Human Brain Project

Citizen's view on data protections and privacy in research projects Poland

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EXECUTIVE SUMMARY

This report summarizes results of a citizen meeting that was organized on the 6 February 2016 in Warsaw (Poland) by the HBP (Human Brain Project). It was an opportunity to reflect on issues related to privacy and data protection in research projects, and to provide their ideas and opinions directly to the researchers and managers of the HBP. The meeting that lasted 3 hours gathered 22 citizens. In the first part of the meeting citizens filled out a questionnaire. The results that stand out are summarised in section 2. The detailed results can be found in an annex. Section 3 discusses the main themes that were raised in the second part of the meeting, in the course of group interviews. These were: differences between private and public entities, anonymisation, sensitive data, consent, and the issue of trust. Section 4 provides an overview of the recommendations formulated by citizens who participated in the meeting.

INTRODUCTION

In February 2016, the Human Brain Project (HBP) hosted citizen meetings in Austria, Bulgaria, Poland, Portugal, the Netherlands and Sweden. The HBP citizen meetings were set up to provide the public with an opportunity to reflect on issues related to privacy and data protection in research projects, and to provide their ideas and opinions directly to the researchers and managers of the HBP. The present report is one of 6 country reports detailing the result of the national meetings. The results of all six citizen meetings will be collected in a main report and delivered to the researchers and managers of the HBP project. The reports will also be made publically available.

The report first gives a brief overview of the context of Poland, before proceeding to the results.

1.1   POLAND

The aim of this report is to analyze citizen's perception of data protection and privacy issues in research project. The goal is to provide HBP researchers and management with input thay can use to plan the design of data collection and processing procedures in the HBP. We will begin with providing some basic information about Poland.

Poland is one of the largest countries in Europe and has a population of approximately 38,5 million people, as of 2014[1]. The biggest cities in Poland are: Warsaw, which is the capital, Cracow and Łódź. Poland is divided into three categories of territorial units. The largest are voivodeships (*województwa*), which are divided into administrative districts (*powiaty*), which consist of communes (*gminy*). According to Article 163 of the Constitution local governments carry out tasks not reserved (either by the Constitution or laws) to other public authorities. The official language is Polish. However, according to the Act of 6 January 2005 on national and ethnic minorities and on the regional languages as the minority languages[2] Kashub is recognized as a regional language. The political system of Poland is parliamentary democracy and the currency is Polish złoty. In terms of UN's Human Development Index, Poland is considered to be highly developed country (ranked 35 in 2013)[3].

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[1] Central Statistical Office of Poland, Basic information on polish demographic development, 2015.
http://stat.gov.pl/obszary-tematyczne/ludnosc/ludnosc/podstawowe-informacje-o-rozwoju-demograficznym-polski-do-2014-roku,12,5.html
[2] the Act of 6 January 2005 on national and ethnic minorities and on the regional languages as the minority languages.
http://isap.sejm.gov.pl/DetailsServlet?id=WDU20050170141
[3] For more information: http://hdr.undp.org/en/content/table-1-human-development-index-and-its-components

The employment by economic sector is as follows: 57,7% services, 30,8% industry and 11,5% agriculture[4]. The largest industrial sectors are: manufacture of food products, manufacture of products of wood and manufacture of metal products[5]. Leading Polish companies included in 2012: PKN Orlen (oil refiner), PGNiG (oil and natural gas company), PGE (power company), Grupa Lotos (oil company)[6]. In addition 7 Polish public companies are featured in the Forbes Global 2000 ranking, which is a list of 2000 world's biggest public companies. This includes: PKO Bank Polski (bank, ranked 623), PGE (power company, ranked 645), Grupa PZU (insurer, ranked 797), PGNiG (gas company, ranked 897), KGHM Polska Miedź (copper miner, ranked 1030), PKN Orlen (oil refiner and petrol retailer, ranked 1091), Tauron (power company, ranked 1781). The ranking is based on four metrics: sales, profits, assets and market value.

In 2011 Poland had a gross domestic product (GDP) of 850 085 million Dollars[7], which made it the ninth biggest economy in the EU and the twenty-third biggest in the world[8]. In the same year the gross domestic expenditure on R&D (GERD) was 6 395 million Dollars (0,75% of the GDP)[9]. Below are the tables showing percentage of the GERD with regard to different sectors.

Percentage of the GERD by financing sector in 2011[10]

Industry	Government	Other national sources	Sources abroad
28,12	55,80	2,69	13,39

Table 1

Percentage of the GERD by performing sector in 2011[11]

Business enterprise	Higher education	Government	Non-profit
30,13	35,10	34,53	0,23

Table 2

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[4] Central Statistical Office of Poland, Kwartalna informacja o aktywności ekonomicznej ludności, 2015.
http://stat.gov.pl/obszary-tematyczne/rynek-pracy/pracujacy-bezrobotni-bierni-zawodowo-wg-bael/kwartalna-informacja-o-aktywnosci-ekonomicznej-ludnosci-iv-kwartal-2014-r-,2,19.html
[5] Central Statistical Office of Poland, Statistical Yearbook of Industry – Poland, 2014
http://stat.gov.pl/en/topics/statistical-yearbooks/statistical-yearbooks/statistical-yearbook-of-industry-2014,5,8.html
[6] For more information: http://www.msp.gov.pl/en/polish-economy/economic-news/3696,dok.html
[7] OECD MSTI database, 2011 figures
[8] Please compare: http://www.msp.gov.pl/en/polish-economy/macroeconomic-analysis/5975,Macroeconomic-Analysis-of-Polish-Economy.html
[9] OECD MSTI database, 2011 figures
[10] Ibid.
[11] Ibid

2   RESULTS FROM THE QUESTIONNAIRE

The meeting in Poland gathered 22 citizens: 10 men and 12 women, who belong to the following age groups:

0-25	**4**
26-35	**11**
36-45	**1**
46-55	**2**
56-65	**3**
66-75	**1**

As regards their employment, participants work in the following sectors:

Health Care	**2**
ICT	**1**
Science	**2**
Government/Public	**4**
Unemployed	**0**
Do not wish to answer	**2**
Other (please share):	**11**

Other sectors included: legal sector, gastronomy and NGO sector. Two citizens stated they were retired and two were still students.

Below we discuss some results from the questionnaires that stand out. The detailed results of the questionnaire can be found in the annex.

The most popular reasons for joining the meeting were: the fact that citizens follow news on privacy and data protection (8 citizens), the belief that the meetings were a good occasion to learn more about data protection and privacy issues in research (7 citizens), and finally the fact that citizens were worried about privacy and data protection (5 citizens). None of the citizens joined the meeting because they liked the opportunity to have their voice heard in a EU research project (or at least this was not the main reason behind their participation).

As regards the meaning of privacy, for the majority of participants (16) privacy means the ability to choose what information about them is shared with other parties.

It may come as a surprise, that when asked who can have access to their data, a slight majority of participants (13) answered that they did not believe there should be any restrictions.

Only one citizen thought that research is more important than the protection of their privacy. Less than a half of participants (9) think that only some types of data should require high level of protection.

The majority of citizens who participated in the meeting (16) do not feel informed enough about who has access to their data and it is being used for. Moreover, a large majority (17) does not know where they can get more information about the use of their data if they need it.

A slight majority of participants (12) worry about their data being used for personal or financial gains instead of scientific progress. All but two citizens think that when they share data, others (for example members of their families) could potentially be affected.

A significant majority of participants (17) consider private data to be data about their activities, political and religious views, health status, who their friends are, as well as their correspondence with others.

3   THEMES FROM THE GROUP INTERVIEWS

3.1   PUBLIC VS PRIVATE

One of the major topics that came up during the group interviews were differences between private and public entities in the context of data protection .

Citizens wondered which entities, public or private, are better at protecting personal data. The answers varied. Some citizens believed that the level of protection did not depend on whether the institution is public or private. According to others, public institutions should, theoretically, be better at protecting data, because they have to follow formal procedures. At the same time, there is a risk that they become too burdened with bureaucratic obligations, which might be detrimental to the level of data protection. Some citizens worried that if data was collected by private entities for financial profit, there might be abuse. At the same time, private entities have more money and better technologies, which results in improved information security. Moreover if they function for financial gain, they have a lot to loose. Still, some participants would be anxious about sharing their data with private companies, especially the international ones.

In other words, participants seem to believe that public and private institutions have different incentives for protecting personal data. While public institutions are legally obliged to do it, private may suffer financial loss if they do not protect data adequately.

Citizens voiced concern that if data is collected by public entities, it might be used for political purposes, since the state can use the "coercive apparatus." At the time, the position of the individual towards the state may be stronger than towards private companies, because in the relation with the state he or she is protected by the public law.

Moreover, citizens wondered whether private entities that process data should be controlled more rigorously than public institutions. In view of some, there should be no difference and controls should fit the specificity of the entity that is controlled. According to others, due to higher level of trust towards public institutions, the controls of private entities should be stricter.

Citizens recalled some concrete examples, when they believed the protection of their data had

been violated, e.g. in courts where the case list (*pol. wokanda*) is public and accessible to everyone.

In the course of group interviews it was stressed that both private and public entities should have the same obligations with regard to data protection. Citizens stressed that the issue of data protection should be regulated by "hard laws," and that there is a lack of trust and confidence in "soft measures."

3.2 VIEWS ON CONSENT

Another major theme of the group interviews was the issue of consent.

Citizens posed the following questions:

- Should minors and people with disabilities be able to decide for themselves about the use of their data?
- Should it be allowed to make access to health care conditional upon the consent for the personal data to be used in research?
- How should consent for sharing of data be given?
- Is it possible to give an informed consent for the processing of personal data with complete knowledge of its consequences?
- What information should be provided within the informed consent clause?
- Is it possible to give consent for processing only some kinds of data, and not give consent for processing the remaining types of data?
- Is there a need for dynamic or broad consent for the purpose of medical research?

Participants agreed that a legal guardian is the person fit to make the decision about using the data of a minor or a person with disabilities. At the same time some argued that every situation should be assessed individually on a case-by-case basis.

Citizens were convinced that it should not be possible to make access to health care conditional upon the consent for the personal data to be used in research.

They agreed that consent should be given in writing, and that it should be clear and understandable. Research participant should be informed about the purpose of the research,

whether their data would be shared with third parties, how the research

process will look like in practice, and the size of the required group. Some citizens stressed that in a consent form the issue of sharing information with third parties should be separated.

Citizens pointed out that it might be difficult to know all consequences of data sharing. This is due to the lack of knowledge or understanding of all aspects of research. Moreover some issues might be impossible to predict at the time when consent is given.

Citizens had doubts whether it would be possible in practice to give consent for processing only some kinds of data gathered in hospitals, and not to give consent for processing the remaining types of data that are in possession of the hospital.

While some citizens believed that dynamic consent would help in controlling who processes the data and for what purpose, it would be impossible in practice. If implemented it would be very burdensome. Citizens expressed the view that there should be a possibility to select broader categories e.g. if we agree to research being done by public or private entities.

3.3   THE USE OF SENSITIVE DATA

Participants paid considerable attention to the issue of sensitive data.

They posed the following questions:

- What, according to you, is sensitive data?
- Does technological progress pose a threat to sensitive data that has already been collected?
- What types of medical research could justify the use of sensitive data?

According to the participants the notion of "sensitive data" covers the following categories: data that may reveal sexual orientation; data concerning political views, heath, sexual life, religion; all data that may be used to divide people into more and less privileged; data concerning "in-born"/"natural" features; data on our views, life styles, affiliations; moreover different types of data depending on the shape of the state (situation in the country) may become sensitive.

With regard to threats that technological progress may pose, participants highlighted that some data might have been collected without prior consent. They stressed that threats may be connected to the lack of proper anonymization. Some threats may come from the transition of paper databases to digital databases. Citizens highlighted that it might be difficult to keep sensitive data disconnected from the internet.

According to the citizens sensitive data could be used for epidemiological research, research in oncology, neurology, pharmacology, but not in cosmetology. Other citizens believed that sensitive data might be used for research that which is beneficial to the society in general; independent on whether to save or only improve life, or research that solves basic problems of a public meaning. Citizens also highlighted that sensitive data may only be used if without it the same results cannot be obtained.

In this context, citizens stressed that there is a risk of falsifying data due to competition between different groups and that private companies may "stretch" results for financial gain, and therefore there is a need for strict control of ethical commissions, especially in the case of for-profit entities.

3.4   VIEWS ON ANONYMISATION

In the course of the meeting citizens discussed the issue of anonymization, and whether deanonymization is difficult and viable.

According to some participants there is no such thing as "bullet-proof" anonymization. There is always a risk of deanonymization, especially since the quality of anonymization is not always satisfactory.

Citizens stressed that deanonymization may be viable for some companies e.g. insurers. They highlighted that the wide use of social media makes de-anonymization easier. If anonymization is not done in a correct way (which is a common fear), the process of deanonymization may be much easier. Moreover in the case of rare diseases, deanonymization may not be difficult to achieve.

3.5   VIEWS ON TRUST AND APPROACH TOWARDS SCIENTIFIC RESEARCH

Citizens also discussed whether society has trust in scientific research. In general they agreed that people in Poland trust researchers who work in scientific centres. This will remain to be the case if the principle of informed consent is respected, research participants receive information about the results, and data is anonymized. Some citizens believe that the level of trust depends on who finances research and who carries it out.

Citizens also discussed whether currently medical research is done for good purposes. According to the participants most people believe this is the case, however there is some level of distrust linked with the fear the sole purpose of research is financial profit.

3.6   OTHER THEMES

Other questions asked in the course of group interviews concerned:
- whether participants expect any personal benefit for allowing their data to be used.
- whether it should be possible possible to limit the protection of personal data for public interest.
- whether besides law, ethical codes should regulate the issues of processing and the protection of personal data.

If research is done by public entities no personal benefit is expected, if by private then yes. Some citizens highlighted that they would not expect financial gain, if the corporations would act not-for-profit. Others said they would like to know the research results. According to other participants the good of the science would be enough.

Some citizens believe that it should be possible to limit the protection of personal data in order for science to progress. However this should not be the case, if the purpose of limiting the level of protection would be financial gain. Other citizens argued that the level of protection could be lowered, if it would be necessary to protect other people or the safety of food.

According to some participants ethical codes make the issue of data protection "too blurry." Since science should be rational and not ideological, civil and criminal liability is required; ethical liability would not be appropriate. At the same time other citizens believe that there is a need for ethics commissions.

As regards particular threats and dangers they may be the result of data sharing, citizens mentioned discrimination and harassment. They fear their data may be manipulated, used against them, for different purposes than it was collected, or by companies that sell data and insurers.

In the course of the meeting some participants also recalled their own experience - one citizen said that their data was sold by a dispatching company to a different one, and they had to demand its deletion. Other citizens highlighted that even though their data was not used in a wrongful manner, there are instances where it is unclear to them how it is in fact used.

Some citizens said that they would not mind their data to be used after their death.

4 RECOMMENDATIONS

Table a	- Standardization of data anonymization by data protection authorities. - The use of personal data for research purposes should be overseen by an ethics commission – a type of „master" commission composed of members of the existing research ethics commission. - There should be standards on obtaining and processing of personal data of children under 13 and disabled people. - Financing of research by private companies should be transparent. - It should be transparent who exactly (which entities) processes personal data in the course of research
Table b	- Ethics commission: professional, collegial, controlled by the society - Scientists should receive anonymized data; data should be anonymized in hospitals at the earliest possible stage; there should be an inter-hospital body to collect and anonymize data with the participation of external entities

	• There is a need for the involvement of independent experts and ngos, who could control the process. • There is a need for educational and information activities in order to raise awareness
Table c	• There should be the same standards for the medical entities and private bodies • Education for people whose data is processed • There is a need to improve the relation between the medical body and patients • Regulations should correspond with pracitce
Table d	• People should be able to give dynamic or broad consent; and make it precise. • In order to implement the idea of informed consent there should be an option to know the details (additional information). • There should be detailed information on third parties who will receive the data. • There should be a system that would allow to check who processes our personal data and what is its scope; this should be secure. • The quality of security measures regulated by laws should correspond to technical norms in practice.
Table e	• There is a need for more societal control over private entities and the way they process data; currently there are no tools for such a control • There is a need for increasing the awareness of people who give consent for processing their data (about the aim of the research, its scope) • There is a need for effective legal provisions in order to protect the individual when their data is being processed contrary to the aim for which it was collected/against the individual's will.Individuals should be offered assistance when they are facing problems concerning the processing of their data

	• There should be a possibility to delete data if the consent is revoked OR the data should be immediately anonymized

Participants agreed that there is a lack of knowledge and awareness regarding issues related to the protection of privacy and personal data not only with relation to scientific research but also in general. There is thus a need of educating and informing the public.

Participants discussed at length the issue of how to control private companies that process personal data. They believe there is a need for more control and transparency.

Citizens highlighted that legal provisions not always correspond with practice, and are sometimes ineffective. There is a need to change this situation.

5 CONCLUSIONS

In the course of the meeting participants discussed at length the issue of how to ensure that private entities who process personal respect rights of those whose data they use. Citizens are aware of the threats that may be a result of processing of personal data, such as discrimination or harassment. Interestingly, it was raised that depending on the political situation different categories of data may become sensitive. Participants in general voiced a strong need of information and education with regard to issues of privacy and data protection.

Despite the fact that the theme of the meeting might have seemed very technical at the beginning, issues that were raised led to very lively discussions at the tables. After the meeting a couple of participants said they would be interested in participation in further meetings.

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4   ANNEXES

Please provide us with the filled in questionnaires.