

Key Objectives

PRIVILEGED is concerned with the protection of individuals' fundamental rights and freedoms, particularly their privacy rights, in relation to the developing use of genetic information and biobanks for research. It examines how existing regulations, particularly privacy and data protection legislation, understands and protects those rights, and how they might be developed within the European Union. Its key objectives are to examine:

- alternative conceptions of privacy interest engaged by research using genetic data and bio-banks and identify whether variations in substance or emphasis may be mapped across geographic, cultural or disciplinary differences;
- the relationship between research using genetic data and bio-banks and alternative conceptions of privacy: assessing the appropriateness of modelling the relationship as one of either harmony or conflict; and,
- the regulation of research using genetic data and bio-banks across the extended research area (EU, EEA, NAS, Israel, Japan and Taiwan), particularly data protection, and evaluate the relationship between such regulation and alternative conceptions of privacy.

PRIVILEGED will make recommendations for research practice and public policy to promote an optimal relationship between research, data protection, and privacy interests within a culturally diverse European research area.

Methodology

- 36-month EC Framework 6 funded Co-ordinating Action Project running from January 2007 to December 2009.
- Consortium of 35 member institutions: members have expertise in medicine, medical law, medical ethics, sociology and biotechnology, and represent all the EU member states, as well as Norway and Iceland, Israel, Japan and Taiwan.
- Three stages of work drawing on the expertise of the members: the first two stages use a questionnaire completed as an academic paper by the member from a national perspective. These answers are compared in regional and project-wide papers. The third stage takes forward specific questions, identified through these papers, in specially convened working groups.
- Each stage of the work includes a workshop to develop discussion and analysis of information between the members.
- Information and resources both for the members and for the public are developed through a website.
- Results are disseminated through publications and reports.

Website

The PRIVILEGED website complements the project by:

- Drawing together links to national legislation, codes of guidance, and other reports and materials relevant to the project;
- Giving an interactive forum where members and the public can generate working definitions of key contested terms within the area, for example, "biobank", and "privacy";
- Offering a space where issues concerning genetic information, biobanking and research can be discussed;
- Providing a communication tool between the members; and,
- Giving a point where the results of the project can be disseminated alongside traditional publications.

Join in the debate at www.privilegedproject.eu

Publication and Dissemination

Alongside the report to the European Commission at the end of the project, the results will be disseminated through volumes of reports for stages one and two, and a special interest issue of a peer-reviewed journal for the final stage. The website is also used for reporting the project, and members are encouraged to use the findings in conference papers.

Stage One

Members were concerned with identifying the interests expressed in research using BBGDs in their nation states reported in already published studies (this was not new empirical work, but a literature review in each state). These were located alongside both theoretical accounts of privacy and the specific concepts of privacy reflected within the use of the language of privacy within partner countries.. The sources for interests expressed could be very varied, from conceptions found in the legislation to concepts found in local newspapers and the like. The purpose was to generate, working from national level up, the widest spectrum of possible privacy and rights expectations that people have been found to hold: to establish the range of interests that were *felt* to be legitimate. The members were grouped into three loose geographical areas, to see if there were any obvious cultural differences within Europe between the member state level and the European level: did the cultural history have a bearing on the concept of privacy.

The preliminary findings are that:

- these are issues that have received very variable coverage between member states;
- some member states, for example where there are well publicized national biobanks, have had national debate, and there are examples of studies where privacy in genetic information and biobanking is discussed and conceptualized;
- the general debate and conceptualisation of privacy is very similar;
- there are not specifically regional traditions emerging in this literature; and,
- there are, however, a number of concepts of privacy which are in play, either individually or together, and which, collectively, might be understood to reflect the broad range of expectations held by individuals.

Stage Two

During this (current) stage of the work members are asked to:

- identify the specific laws and regulations which govern the use of genetic information in research and biobanking in their nation states;
- analyse this regulation in the context of the expectations of privacy that were identified in stage one of the project; and,
- identify how this regulation is observed in practice, though literature review and discussion with the relevant authorities and scientific communities in their country.

What is already emerging is that there is significant harmonization of data protection law (through the implementation of Directive 95/48/EC across the member states), although there are significant questions specific to genetic information which are left unresolved, for example concerning the relationship between data and samples, and the adequacy of protection for genetic group rights (for example family) within the individualistic framework of data protection law. Where there are specific laws relating to biobanks and to genetic information, and in privacy law generally, these issues remain significant.

Stage Three

Here the members will focus on developing recommendations, building on the findings of the first and second stages of the work. The members will work in sub-groups that cut across the geographical groupings and will focus on particular areas of concern identified within Stage Two, producing specific recommendations on each issue.

The purpose of the recommendations is not to prescribe particular a particular approach; it is to identify the implications of taking particular regulatory approaches for the protection of particular concepts of privacy and particular conceptions of relevant privacy interest as expressed by various groups. It will be able to identify, for example, the implications if the expectation is for a particular conception of privacy amongst a particular group, for that expectation if specific regulatory measures were to be implemented.

These recommendations will also identify the broader impact on other conceptions of privacy that follow from such a policy choice.

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