the individual” (Korts 2004 b, 248). For example, ELSAGEN survey conducted in Estonia revealed that three quarters of the respondents would allow the Police to access the genetic data stored in the National Gene Bank for the purposes of criminal investigations. (Korts *et al.* 2004:144). The issue of balancing the interests of society and individual is further illustrated by Putniņa who indicates that public images of the Latvian Genome Project include de-colonization motive (establishing Latvians’ control over their genetic legacy, thus resisting historical legacy of colonization) and objectification of the Latvian nation (through research on a “Baltic gene” – an alleged socio-political inscription in genes, that distinguishes Latvians, Lithuanians, Estonians and Finns on the one hand, from Russians on the other hand) (Putniņa 2003: 236-238).

Another important feature related to too optimistic attitudes towards the Estonian genome project deals with the way the national genome study used to be presented to the potential gene donors in the official documents placed at that time on the project’s website. For example, during the initial stage of the project the Gene Donor consent form included some therapeutic promises that could not in principle be fulfilled by the national Genome project. Describing possible benefits, the information accompanying the gene-donor consent form from 2001 merely said that “The Gene Bank provides a gene donor with an opportunity to assess his or her health risks and diagnose illnesses more precisely, prevent falling ill and receive more effective treatment in the future” (Information about the Gene donor consent form, 2001). How distant this “future” might be, and how uncertain the process of finding effective treatment for genetic disorders still is, remained unexplained in the written information documents given to the patient (Gefenas 2004: 127-128). (It should be noted, however, that at the present the official documents of the project do not anymore contain the pieces of misleading information).

Even though genetic privacy issues were not at the centre of public debates over the projects, these issues were addressed in detail in legal documents that accompanied them. For example, the Estonian Human Genes Research Act explicitly states that besides establishment and maintenance of the database and its utilization for genetic research purposes, its other objectives are „to ensure the voluntary nature of gene donation and the confidentiality of the identity of gene donors, and to protect persons from misuse of genetic data and from discrimination based on interpretation of the structure of their DNA and the genetic risks arising therefrom“ (Art. 1.1). The measures of privacy protection include: classification of identity of a gene donor after coding; donor’s right

not to know their genetic data and the right to apply for the destruction of data that enables identification; prohibition of any use other than scientific, public health, and statistical research and research into and treatment of illnesses of gene donors (including access by the police, employers, and insurance companies). The Latvian Human Genome Research Act is somewhat more succinct than the Estonian counterpart but it also involves some additional measures of privacy protection. For example, a gene donor has the right “to restrict the scope of research performed on his or her genome” (Art. 11.1.4). In the 2003 amendment a new paragraph was added which stated that research on the deceased individual’s genome can be carried out only if the individual during his or her lifetime expressed such a will (Art. 3.6).¹

Similarly, predominantly positive attitudes towards the national genome project were reported in Latvia as well. Study involving interviews with Latvian scientists that were taking part in the Project, journalists and lay public showed that privacy of persons donating biological material was a comparably minor issue in public debate, the main topics being related to the development of science and biotechnology and the ideology of the nation-state (Putniņa 2003).

3. Privacy debate in related contexts: attitudes towards privacy issues in genetic testing (Eurobarometer studies) and health care

Scarcity of data on public attitudes towards privacy issues in research involving genetic databases and biobanks can be partly supplemented with data about public attitudes towards privacy issues in other related contexts. In this report we will shortly discuss two such contexts: genetic testing and health care.

One issue of the Eurobarometer – *Social Values, Science and Technology* – includes questions on the public attitudes towards use of genetic testing (Eurobarometer 2005). In general, it shows that the public in the New European States region is more positive towards the use of genetic testing for societal and healthcare purposes than the European average. Let us discuss the results in turn.

In all the countries presented in this report, the public was more favorable towards “developing for children of a genetic test that would identify their talents and weaknesses” than the European average (Eurobarometer 2005: 89-90). It is difficult to evaluate this result since the wording of the phrase is ambiguous. At least three different contextual interpretations of the phrase “genetic test” are possible: preimplantation

¹ Some additional data about legal approaches to genetic privacy can be derived from public consultation about a draft proposal for a Parliamentary Act on genetic data and biobanks that was initiated by the Hungarian Ministry of Health in 2004. Several Bills have failed during the legislative process (reasons include fear of opening the debate on pre-implantation genetic testing, uncertainty about biobank types, and the fact that some opponents saw it as a case of genetic exceptionalism) but the current version is expected to be adopted soon.

genetic tests, prenatal genetic tests, and genetic tests on children after they are born. The first two interpretations could imply that the results of the survey suggest possibility of favourable attitudes towards eugenic practices. However, a more convincing explanation would probably emphasize the lack of public awareness about possible implications of such a scenario in the context of strong optimistic attitudes towards science and biotechnology.

Developing for everybody a genetic test that would tell us about diseases we might get, even if we cannot do anything about them is also accepted more favorably by public in the NMS (Eurobarometer 2005: 89-90). Perhaps this result may be explained by the fact that the concept of right not to know is still relatively unknown to the public as well as by the lack of knowledge of possible psychological and social implications of such genetic testing techniques. Eurobarometer *Europeans and Biotechnology* – another public opinion survey that includes all the relevant NMS (except Bulgaria) – also shows that respondents in the NMS are more likely to take a genetic test for diseases than an average European (Eurobarometer 2006: 53-4).²

Both Eurobarometer studies addressed the issue of large-scale population genebanks, used for research on diseases. It is interesting to note the differences of the results of those two surveys. According to the Eurobarometer conducted in 2005 (Eurobarometer 2005: 89-90) respondents in all the countries except Hungary and Czech Republic were more favorable than European average towards “storing all the genetic data of our population in data banks in order to study the genetic causes of human diseases”. In case of Eurobarometer 2006 (Eurobarometer 2006: 53-4), when asked whether they would allow “banking of their genetic data for disease research” only Estonians found it more acceptable than European average. This difference can at least partly be explained by the wording: the 2006 survey phrase involves a clear reference to personal involvement of the respondent and therefore may be less attractive.

The last issue addressed in the Eurobarometer studies that could have some direct bearing on genetic privacy issues is positive attitude towards idea of storing everyone’s genetic data for the purposes of criminal investigation. Both studies have shown that people in the NMS (with Hungary as an exception) are even more positive towards this use of genetic information than the European average, which in itself is as high as 59 % (Eurobarometer 2005: 89). This may be interpreted as a community orientated approach that is probably rooted in lack of respect towards privacy. This approach is based on the idea that individual liberties may be sacrificed in order to benefit the society as a whole and finds relatively wide acceptance in the NMS. It could probably be claimed that the historical roots of such a tendency originate from the totalitarian past.

² Predictive genetic tests for curable diseases are accepted especially favorably. For example, a study conducted in Poland revealed that 96 % of women accepted performance of genetic testing to establish possible mutations causing breast cancer (Śluzar-Lewińska et al. 2007).

In general the term privacy is more common in the context of media ethics or in human rights discourse rather than in the context of health care. It could be noted that even the terminology of data protection is very rarely used in the context of medical or research ethics. It seems, however, that the values and principles implied by the “privacy” discourse are more often addressed in terms of confidentiality and informed consent, which appear to be more common concepts in the field of healthcare. The reason of such a terminological prevalence might be that confidentiality (which, roughly speaking means doctor’s commitment to preserve secrecy of patients’ personal information) is a traditional principle of medical ethics, the Latin word used in medical context for centuries. Therefore, public debates on confidentiality and informed consent could to some extent be regarded as an analogy to privacy discourse, because both confidentiality and informed consent could be seen as terms corresponding to the informational, decisional and bodily privacy to use the Allen’s terminology³. For example, public debate that was portrayed by the media concerning new draft of Patients Rights Act (2005) in Lithuania focused on the issues of “confidentiality” and “informed consent”.

We were provided with quite an illustrative example of the breach of patient’s right to confidentiality/right to privacy in Latvia:

On January 3rd, 2003 one of Latvian television channels featured a story about a woman who has refused blood transfusion. The broadcasted material contained information that this woman has a tumour and if the blood transfusion will not be performed, then the outcome can be lethal. The doctor did invite television reporters because she hoped that this would persuade her patient to agree to the blood transfusion. The patient was filmed in her hospital ward.

The official resolution of the Human rights office concludes that actions of the doctor were the breach of patient’s rights for privacy: “Since one’s presence in hospital ward means that one can count on certain amount of privacy and as far as one’s decision to accept or refuse medical care belongs to the sphere of privacy, to invite television to the hospital to influence this decision constitutes the breach of patient’s right for privacy. The breach of privacy *can also be established because of the breach of confidentiality principle.*”⁴

Another example concerning privacy related terminology could be extracted from public discussions about Latvian Genome project, where the term “privacy” itself was mentioned very rarely, if ever. Instead different phenomena that fall within the scope of the general notion of privacy were used: high confidentiality of sensitive personal data, accessibility of such information, *codification* of information on biological materials and *anonymity* of phenotypic information, multilevel *data protection* system, actions in case of *illegitimate disclosure* of participant’s identity, etc⁵.

³ Allen, L. A. (2004) “Privacy in Healthcare” in *Encyclopedia of Bioethics*. Stephen, G. P. (ed). New York: Thomson Gale. pp 2120-2129.

⁴ Aktuālie cilvēktiesību jautājumi Latvijā 2003. gada 2.ceturksnis. Available from <http://www.vcb.lv/zinojumi/2003.g.2.cet.doc> [accessed 10th September 2008]

⁵ Latvian report provided by S. Mezinska and V. Silis.

4. Concluding remarks

It seems reasonable to claim that the region is characterized by low level of public discussion concerning genetic privacy.⁶ Public discussions on privacy are mainly focused on privacy problems in media, human rights discourse but not in medicine or scientific research. Czech partners report that the main concerns are about privacy in hospitals and retirement homes, protection from misuse of data by banks and other commercial companies, loss of privacy due to modern technologies such as the internet, mobile telephones, CCTV cameras, and the amount of information that the state keeps about citizens.

The fact that discussions over genetic privacy are not widespread in the region can be interpreted in several ways. First, it is possible to argue that the lack of public debate indicates a rather low level of public awareness of new technologies and risks associated with them. Second, the fact that the debates on non-genetic privacy issues are much more common than the debates on genetic privacy can be interpreted as an attitude of the public to consider genetic privacy as a particular kind of privacy issues that does not deserve special attention or debate. The third interpretation is to claim that people do not feel that scientific technologies that involve genetic information are part of their everyday lives – there are other privacy issues that are linked with much more familiar and much more important features of their lives. The fourth interpretation is connected to the issue of paternalism. Some experts argue that physician-centered, paternalistic decision making is prevalent in the NMS region (Gefenas 2004: 124, Searight and Gafford 2005: 519). This is also confirmed by some studies (Grabauskas *et al.* 2004).⁷ Paternalistic attitudes would at least partly explain why the public is relatively little interested in privacy issues in healthcare context and thus why there are few if any intense public debates on these issues in the region. Paternalistic attitudes might also partly explain why the level of trust in the researchers implementing the Estonian Genome Project is exceptionally high (trusted by 80% of the respondents).

⁶ This inference is based on responses by regional partners and (Matthiessen-Guyader 2005).

⁷ However, Flash Eurobarometer on „Data Protection in European Union“ shows that confidence levels in medical services and doctors in terms of data protection are on average lower in the New Member States region than in other parts of the European Union (Eurobarometer 2008: 11).

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