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PRIVILEGED Project

Stage 1 Northern Regional Report

(Post Bawtry workshop version)

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Report on questions 1: The Language of Privacy

For the purpose of the regional report on the language of privacy, I have divided the countries into five groups according to similarities in national languages:

- a. English language (UK)
- b. German language (Germany and Austria)
- c. Scandinavian languages (Denmark, Sweden, Norway, Iceland) and Finnish
- d. Franconian languages (Belgium, Netherlands)
- e. Non-European languages (Japan and Taiwan)

These five parts will be followed by concluding remarks that will point out some similarities and differences in using terms having that same or similar meaning as the English word *privacy* across the twelve countries of the PRIVILEGED Northern region.

a. English language

In English the first recorded use of the term *private* as "not open to the public" is from 1398. The term *privacy* as a noun didn't appear in English until the 15th century (around 1450). The term grew popular in the 17th century as a preferred alternative to the snobbish overtones in common. The use of the term of *private persons* as "not holding public office" it is recorded from 1432. The term *private soldier* as "one below the rank of a non-commissioned officer" is from 1579, *private enterprise* was first recorded 1844, *privatization* is attested from 1959, and *privatize* was first used in 1968.¹

There are relatively few seminal works from the UK on the nature or foundations of privacy. A selection includes: Raymond Wacks published the "Poverty of Privacy" and *The Protection of Privacy* in 1980, *Personal Information, Privacy and the Law* in 1989, edited *Privacy Volumes 1 and 2* in 1993, and wrote *Privacy and Press Freedom: Rights in Conflict* in 1995. Charles D. Raab co-wrote *The Governance of*

¹ See *Online Etymology Dictionary* and the *Webster's Online Dictionary*.

Privacy with Colin J. Bennett (Canada) in 2006. Graeme Laurie wrote *Genetic Privacy* in 2002.

b. German language

In German the concept of privacy is best translated as *privatsphäre* (which exactly means *private sphere*). The private sphere characterises the domain of a person which is not public and guarantees the respect of human dignity and the right to free development of one's personality (as in the German constitution). The private sphere of a person means that the person can decide who is going to know what about them. Thus, several private spheres may be attributed to each person since the kind of information a person would be prepared to disclose depends on the receiver of that information, e.g., family members, friends, the employer, or the public.

c. Scandinavian languages

The Danish concept closest to the English privacy is *privatliv*, which literally means *private life*. It is mostly used in relation to informational privacy and is used as something that people can protect from the public. However, the concept of *privatliv* is not as broad and generic as the English equivalent.

Another possible translation of privacy is *uforstyrrethed*, literally meaning *non-disturbedness*. It relates more to spatial privacy and to being without the presence of unwanted people. In a number of cases the concept of integrity (*integritet*) is used where English speakers might have used privacy, in particular in relation to the phrase "respect for privacy" which would typically be "respect for integrity" in a Danish medical context. The Latin roots of integrity (wholeness) points to a shared notion of a zone of non-violation and interference also recognizable in the spatial notion *uforstyrrethed*. Occasionally, reference would be made to confidentiality instead of privacy.

The term most used in Sweden to describe the equivalent of English privacy would be *personlig integritet* which literally means *personal integrity*. There is no agreement on a single definition of this concept. Having integrity means to be aware of one's goals, to follow one's own conviction and to withstand pressure of influence from others, being honest and irreproachable, having the right to have one's individual character and inner sphere respected, and not be subjected to personally disturbing intrusions.² In a recent public report on the protection of personal integrity, it is submitted that the English concept of privacy is wider than the Swedish "personal integrity", since the English term would seem to cover also personal independence and self-determination.³

The concept *privatliv* (which means *private life*) is also used in Sweden, more or less as a synonym of personal integrity, although less frequent. The Swedish partner reported that in more reasoning texts the two concepts are not seen as interchangeable

² Supra.

³ See the public report of the Committee for Integrity Protection: *Skyddet för den personliga integriteten – Kartläggning och analys (SOU 2007:22) Part 1, p. 53.*

synonyms.⁴ In situations where disclosure of information is restricted the term *tystnadsplikt* (duty/obligation of silence) or *sekretess* (secrecy) would be used. In research ethics or business relations the concept *konfidensialitet* (confidentiality) might be used.

In Norwegian the concept of privacy can be best translated as *privatlivets fred* (in direct translation: ‘the peace of the private life’). In dictionaries *privatlivets fred* is described as the life of a person outside of profession or service. Since the 1902 Penal Code there is a prohibition against violations of the *privatlivets fred* by making personal and domestic information publicly known. Other words exist in Norwegian using the root *privat* such as *privatbil*, *privatklinikk*, *privatlege*, or *privatperson*. Another term that is being used is *personvern* (in direct translation: *protection of person*).⁵ The term *personvern* consists of two words: *person* refers to the individual human being, while *vern* has multiple meanings, from physical structures of defence via protection against violence and abuse to organized protection of groups. The primary understanding of the word combination is “the protection of the interests of persons to have control with information which describe them”.⁶ The seminal works include an article by Ragnar Dag Blekeli (1974) where he explained the shift of use from *privatlivets fred* to *personvern*. The word *personvern* was mostly created with the development of computer technology. Bleki understood *personvern* as the individual’s interests in protecting their personal information in relation to other persons’ and institutions’ interests.

In Iceland the term used for privacy is *friðhelgi einkalífsins*. More recently the word *persónuvernd* (*vernd* means *protection*, *patronage*, *support*) has also been used, but more in relation to data protection.

(Finland: Lasse has been asked and additional question on this and I am waiting for his response.)

d. Franconian languages

In Article 10 of the Dutch Constitution the right to privacy is laid down as *recht op bescherming van de persoonlijke levenssfeer*, which can be translated as ‘right to protection of private life’. The Constitution has additional provisions on informational privacy/data protection (i.e. processing of personal data) and on the rights of access to and correction of such data.

The Dutch term *persoonlijke levenssfeer* is widely used in literature and the media. The term has more or less the same meaning as it has in English. However, the concept of privacy is not clear in the Netherlands and it is not well delineated and

⁴ E.g. Strömholm (1971) p. 698 and SOU 2007:22 p. 62, Beckman (2002) p. 21, Hansson (2006) p. 271.

⁵ The most recent expression is “personopplysningsvern” (in direct translation: protection of personal information).

⁶ LE Bygrave. *Personvern i praksis. Justisdepartementets behandling av klager på Datatilsynets enkeltvedtak 1980-1996* (Oslo: Cappelen Akademisk Forlag, 1997), 12.

elaborated. In the Netherlands, it is first of all associated with control over personal information. In a wider sense, *persoonlijke levenssfeer* relates to a private sphere where one can withdraw from the public domain (the right ‘to be let alone’).

In Belgium the word used in Dutch language would be the fonetic transcript of the English word *privacy* (fonetic : *praivesie*, sometimes *privesie*). An alternative term used would be *privé leven* which means exactly *private life* in English. French-speaking people in Belgium would use *vie privée* which also means *private life* in English.

e. Non-European languages

In Japanese there is no native word having the same concept of English word *privacy*. To express the concept, they use the word showing the sound of English word of *privacy* in Japanese letters (Japanese syllabary). When using it, they tend to have in mind so called passive meaning of privacy, i.e. protecting a person’s personal information from wrongful disclosure, rather than its positive meaning i.e. self-determination and autonomy in the field of personal matters.

In Taiwan there is a concept “yin-sih” equivalent to “privacy.” The dictionary edited by the Ministry of Education defines “yin-sih” as the “private matter that is secret and desired to be unknown to others.”⁷ The following examples show how the concept is used in daily lives: (1) “It is immoral to disclose others’ yin-sih (privacy);”⁸ (2) you intruded my yin-sih (privacy) by entering my room without permission. The meaning of the concept “yin-sih” is very close to privacy in English probably because the concept is transplanted from the Western world. Whether the concept of privacy exists in traditional Chinese culture, which plays a critical part in Taiwanese culture, is arguable. However, apparently it is the Western idea, rather than traditional Chinese culture, that dominates the current understanding of privacy in Taiwan.⁹

Concluding remarks

Latin was an official language in Europe for almost two thousand years and many European languages either developed from Latin (e.g. Italian) or were strongly influenced by it (such as English). The term *privacy* in many languages has its roots in Latin. A similar word, that was used in Ancient Greek and gets translated into Latin as *privat*, is the adjective *idios* (meaning one's own, pertaining to oneself, private or personal). The word is used as the opposite to *idios* in the first case is *demios*

⁷ <http://dict.revised.moe.edu.tw/cgi-bin/newDict/dict.sh?cond=%C1%F4%A8&pieceLen=50&fld=1&cat=&ukey=-852409274&serial=1&recNo=0&op=f&imgFont=1> (last visited 2008/5/23) (in Chinese)

⁸ Id.

⁹ Shin-yi Peng, Privacy and the Construction of Legal Meaning in Taiwan, 37 International Lawyer 1037, 1041-42 (2003).

(belonging to the people, public) while in the second case the opposite is *kinios* (common, shared in common).¹⁰ The Ancient Greek word *idios* is translated into Latin as an adverb *privatim* (apart from State affairs, for one's self, as an individual, in private, privately, in a private capacity.) It was used as the opposite to *publicus* and *communis* (public, communal). *Privatim* comes from *privus* (one's own, individual) using the old Latin *pri* which means *before*. The adverb is *privato* (at home) and the substantive *privatus* (a man in private life, citizen) is the opposite of *magistratus* (a magistrate, public functionary, public servant or civil officer).

It is difficult to compare the language of privacy across the 12 languages; however, there seem to be some similarities:

- Overall, there are not many seminal studies on the language of privacy in national languages
- While in most languages the Latin root *privatim* is used, there usually isn't an exact translation of the term *privacy* in national languages. Just like in Latin where the word was used as an adjective rather than a noun, it is used in many languages as an adjective often forming a new term with a noun (e.g. *privatliv* meaning *private life* in Danish and Swedish, *privatsphäre* meaning *private sphere* in German, or *privatlivets fred* meaning *peace of the private life* in Norwegian. In Belgium they would use either the Dutch term *privé leven* (*private life* in English) or *vie privée* (*private life*) in French.
- In many countries there are other words used that has the same or similar meaning as the English *privacy*. In many (but not all) languages this word is formed using the root *person* that comes from the Latin word *persona* meaning *human being*. In Swedish this word is *personlig integritet* (meaning *personal integrity*), in Icelandic *persónuvernd* (meaning *personal protection*), and in Dutch *persoonlijke levenssfeer* (*personal life-sphere*).
- Some countries also use the English term *privacy* in their national languages. In Belgium the word used in Dutch language would be the phonetic transcript of the English word *privacy*. In Japan they use the word showing the sound of English word of *privacy* in Japanese letters.
- The terms that equal English word *privacy* are usually mentioned in the Constitution or other important legislation. However, as this report doesn't deal with legal meanings, this isn't reported here.

¹⁰ Book 3 line 82.

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Report on questions 2: Eurobarometer

Structure:

- Introduction
- Social Values, Science and Technology Eurobarometer
- Europeans and Biotechnology Eurobarometer
- Concluding remarks
- Criticism of Eurobarometer
- References

Introduction

In this chapter two Eurobarometers (public opinion surveys of European citizens) which contain information on public attitudes towards privacy and genetic research will be analysed from the perspective of the 10 European states that belong to the PRIVILEGED Northern states.

The first Eurobarometer report is the 2005 ‘Social values, Science and Technology’. Question 15a 3 asked: “How important people think protecting information about private life from misuse and exploitation will be in ten years.” Other relevant questions are in part 17 about the extent that people would approve of possible future applications of genetic science and technology over the next 20 years. We chose these four questions that are most relevant for the PRIVILEGED project:

“To what extent, if at all, do you approve of its use?

- Storing everyone’s genetic data so that criminals can be caught easily
- Storing all the genetic data of our population in data banks in order to study the genetic causes of human diseases
- Developing for everybody a genetic test that would tell us about diseases we might get, even if we cannot do anything about them
- Developing for children a genetic test that would identify their talents and weaknesses”

The second Eurobarometer report was conducted by Gaskell et al. (2006) and is called ‘Europeans and Biotechnology in 2005: Patterns and Trends’. The five most relevant questions were asked in part Q5.3 on opinions about the uses of genetic information. In the five questions respondents were asked:

“Would you be willing

- To take a genetic test to detect any serious disease that you might get?
- For your genetic information to go into a national data bank for research into the origins of diseases?
- For (appropriate government agency handling social security) to have access to people’s genetic information?
- For private insurance companies to have access to people’s genetic information?
- For the police to have access to people’s genetic information to help solve crimes?”

Social Values, Science and Technology Eurobarometer

Question 15a item 3 – “Protecting information about our private life from misuse and exploitation: How important do you think it will be for our society in ten years time?”

To quote from the Eurobarometer report: ‘94% of EU respondents believe that protecting information about our private life from misuse and exploitation will be

important for our society in ten years time. In fact, two in three believe this will be very important.' Out of this total, 76% think that protecting information will be 'very important' and 27% 'fairly important'.

When comparing the 10 countries of the Northern region that participated on the survey, in all these countries between 94 and 97% of respondents believe protecting information about our private life from misuse and exploitation will be important, which is above average. With the exception of the Czech Republic which came on the top, all countries of the Northern region are among the countries with highest ranking of the importance of protection of privacy in the future.

When taking only the answer 'very important' into account, the least concerned about the future protection of privacy in the Northern region are Germans (69%), which is still higher percentage than most countries of the Southern and new EU States. However, the countries that had most citizens responding that this will be 'very important' are the two countries outside the EU, Iceland (83%) and Norway (81%), followed by the UK (77%), and Austria and Sweden (both 76%). The Norwegian partner comments the result in following way: "It must be fair to conclude that the answer to this question suggests that the protection of private life and particularly one's own data is seen as an important societal value and task by a great majority of the population. The broad agreement on the future need for protection against unauthorised access to personal information also indicates an increasing awareness of the possibilities of disclosure of confidential information and public concern with privacy and the use or misuse of personal information."

When adding the answers 'very important' and 'fairly important' together, Finland is on the top with 98% followed by Belgium and Norway (both 97%) with Iceland having only 94%. (This shows that when considering the answer 'very important' alone, or adding both 'very important' and 'fairly important' together, there are different results, as Iceland comes either on the top or bottom of the 10 Northern states.)

Question 17 – Possible future applications of science and technology over the next 20 years: "To what extent, if at all, do you approve of its use?"

1. Storing everyone's genetic data so that criminals can be caught easily

Only 33% of Europeans are in favour of storing everyone's genetic data so that criminals can be caught easily (if it is highly regulated and controlled), while 21% would never approve of it.

In the 10 countries of the Northern region, the average percentage of responses 'never' is at the European average at 21%. However, one country is an exception:

Iceland has by far the highest percentage of citizens that are most likely to disagree with creating genetic data banks for the purposes of catching criminals (43%). Other countries of the Northern region with high scepticism towards police DNA databanking are Finland (27%) and Belgium and Austria (both 25%). The least sceptical are Denmark with 12% and Norway and the UK both with 13%.

2. Storing all the genetic data of our population in data banks in order to study the genetic causes of human diseases

The answers to this question give a different picture as 41% of Europeans approve of storing genetic data in order to study genetic causes of human diseases if it is highly regulated and controlled. As the Eurobarometer study says: ‘The proportion which would never approve of this is considerably lower when compared to observations made above with regard to other uses of genetic data’.

When comparing the 10 countries of the Northern region that participated on the survey, in all these countries in average 17,5 % of citizens said ‘never’ of storing genetic data in order to study genetic causes of human diseases, which is only insignificantly higher above the European average, where 17% radically disapprove of it. However, there are some highly sceptical Northern states such as Denmark (31%) and Austria (27%) that belong among the most sceptical about this issue in Europe. On the other hand, the lowest scepticism is in the UK where only 7% would never approve of storing genetic data for studying genetic causes of human diseases. Iceland is also an exception with just 8% of respondents saying that they would never approve of such biobanking (which is a contrast in comparison with 43% saying ‘never’ to police databanks in the same country).

Northern countries are in general more likely to approve of storing genetic data for studying genetic causes of human diseases given that this is properly regulated and controlled (44,2% compared to the European average 41%). Sweden is most approving (52%) followed by Iceland (51%), on the other hand Germany (34%), Austria (37%) and Finland (38%) are least approving.

3. Developing for everybody a genetic test that would tell us about diseases we might get, even if we cannot do anything about them

Regarding developing of genetic tests, in the EU one third (34%) would never approve of this, while in the 10 Northern states people are in average more sceptical with 41%. The Northern region country with the highest percentage of radical disapproval with “developing for everybody a genetic test that would tell us about diseases we might get, even if we cannot do anything about them” is

Netherlands (47%) followed by Denmark and Iceland (both 45%). The Dutch partners say they have no special explanation for this; however, after public discussion of these topics there “may be more awareness about information that can be burden rather than a benefit to individuals.”

Out of the Northern countries, it is UK that has the lowest percentage of citizens who said ‘never’ to genetic testing for diseases (23%), UK is thus the only country of the Northern region that is below the 36% average disapproval in Europe. This is consistent with the overall UK optimism for genetic biobanking for the purposes of research showed in answers to question 17.2 above.

The average EU approval of developing genetic testing for diseases (if it is highly regulated and controlled) is 27%, with the 10 Northern countries showing more scepticism and giving it only 21% average approval. Again, all 10 countries of the Northern region are below the European average with the exception of the UK where 30% of people approve of it. The least approving country (and also ranking 2nd lowest in Europe after Switzerland) is Denmark with 14%, followed by Netherlands (16%) and Sweden (18%).

4. Developing for children a genetic test that would identify their talents and weaknesses

Regarding developing genetic testing to identify talents and weaknesses of children, more than half of respondents in the 25 European countries would never agree with it (54%). The Northern countries in average disagree with such testing more than citizens in Southern and Eastern Europe. Thus, the average of disapproval in the 10 Northern countries is significantly higher, 60%, with Norway and Sweden (both 76%) ranking second most disapproving in Europe after France. On the other hand, Finland had the lowest percentage of disapproval of all Northern states (49%).

The percentage of people in Europe who approve of genetic testing to identify talents and weaknesses of children (if it is highly regulated and controlled) is only 19%. The percentage between the 10 Northern countries is even lower with 16%. Iceland and Finland had the highest percentages of approval (26% and 21%), while the other Scandinavian countries ranked between the most sceptical in Europe with only 6% approving of developing genetic testing to identify talents and weaknesses of children in Norway, 9% in Sweden and 10% in Denmark. The Norwegian partners commented on their low national ranking: “Norwegians have the lowest approval for developing genetic tests for children that could identify their talents and weaknesses (6%) as well as developing treatments to get rid of people’s bad

habit as smoking and alcoholism (13%). This suggests a high level of awareness about possible misuses of genetic tests and treatments and a profound concern about genetic discrimination.”

Europeans and Biotechnology Eurobarometer

25 EU countries participate in this survey. Iceland and Norway didn't participate, so it is possible to compare only 8 countries of the Northern region. However, the Norwegian partner has sent us links to studies on similar topics of privacy, biotechnology and informed consent conducted in Norway in the last 6 years.¹¹ Norway has also conducted the national survey on attitudes towards privacy in 1997 (more in the country report).¹²

Chapter 5.3 – Opinions about the uses of genetic information:

1. "Would you be willing to take a genetic test to detect any serious disease that you might get?"

In average 64% of citizens in EU countries responded that they would take a genetic test for diseases (responded either 'yes, definitely' or 'yes, probably'). Four of the Northern countries ranked lowest with Austria giving smallest support (45%), followed by Denmark (50%), Germany (52%) and Finland (58%). On the other hand, Belgium respondents found this most acceptable in the whole EU with 81% agreement. Germany is the country where the largest percentage of citizens in Europe would never be willing to take a genetic test to detect any serious disease

¹¹ T Hviid Nielsen, Ø Seippel, T Haug. "Hva mener og vet nordmenn om bioteknologi. Noen resultater fra Eurobarometer 58.0 (2002)." (What Norwegians mean and know about biotechnology. Some results from Eurobarometer). Working paper nr. 20. Center for technology, innovation and culture. University of Oslo, 2003. J Holmen, MB Kjelsaas, Ø Krüger et al. "Befolkningens holdninger til genetisk epidemiologi illustrert ved spørsmål om fornyet samtykke til 61246 personer – Helseundersøkelsen i Nord-Trøndelag (The attitudes of the population to genetic epidemiology illustrated by renewed consent for 61246 persons – The Nord-Trøndelag Health Study)." *Norsk epidemiologi* 2004; 14: 27-31. [http://www.medisin.ntnu.no/ism/nofe/norepid/2004\(1\)_08-Holmen.pdf](http://www.medisin.ntnu.no/ism/nofe/norepid/2004(1)_08-Holmen.pdf). Accessed May 5, 2008. B Stegmayr, K Asplund. "Informed consent for genetic research on blood stored for more than a decade: A population based study." *British Medical Journal* 2002; 325: 634-635.

¹² Statistics Norway, 1997.

that they might get (27,7%). Greece is second (26%) and another country of the Northern region, Denmark, is third (25,3%). In average, the 8 Northern countries are more sceptical than the rest of the EU with only 60.5% support.

2. *"Would you be willing for your genetic information to go into a national data bank for research into the origins of diseases?"*

In the 25 EU countries more than half (58%) of respondents would allow banking of their genetic information for disease research. In average the 8 Northern countries are more likely to allow banking of their genetic information for disease research than the rest of the EU as the percentage of acceptance is 63%.

The highest ranking (both in the EU and Northern countries) is the Netherlands and Denmark (76% answered either 'yes, definitely' or 'yes, probably'), followed by Sweden (74%) and Belgium (69%), which ranked fourth after France. However, other states of the Northern region are amongst the most sceptical about allowing banking of genetic information for research; In Germany 42% answered 'yes', and in Austria only 37%, which means that these two countries have the lowest percentage of acceptance in the EU. The Austrian partner suggested that one reason for the low acceptance rates relating disease and diagnostic genetic testing might be the lack of information in the public, but deficiencies in confidence must also taken into consideration.

As pointed out in the Eurobarometer survey when comparing questions 1 and 2: "Interestingly, in the Nordic countries – Sweden, Finland, Denmark, and Netherlands – more people would agree to allow their genetic data to go into a national bank for research, than would take a genetic test themselves. Is this evidence for the communitarian ethics?" However, the Dutch partners do not agree as they think this is "probably rather (a relatively high degree of) trust and confidence in biomedical research."

3. *"Would you be willing for (appropriate government agency handling social security) to have access to people's genetic information?"*

The willingness to give governments access to genetic information is significantly low all across Europe as only one quarter of respondents from the 25 EU countries would probably or definitely allow government access to their genetic information. The only EU country of the 8 Northern countries that has higher percentage of willingness than the European average is Denmark with 40%. On the other hand, citizens in Germany are least in favour of giving governments access to genetic information as only 9% approve, which ranks them last in the EU. In average the 8

Northern countries would be just insignificantly less willing to give governments access to their genetic information than the rest of EU.

4. *"Would you be willing for private insurance companies to have access to people's genetic information?"*

In average only 14% of citizens in EU countries responded that they would allow private insurance companies to have access to people's genetic information. In the Northern countries people are more cautious, as in average only 9% would agree. Four Northern countries ranked lowest in the EU with Sweden (4%), Germany (5%), Denmark (6%) and Netherlands (7%). The only Northern country that ranked above the EU average is the UK with 19%.

The Dutch partner mentions that the Eurobarometer "rightly observes that the Netherlands are among the countries that are more inclined to support diagnostic uses than societal uses. However, one of the social uses (access for the police to genetic information) receives much more support in the Netherlands than the EU average. This may be influenced by recent crime cases with a high profile in the Dutch media."

5. *"Would you be willing for the police to have access to people's genetic information to help solve crimes?"*

Regarding this question 59% of EU respondents would allow access, which is lower than in the 8 Northern countries where 66% would allow access. However, there are several very sceptical countries in the Northern region; Austria ranks last (and fourth last in the EU) as only 49% would allow police and access to genetic information, followed by Germany's 50%. On the other hand, Denmark and Netherlands are most willing in the EU to allow police access with 76%, followed by Sweden and Malta (73%) and the UK (72%).

Concluding remarks

Analysis of results from the two Eurobarometers is difficult and highly speculative; however, there are clear patterns that show similarities and differences. The 2005 'Social values, Science and Technology' Eurobarometer showed that people think protecting privacy from misuse and exploitation will be extremely important in the future. It also showed that respondents were quite a lot in favour of using genetic biobanking for the purpose of scientific research

(especially for the purpose of studying genetic causes of diseases rather than possible individual's future diseases). However, more than half of respondents said 'never' to developing genetic tests for identifying talents and weaknesses of children. Also, one third of respondents across the EU found police DNA banking acceptable.

The 2005 'Europeans and Biotechnology' Eurobarometer showed slightly different results as respondents would be more willing to take genetic test to detect diseases they might get (64% across the EU) than offering their genetic information to be used for research into origins of diseases (58%). However, respondents were more in favour of using genetic biobanking for the purpose of scientific research rather than for the purposes of the police, government or insurance companies. But 59% would give police access to genetic information, which is almost a double compared to the 'Social values, Science and Technology' Eurobarometer conducted in the same year!

According to the 'Social values, Science and Technology' Eurobarometer, the 10 Northern states are slightly more concerned about the future misuse and privacy in comparison with the rest of the EU. They equally accept storing genetic data for police purposes and for research into causes of human diseases. However, the Northern states are significantly more concerned about the developing genetic tests for individual's potential future diseases as well as for identifying children's talents and weaknesses.

The 2005 'Europeans and Biotechnology' Eurobarometer showed similar results when comparing the 8 Northern states (Iceland and Norway didn't participate) with the whole EU. Northern states are more willing to allow genetic banking for disease research; however, they are less interested in taking genetic tests for identifying their possible future diseases than the rest of the EU. The 8 states also find it less acceptable to give insurance companies access to genetic data, and they find it more acceptable to allow police access to genetic information.

Criticism of Eurobarometer

The criticism of Eurobarometer is the same as of any quantitative survey; the results have limited reliability as the surveys are conducted only on selected part of population. Eurobarometers are conducted on only 1000 people per country. But the main limitation is that respondents only 'tick boxes' of questions that can be misunderstood or understood in several ways, and the final evaluation and interpretation of such survey is thus difficult. The questions that are put to

respondents are often very simple and thus can be understood in different contexts. For example, the ‘Europeans and Biotechnology’ Eurobarometer question: “Would you be willing for the police to have access to people’s genetic information to help police solve crimes” can be understood in many ways. Is the question asking about individual police situations (such as collecting DNA from crime suspects, or relatives of a missing person), or is it about creating a nation-wide police DNA database that will be created by collecting every citizen’s genetic data? People probably understood it the first way as 59% of EU respondents agreed. However, when almost identical question was asked in the ‘Social values, Science and Technology’ Eurobarometer (“Storing everyone’s genetic data so that criminals can be caught easily”), only 33% of respondents in the EU found it acceptable. This is probably because this question included the word ‘everyone’ and suggested a nation-wide genetic bank.

Other surveys are also raising doubts about the accuracy of Eurobarometer results. For example, the UK ranked very high in willingness for the police to have access to people’s genetic information to help solve crimes. According to the ‘Europeans and Biotechnology’ Eurobarometer 72% in the UK would be willing to allow this, while the EU25 average is 59%. But other UK studies have shown the contrary position, that the majority of people would not allow the police to have access to genetic information (see 3.d in Jessica’s part).

Another problem is that people can get confused by what is meant by various terms, such as ‘police’ and ‘government’. As the partner from Finland reported: “The Finnish attitudes on science biobanks are rather favourable, since two thirds would allow their own data to be stored in a biobank. Even though only 25 % would allow government access to their genetic data, 66 % would allow police to use it. This result quite clearly shows that the lay people have difficulties to understand the concept of government and the different organisations belonging to its administrative branch.”

Also, the question “Would allow banking of my genetic info for disease” doesn’t make it clear if this is for research done by private companies or by independent non-profit research institutions. In the ‘Social values, Science and Technology’ Eurobarometer, similarly misleading question asks if people approve of “Storing everyone’s genetic data so that criminals can be easily caught.” The question suggests that storing genetic data will lead to easy catching of criminals.

The Eurobarometers conducted across many European countries also face the problem of inaccurate or dubious translation. As shown in the chapter on the language of privacy, even the term *privacy* has slightly different meanings in many European languages as there often isn’t an exact term with the same meaning as in

English. Translating individual words and thus slightly changing the meaning of them can significantly alter the context of the sentence and thus final results.

Another problem with the Eurobarometer is that some countries might culturally tend towards giving more radical answers, while other countries are more inclined to give answers such as: 'yes, probably'. This might be purely a cultural thing, which may have nothing to do with the country's attitudes, and can again alter conclusions and analysis.

References

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