



Human Brain Project

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

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EXECUTIVE SUMMARY (1/2 PAGE)

The Austrian citizen meeting was held in the Volkskundemuseum in Vienna on the 30th of January 2016. 31 citizens took the opportunity to participate in the debate about data protection and privacy in research projects in the European Union. Within this 3 hours meeting, participants at 6 tables completed a questionnaire, conducted group interviews and developed recommendations.

The meeting revealed clear perceptions about sensitive data, uncertainties about their protection, limited ideas of misuse and waiver of a certain degree of privacy in favour of common good as long as the most sensitive data are protected carefully. Nevertheless, it is clear that the citizens expect a kind of personal authorisation; although the perceptions differ how often this consent should be obtained and to which extent it covers single research projects or entire types of research. However, anonymisation is generally expected.

Ultimately, the meeting in Vienna may be summarised as a clear request for information, transparency and control embedded in an unambiguous legal framework to raise citizens' awareness, strengthen their self-determination and options to chose from on the one hand side, and to deter misuse of sensitive data on the other side.



1 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 out 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 publicly available.

Before proceeding to the actual results, the report gives a brief overview of the Austrian context.

1.1 AUSTRIA

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

The Republic of Austria is a parliamentary democracy, consisting of nine independent federal states. The country has a population of nearly 8.6 million people (2015) and with almost 1.8 million people living in Vienna, the capital is both the largest city and the most populous state. Official languages are German and the regionally spoken languages Slovene, Croatian and Hungarian. With a nominal per capita GDP of 38.540 EUR (2014), Austria is one of the richest countries in the world. A highly advanced industry, which make up about a third of the GDP of 329.3 billion EUR (2014) and the services sector with some two-thirds of the GDP dominate the economy. Next to the major industrial sectors, mechanical engineering, structural steel work, motor vehicle trade and chemical, electrical and electronics industry, tourism traditionally constitutes an important part of the Austrian economy. Other essential economic sectors are real estate activities and other economic services, education, human health and social work activities.¹

In 2011, the Austrian R&D expenditures amounted to 8.3 billion EUR, which corresponds to 2.7% of the GDP. The industrial sector accounted with 46.2% for more R&D expenditures

¹ Statistik Austria, Statistisches Jahrbuch 2016, available at:
http://www.statistik.at/web_de/services/stat_jahrbuch/index.html



than the government, which financed 35.8% of the total R&D expenditures. 16.9% were spent by sources abroad and the contribution of other domestic sources added up to 1.1% of all Austrian R&D expenditures. Aggregating 68.8% of the R&D funded activities, the research landscape is dominated by the business enterprise sector, followed by the higher education sector performing 25.6% of R&D funding in 2011. The proportion of the governmental research activities amounted to 5.1% and 0.5% were apportioned to the private non-profit sector.²

² OECD MSTI database, 2011 figures, available at: http://stats.oecd.org/Index.aspx?DataSetCode=MSTI_PUB



2 RESULTS FROM THE QUESTIONNAIRE

31 citizens took part in the Austrian meeting and gender was almost equally represented (16 men, 15 women). The participants covered almost all classes of age, except for the group of 76-100 year olds. Attempts were made to represent the Austrian demographic structure as far as possible, nevertheless the age group of 0-25 year olds (9 participants) was slightly and the 56-65 year olds (7 participants) was clearly overrepresented. The age groups of 26-35 (5 participants), 36-45 (4 participants) and 66-75 year olds (4 participants) matched very well with the Austrian demographic structure. With only 2 representatives of the 46-55 year olds, this age group was clearly underrepresented. Unfortunately, no citizen older than 76 years participated.

Overall, the participants were well educated. Only 3 persons had no higher qualification than compulsory schooling, 9 participants left secondary school without and 7 with higher education entrance qualification. At the time of the meeting, 7 participants were still in school and 6 persons held a higher educational qualification. 2 participants were looking for work and 7 were retired.

Effort has also been made to represent rural parts of Austria in this meeting. 19 participants are living in the countryside and small towns, 13 of these were from Lower Austria and 6 from Burgenland. 12 participants are living in Vienna. Additionally, 5 persons with migration background contributed to a cultural diversity in the meeting.

2.1 PRIVACY

The participants of the Austrian citizen meeting almost entirely agree that privacy constitutes the own ability to choose what information is shared with third parties.

[Graph Question 6]

They also consider the same kind of data as private, namely data about activities, political views, religious views, health status, friends and correspondence. By ticking all answers available, almost each individual expressed a broad view of privacy.

2.2 PROTECTION

As the participants agreed on the meaning of private data, as diverse are their views about protecting them. Anonymisation as well as an Ethics committee's evaluation alone seems not an adequate protection of private data. Anonymisation is rather expected in research projects anyhow. For the participants, an *additional* review of an Ethics committee seems trustworthy. Nevertheless, to almost one third it is important that they are asked for their informed consent,



also if their data have been anonymised. Generally speaking, the participants rather prefer informed than broad consents.

[Graph Question 7]

Thus, anonymisation alone is seen insufficient in research projects, and that is also reflected in the answers of question 16: “do you think anonymisation is adequate protection of your personal data?”. 7 participants are uncertain about the effectiveness of anonymisation and 16 worry about persons selling their private data, techniques breaking anonymisation or misuse by insurance companies or research.

[Graph Question 16]

Although almost all participants consider a lot of information about their lives private they are willing to give up privacy of most of the data when it comes to the trade-off between data protection and value of research data.

[Graph Question 9]

Protection plays also an important role when it comes to the question who may legitimately collect personal information about people. From the point of view of 11 participants, the government is allowed to collect data in order to ensure security. Public institutions, which collect personal data for research purposes come second. It is worth mentioning that 5 participants could not agree with the answers available and noted that nobody is allowed to collect personal data without an explicit consent.

[Graph Question 17]

2.3 USE

Anonymisation and authorisation are clearly the key drivers in the way personal data might be used in research projects. Even if the data are anonymised, 11 participants only allow their use in research projects they agreed to and 8 allow the use in all types of research they agreed to. 5 persons trust the appreciation of the researchers and permission is indispensable for 5 participants if their data are not anonymised.

[Graph Question 18]

The participants’ main concern regarding the use of their data in research projects clearly is that their data serves personal or financial enrichments instead of scientific progress. Many participants also worry that their data provided for research purposes could be used against them.

[Graph Question 12]



On the other side, the participants are quite open in regard to who may have access to their data in research projects. Half of the participants believe that there is no need for restrictions, one third think that public institutions as well as private enterprises may use their data for research purposes.

[Graph Question 8]

Opinions about the qualification scientist should have when handling with private data are diverse but it stands out that the participants expect them to use their data only for research projects they agreed to and inform them if they find indications about illnesses.

[Graph Question 14]

Two-thirds of the citizens are aware that providing their data for research projects could have impacts on their families.

[Graph Question 13]

2.4 INFORMATION

Almost all participants do not feel well informed about the use of their personal data by third parties. The vast majority also does not know where they can gather information about the use of their data.

[Graph Question 10]

[Graph Question 11]

2.5 GENERAL

The motivation of the citizens to take part in this meeting was very diverse. The most deciding reasons were, to be heard in a EU research project, because one was up-to-date with privacy issues and to learn more about the topic. Only 2 persons were worried about data protection primarily.

[Graph Question 4]

The vast majority think that the information brochure gave a good overview of the topic; nevertheless 4 persons found it difficult to understand.

[Graph Question 5]

More than one third felt that the questionnaire matched well with the brochure. But it is remarkable that 15 participants stated (in written form on the questionnaire) that regarding the complexity of the topic and in order to capture the full picture of their opinions, it would have been necessary to allow more than one answer.



3 THEMES FROM THE GROUP INTERVIEWS

3.1 THE MEANING OF PRIVACY

3.1.1 What is personal data

The question what kind of data are personal did not explicitly arise in the group interviews. It rather seems that there was no discussion needed about this topic. Some participants believed that Austria is more sophisticated in the matter of privacy issues than other countries. Since the dangers of a transparent society were beyond dispute, the discussion was directly extended to what kind of data requires which kind of protection.

3.1.2 Reflections on consequences of misuse, who is affected/how

The participants directly associated misuse with commercial use. Besides that there were concerns about the misuse of personal data by insurances, the discussion was neither led on a personal-affected level nor were consequences of misuse addressed. The participants rather reflected about prevention of misuse and respective responsibilities.

3.2 PROTECTION OF PERSONAL DATA

3.2.1 Views on anonymisation

The participants asked each other what anonymisation means to them and if they generally feel anonymous. They reflected about who decides what is seen as anonymous. And they asked if data protection is nowadays possible at all. They concluded that one cannot secure oneself against deanonymisation. The debate about anonymisation got quite technical with questions like how secure can processes of anonymisation be and which security standards are necessary? Furthermore, the question arose who might be interested in deanonymisation. Some participants stated that *they themselves* want to decide who is allowed to know something personal about them.

3.2.2 Perspectives on consent

Consent is a fundamental part in data privacy for the participants. Therefore, questions regarding consent restrained on an overall level why anybody should have the right to collect personal data without being authorised at all. It was also questioned, which kind of data generally is/should be allowed to be collected without consent and how far the government is/should be allowed to gather those?



3.3 ACCESS AND USE OF PERSONAL DATA IN RESEARCH PROJECTS

3.3.1 Attitudes towards the use of private data

The debate about the use of private data in research projects included transparency, information, control and security. Anonymisation was strongly associated with information flow and transparency, e.g. what happens with the data, how can one be sure about anonymisation procedures, is information available about which data are collected and how and in which project they are used? Some participants demanded detailed and understandable information beforehand, and that the government could provide an Internet platform and information materials. Furthermore, control and security were very important issues for the participants. Who controls the observance of data privacy, the persons who have access to personal data, the transfer of data to third parties and the deletion of personal data? How long are personal data stored? And who controls the controller?

3.3.2 Perspectives on consent

The subject of consents was rarely discussed in the group interviews. Some participants considered dynamic consent as the best option, others demanded for consent before the publication of the results. One participant asked what about signing consents on behalf of disabled persons.

3.3.3 Who may have access to personal data

The main concern about who may have access was that public research institutes could pass them to private companies. The participants discussed how many and which kind of researchers should be admitted.



4 RECOMMENDATIONS

TABLE 1

The most pressing issues of table 1 concern the guarantee of data protection in research projects:

1. Data protection, the control of its observance and confidentiality are important issues if personal data are used in research projects. Addressing these, the participants recommend that persons who handle sensitive data have to be upskilled constantly in order to raise their awareness.
2. In order to guarantee an appropriate qualification of each project associate, the participants suggest that all staff working with personal data is preliminary appointed.
3. According laws and routine controls should ensure data protection and the deletion of personal data.
4. The participants also expect transparency on the distribution of personal data and how they are used. Therefore, detailed and readily understandable information should be given to all persons affected beforehand.
5. Finally, the participants request a competent authority that provides help in situations of data protection infringements. Brochures and Internet platforms operated from a governmental department could inform those affected.

TABLE 2

The discussion of table 2 dealt with the approval of personal data in research projects.

1. Since research depends on sufficient data, the participants agree in sharing a certain degree of private data.
2. However, with the obligation that data are only shared with public institutions and not with private enterprises.
3. The participants also demand that these institutions are obligated to answer inquiries of citizens about the usage of their data.
4. Additionally, the research institution could share the profit they gained with the usage of sensitive data in form of public appreciations, if the persons affected desire it.
5. In order to prevent misuse of personal data the participants propose annual controls.



TABLE 3

The participants of table 3 recommend one solution for all concerns identified in the group interview, namely by establishing an independent authority.

1. The participants suggest that an independent authority knows about all personal data used in each research project.
2. It also makes sure that the processes are transparent and provides all citizens concerned with information on transfers and the usage of personal data.
3. Additionally, it prevents misuse and the commercial use of personal data through controls.
4. This independent authority also evaluates the relation between an individuals' protection and the common good.
5. Finally, it has to clarify which data are collectable without consent and has to lock sensitive ones.

TABLE 4

The participants of table 4 lay down some ground rules for the usage of private data in research projects.

1. It is important to define anonymity. The participants wish anonymity being recognised as the personal preservation of identity.
2. Additionally, the participants agree that nobody should be entitled to use personal data without consent.
3. In order to ensure these personal rights citizens need to be able to gather information about the usage of their data. The participants suppose information campaigns by the EU or at national levels to sensitize all citizens.
4. The participants are worried about data misuse and ask for legal consequences like custodial sentences, compensations and fines.
5. Finally, control mechanisms are a pressing issue for this table. The participants propose a supervisory body that conducts controls anonymously. It also should be considered to check the inspectors themselves.



TABLE 5

For the participants of table 5 the key to privacy in research lies in a reliable communication.

1. The participants wish to clarify the concept of anonymity and demand for precise information about data privacy acts.
2. The participants fear that public research institutions share sensitive data with private enterprises. In order to avoid misuse they call for detailed information on research purposes and possible data transfers.

TABLE 6

The participants of table 6 are convinced that there is de facto no anonymity and they see the legislative power in duty to develop an appropriate framework for the usage of sensitive data in research projects.

1. In order to avoid misuse, the participants ask for extensive controls of persons and organisations involved in research projects with access to personal data.
2. Additionally, the participants disagree with the commercial usage of purchased private data and recommend a duty to disclose for all users of sensitive data.
3. In order to raise citizens' awareness for privacy issues it should be possible to inspect "personal files" with all information stored.
4. Finally, the implementation of all recommendations rests in the hand of the legislative power.

A lot of topics recurred and many concerns overlapped at the tables. Most pressing issues for almost all tables were control (table 1, 2, 4, 6) and transparency (1, 2, 3, 6), in order to prevent misuse of personal data, and concerns about commercial enrichments by use of sensitive data (table 2, 3, 5, 6). Tables 1, 4 and 5 wish for greater enlightenment about the use of private data before and during research projects and in order to raise citizens' awareness. Tables 1, 4 and 6 call for an unambiguous legal situation to determine legal consequences for data protection infringements. Tables 3, 4 and 5 demand clarifications regarding authorities and definitions of anonymity. Independent authorities, which monitor research institutions and give assistance to persons affected by data misuse, are essential for tables 1 and 3.



5 CONCLUSIONS

In conclusion, the Austrian citizen meeting revealed four basic requirements for the usage of sensitive data in research projects: information, transparency, control and laws. These cornerstones represent four different levels and build on one another:

- Enlightenment occurs on the citizen-level by providing detailed information about research projects and data usage in order to raise awareness and protection
- Transparency occurs on the institutional-level and concerns their research purposes, results, profits and data-sharing in order to raise trust
- A supervisory authority works super-institutional and ensures the observance of data privacy with specific control mechanisms
- An appropriate legal framework builds overall guidance and definitions and pursue infringements

The meeting showed that thoughts about misuse of personal data are restricted to purposes of profit. The participants clearly differentiated between public research institutions on the one hand side, which are supposed to work in favour of the common good, and private enterprises on the other side, which aspire after enrichment. The unknowingly commercial use of sensitive data was obviously rejected. Additionally, having common good in mind and despite the fact that the participants have precise ideas about privacy, they are willing to give up a certain degree of privacy. As long as the usage of private data is consented to the specific research project respectively to the research field *additionally* to anonymisation, the majority do not think restrictions in access necessary.

Furthermore, the questionnaire revealed that uncertainties exist regarding appropriate protection and anonymisation procedures.

Finally, the meeting suggest the assumption that ethics committees do not appear trustworthy but further studies would be needed to examine this issue in detail.



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ANNEXES



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Please provide us with the filled in questionnaires.