EU citizens want to be informed of the use of their personal data

Recommendations from citizens to the Human Brain Project (HBP)

INTRODUCTION:

In February 2016, the Human Brain Project (HBP) hosted citizen meetings in Austria, Bulgaria, Poland, Portugal, the Netherlands and Sweden[1]. The aim of the meetings was twofold; 1) understand how EU citizens think about the use of personal data in research projects, and 2) to provide EU citizens with the opportunity to provide recommendations on the use of personal data to the HBP. Across all six countries the key recommendations coming from the citizens can be summarized in eight points (Figure 1).

Figure 1: The eight shared recommendations on the use of personal data in research coming from citizens in Austria, Bulgaria, Poland, Portugal, the Netherlands and Sweden.

RECOMMENDATIONS FROM EU CITIZENS TO THE HBP:

1. There should be transparency on who uses personal data in the HBP, as well as how the data is being used;
2. Communication should be clear, detailed and honest
3. Citizens would like to know about control measures taken for protection of data
4. The HBP should explain the approach taken to get consent for the use of data
5. Data from citizens should be safeguarded from use by for-profit third parties
6. The citizens would like it to be clear where they can ask questions and find more information about the use of their data by the HBP

THE HBP CITIZEN MEETINGS

The meetings were organized locally in the involved countries. All materials were translated into national languages. The meetings lasted 3 hours. At each meeting there were between 20-30[2] participants[3]. The meetings all followed the same structure[4]. First, the participants the local organisers presented the themes of the meeting[5]. Then the participants filled in a questionnaire. For the last part of the meeting, the participants interviewed each other in small groups. Together they developed and

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[1] The meetings took place in Vienna (Austria), Plovdiv (Bulgaria), Warsaw (Poland), Lisbon (Portugal), Breda (The Netherlands), and Malmö (Sweden). The discussions cannot be taken to reflect any position in the population because recruitment was centred around main cities. The aim of the meetings was to get insight into major tendencies, and possible cultural differences in how citizens think about privacy and data protection in relation to research in different EU countries. The samples are large enough to give insight into major themes of discussion among citizens living in and around larger cities in the countries sampled.

[2] The Swedish meeting is an exception with only 8 participants. In total 123 individuals participated in the HBP citizen meetings.

[3] The gender distribution was fairly equal at the meetings. All meetings had a mix of younger and older people.

[4] A standard program, and standard presentation can be found here: http://www.tekno.dk/article/citizen-meetings-in-the-human-brain-project/?lang=en

[5] Before the meeting the participants received an information leaflet with background information. The presentations gave a summary of the information in the leaflets. The information leaflet can be found here: http://www.tekno.dk/wp-content/uploads/2015/10/HBP_Cit_meetings_informationleaflet.pdf

wrote what they saw as key issues related to the use of personal data in research and they made recommendations on actions towards issues identified. Following the meetings, the local organisers delivered a country report summarising the discussion and recommendations coming from their national meeting. The country reports are available online[6].

THE PROVISION OF CLEAR INFORMATION

The need for clear, detailed and honest information was highly prioritised by the participants. The citizens agreed that there is a great need for information on how personal data is being used. They thought there was not enough awareness about the use of personal data, and they worried about misuse. When talking about misuse, the citizens explicitly mentioned concerns about for-profit research. To them the connection between the common good and for-profit research was not clear.

Across all countries a high percentage of the participants answered that they did not feel well-informed (76 %). The tendency is strongest in Austria and Bulgaria, were 97 % and 93 % respectively picked this answering option. In the Netherlands, Poland and Portugal the majority of participants also answered to feeling uninformed. However, in those countries some participants did answer that they felt ‘informed enough’ (10, 23 and 12 % respectively).

In question 11, a clear tendency can be seen in the answers across all countries, with most answering that they do not know where to find more information about the use of their data (82 %).

The need for information can be seen again in the citizens’ reply to questions 10 and 11 from the questionnaire (*Figure* ***2***)[7].

Figure 2: Question 10 and 11 from the questionnaire, where the citizens were asked to answer if they felt informed enough about the use of their data by third parties (10), and if they knew where to find information about the use of their data in research projects (11).

76 % of citizens do not feel informed enough about who has access to their data and what it is being used for. They are 97 % in Austria, 93 % in Bulgaria, 83 % in The Netherlands, 73 % in Poland, 82 % in Portugal and 29 % in Sweden.

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82 % of citizens do not know where to get more information about the use of their data if they need it. They are 84 % in Austria, 90 % in Bulgaria, 80 % in The Netherlands, 77 % in Poland, 89 % in Portugal and 75 % in Sweden.

82 % of citizens do not know where to get more information about the use of their data if they need it

In Portugal, the participants explained that they would feel more comfortable sharing their data if they received detailed and clear information on how it would be used and by whom. Most of the participants expressed a desire to be informed about the results of the research that their data would be used to perform. They explained that such feedback could be a form of compensation for sharing data.

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[6] The country reports are online here: http://www.tekno.dk/article/citizen-meetings-in-the-human-brain-project/?lang=en

[7] In interpreting the questionnaires, we were mainly interested in main tendencies. The answer rates in the figures do therefore not necessarily amount to 100 percent, as all answer frequencies below 10 percent have been left out.

Consistent and clear information on citizen’s data, and the possibility to track its use, was considered an important component of data protection.

The Portuguese participants call for more information was echoed in the discussions in the other countries as well, e.g. in Austria where enlightenment about the use of private data in research was seen as a good way to raise citizen’s awareness about data sharing and protections.
The Bulgarian participants also framed the information issue as one of a lack of awareness. They commented that people are not aware of the possible risk associated with the use of personal data. They suggested to: organise awareness-raising campaigns, especially among students, and focus on methods for prevention of data misuse; develop an online platform to enable the control of access to citizens’ personal data, to ensure transparency on who requests access to one’s personal data, how often, and for what purpose; Require personal consent everywhere when access to personal data is required; and work with children and youth as a priority to educate them about the protection of personal data and their information rights.

These discussions form the basis for recommendations 1 and 2:

1. There should be transparency on who uses personal data in the HBP, as well as how the data is being used
2. Communication should be easily available, clear, detailed and honest

MEASURES FOR PROTECTION OF PERSONAL DATA

Regulation and control was an issue that was often discussed in connection with the need for information. In general, participants expressed a need for insight into how their data was being used or not used, and they expressed a desire for some level of control of how their data is used. The citizens were asked to give an answer to the question how they would like their personal data to be protected (question7)[8]. The citizens did not favour one option for data protection, but the most favoured options might in general be said to be quite restrictive.

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[8] For question 7 there were 11 answering options. 1) I think anonymisation is adequate protection, 2) I think Ethics committees can decide if my data is adequately protected, 3) I think my data should be anonymised, and I think an ethics committee should also review if the protection is adequate, 4) I think, I should be asked for my informed consent every time researchers would like to use my data, also if my data has been anonymised, 5) I think, I should be asked for my informed consent every time researchers would like to use my data, except if my data has been anonymised, 6) I think, it is enough if I am asked for broad consent (types of research my data can be used for), also if my data has been anonymised, 7) I think, it is enough if I am asked for broad consent (types of research my data can be used for), except if my data has been anonymised, 8) I think it is enough if I am just asked once for my informed consent for all types of research, even if my data would be anonymised, 9) My personal data does not need to be protected, 10) Do not wish to answer, 11) Other (please share)

Figure 3: In this question the citizens were asked to indicate how they would like their personal data to be protected. The answers show the citizens across all countries are quite restrictive in choosing measures of protection for their data. The most popular answering options were that data should both be anonymized, and an ethics committee should oversee that measures of protection were adequate, and that the citizens would like to be asked for their informed consent even if their data was anonymized.

27 % of citizens want to be asked for their informed consent every time researchers would like to use their data, also if the data has been anonymised. They are 29 % in Austria, 21 % in Bulgaria, 39 % in The Netherlands, 27 % in Poland, 18 % in Portugal and 25 % in Sweden.

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22 % of citizens think their data should be anonymised, and think an ethics committee should also review if the protection is adequate. They are 26 % in Austria, 25 % in Bulgaria, 19 % in The Netherlands, 18 % in Poland, 33 % in Portugal and 13 % in Sweden.

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The local organisers reported in the country reports, that people sincerely felt there should be some control with the access and use of their data, but disagreed as to what would be enough control, the value of anonymisation, and how much trust to put in oversight like ethics committees (Bulgaria and the Netherlands). In the Netherlands the participants discussed if ethics committees would have the necessary technical insight. It is interesting that in all reports, the participants make the general recommendation that there should be an independent body responsible for oversight of data use. The answers from the Swedish meeting differ from the other countries in that the participants explained to be in favour of some form of dynamic consent. From their perspective, dynamic consent would allow the protection of data to be updated continuously, and would allow for individuals to stay informed about the use of their data[9].

In their discussions of consent some of the Portuguese participants considered the possibility of a gradual transition from informed consent to dynamic consent, while other of the Portuguese participants suggested the option of broad consent. The participants did not reach a consensus in their discussion on the type of consent, but they all agreed that consent is an important instrument for protecting their right to make free and informed decisions on the use of their data. Participants also considered the issue of consent regarding anonymised data, and some of them considered it to be important to give consent for anonymised data as well.

Control, and some form of consent, was important to citizens independent of country. No clear preferences for a specific type of consent or anonymisation can however be concluded from the answers.

The findings are interesting when compared to the findings from question 8 about access to data (Figure 4). The majority of the participants across all countries found that their data might be used for research, but only under strict control.

Figure 4: In question 8, the citizens were asked to answer the questions of who they thought could have access to your data. The answers do not match the answer pattern from the other questions. The answers show that the participants thought that

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[9] Se the conclusions in the Swedish country report for details on this discussion. Another suggestion made during this meeting, was to develop a 'private key' for individuals to access and allow sharing of their data.

both public and private organisations might use their data, but only if the usage of the data was strictly controlled.

> *58 % of citizens think both public organisations as well as private industry can use their data for research, but they should be strictly controlled for living up to the latest anonymisation standards and an ethics committee should review all procedures*
> *They are 52 % in Austria, 53 % in Bulgaria, 50 % in The Netherlands, 59 % in Poland, 57 % in Portugal and 75 % in Sweden.*

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At all the citizen meetings, the question of access was a major theme. During the Portuguese meeting, participants expressed concern about the possible misuse of data, especially about the possibility of data being used for personal or financial gain instead of scientific progress. The majority of participants agreed with the view that personal data needs to be protected. They found that organisations, both public and private, which collect, access, and use data, must be controlled and supervised by an independent body. Citizens agreed on the need of international regulations on data protection and privacy. A widely shared opinion was that medical doctors, researchers and scientists, to access personal date, should work for institutions certified by the State, and under the supervision of ethical committees and external controllers, who ensure the enforcement of data protection norms, including anonymization.

The discussions on consent form the basis for recommendation 3 and 4:

3. Citizens would like to know about control measures taken for protection of data
4. The HBP should explain the approach taken to get consent for the use of data

SOURCES OF CONCERN

For-profit exploitation of personal data was a controversial topic at all the meetings. In general, participants were much concerned with the common good value of research. Citizens explained they would be willing to sacrifice some protection for research that would contribute to a greater good for everyone. In this connection public and non-profit organisations were seen as safeguards for research contributing to the common good The concern with for-profit research can be found back in the answers to question 12 (*Figure 5*).

Figure 5: In question 12, the citizens were asked about their main concern regarding the use of their data for research. Across all countries citizens can be seen to worry about the use of their data for personal or financial gain.

52 % of citizens worry about their data being used for personal or financial gains instead of scientific progress. They are 55 % in Austria, 35 % in Bulgaria, 30 % in The Netherlands, 57 % in Poland, 77 % in Portugal and 57 % in Sweden.

52 % of citizens worry about their data being used for personal or financial gains instead of scientific progress

When the participants were asked about their main concern regarding the use of their data, the majority answered that worry about the use of their personal data for personal or financial gains instead of scientific progress, is their biggest concern (52 %). Interesting differences between the countries can also be observed. Citizens in Austria, Bulgaria and Poland expressed concern about their data being used against them (52, 26 and 35 % respectively). Citizens in the remaining countries were less concerned with data being used against them. Instead, the Dutch and Swedish participants expressed concern about where their 'data might end up' (45 and 29 % respectively). The Bulgarian and Swedish participants in turn also expressed as their main concern if research would actually benefit society (18 and 14 % respectively). The Dutch, on the other hand, were concerned with if research would benefit them (17 %).

The Portuguese is the group, with the largest majority expressing a concern with for-profit research. The concern was repeated in their discussions, where the participants in the Portuguese meeting talked about the importance of research being for the common good. They considered that public and non-profit organizations where best to safe guard the common-good contribution of research.

When the participants in the meetings were asked to evaluate anonymisation as a data protection, a number of reasons for doubt emerged in their answers (question 16 in Figure 6).

Figure 6: Question 16, where the participants were asked to evaluate anonymisation as a measure for data protection. Across all countries citizens seem to either be unsure about anonymisation (19 %) worry about technological developments like supercomputers (17 %).

19 % of citizens are not sure if anonymisation is adequate protection of their personal data. They are 22 % in Austria, 10 % in Bulgaria, 24 % in The Netherlands, 23 % in Poland, 23 % in Portugal and 13 % in Sweden.

19 % of citizens are not sure if anonymisation is adequate protection of their personal data

17 % of citizens worry about new technological developments like e.g. super computers that can break anonymisation procedures. They are 13 % in Austria, 12 % in Bulgaria, 21 % in The Netherlands, 41 % in Poland, 14 % in Portugal and 0 % in Sweden.

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Across all countries citizens seem to either be unsure about anonymisation (19 %) worry about technological developments like supercomputers (17 %).

In Poland, the participants discussed at length the issue of how to ensure that private entities who process personal data respect the rights of those whose data they use. Citizens e.g. worried about misuse, such as discrimination or harassment. Participants in Poland pointed to the influence of the political situation in relation to what data might be considered sensitive.

In Portugal, all participants expressed concern about the possible misuse of data and emphasized the need to create a system of regulation and control of organizations and individuals that collect and use data. For most of the groups, such control should be carried out by an independent organization while one group recommended that organizations and data users should follow and respect a professional code of conduct. Furthermore, three groups suggested the legal establishment of penalties for organizations and individuals which have misuse data.

In the Netherlands, much of the discussion about concerns was framed in terms of responsibility and ownership. E.g. the participants wondered, if data is public, who is responsible for it? Would it be hospitals, government(s) or individuals? They also struggled with the question about the rights of elderly patients, and wondered if data sharing would become a prerequisite to take part in certain medical studies or to get access to treatments?

In their discussions, the Swedish participants were particularly concerned with the question how new technological development would affect the protection of data. They worried that citizens could be left vulnerable to sudden and unexpected improvements in re-identification technology. The group emphasised that they wanted policy makers to take the risk seriously, and as far as possible to provide technical protection of data and to develop a protective system which adapts to technological developments.

The Bulgarian participants suggested that there should be a coherent national policy on the protection of personal meta-data, and with a clear definition of the range of data considered of high risk (e.g. ethnicity, nationality). They also suggested that annual upgrades of the data protection technologies (including both software and hardware), should be a requirement, and they recommended the creation of common EU legislation and rules for the export (sharing with third parties) of data and the handling thereof by the respective recipients.

The Bulgarian participants were also concerned with trading of personal data. They suggested that strict EU and national regulation should be in place, and that awareness among people should be improved, so that they would know where to demand protection from exploitation. Finally, the participants suggested that severe sanctions should be imposed in case of misuse of personal data.

The discussions on concerns and data protection measures led to recommendation 7 and 8.

5. Data from citizens should be safeguarded from use by for-profit third parties
6. The citizens would like it to be clear where they can ask questions
and find more information about the use of their data by the HBP

RECOMMENDATIONS TO THE HBP

Ultimately, the discussions and the answer to the questionnaires may be summarised as a clear request for information, transparency and control embedded in an unambiguous legal framework to raise citizens' awareness, strengthen their options for control and action and to deter misuse of sensitive data. If data protection is well handled and information provided in a clear and unambiguous manner, showing how the research contributes to the common good, then citizens are very open to the use of their data for research.

This newsletter is written by DBT senior project manager Lise Bitsch.

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The DBT leads the HBP SP12 engagement activities with stakeholders and the general public. More about the HBP and SP12 here: https://www.humanbrainproject.eu/

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