



Human Brain Project

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

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EXECUTIVE SUMMARY

The Swedish HBP citizen meeting brought together a small group of eight participants to discuss the issues of data protection and privacy in research projects. The participants expressed concerns about the risks to their personal data, due to rapidly evolving technology. Many participants were especially worried about the role of private companies and the profit motive in research. Other participants felt that the current regime for data protection was good enough and that they did not see a problem with private companies using data. Broad agreement existed on the need for individuals to be able to choose when and how to share data as well as the importance of benefits of research being available to all.

The majority of participants did not view anonymisation on its own as sufficient protection for their data. Dynamic consent, was seen as positive by many participants because it would allow data protection to be upgraded continuously and would keep them in the loop.

There was widespread agreement that it is the individual who needs to have a say in what is personal data. The group recommended that HBP conduct a frank conversation about the values and risks of data sharing in research with members of the public in the future.



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 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 Sweden, before proceeding to the results.

1.1 SWEDEN

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 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 Sweden.

Sweden has 9.593 million inhabitants (2013) and an area of 450,000 km², one of the least densely populated countries in Europe. Sweden is the 3rd largest EU country in land area, after France and Spain. Swedish GDP per capita in 2013 was 55,660.15€ (2013)

The official language is Swedish and Sweden is a parliamentary democracy.

When it comes to research and innovation the R&D expenditure as a percentage of GDP is 3.25%. R&D funding per capita is \$ 1 420.20. The percentage of R&D funding financed by industry is 57.64%, financed by government 27.46%, by other national sources 3.90% and financed by sources outside Sweden is 11%. The percentage of R&D activity is 69.07%, by higher education institutions 26.30%, by Government 4.31% or by private non profit institutions 0.32%.¹

¹ OECD MSTI database, 2011 figures



2 RESULTS FROM THE QUESTIONNAIRE

The meeting in Malmö was held on the 27th of February between 9.30 and 13.00 at Malmö Museum. Due to recruitment problems and an unexpected high level of drop outs relating to ill health the group was smaller than we planned for. Eight participants took part on the day, five women and three men. Two participants were under 25, two were between 26 and 35, two were between 36 and 45, one was between 46-55. We had no participants over 55. The participant group was therefore underrepresented when it came to men and the oldest demographics.

The group was mixed when it came to education and fields of work. We had two participants with just basic schooling, two who had completed the gymnasium degree, two who had a completed secondary education degree and one with a research degree. We had six delegates who were born in Sweden and two who were born outside Sweden.

The chief motivations mentioned by the participants for taking part were learning more about the topic of brain science and research, a pre-existing interest in the topic and chance to have a say.

When assessing the materials the majority of participants felt it gave a good overview, a minority however felt it was biased in some ways.

“Somewhat leading because some of the questions were distilled down to ‘development vs paranoia’, which is much too narrow...”

In certain question responses there seems to have been some confusion about topics and the options presented, despite the participants having access to the reading material in advance.

2.1 VIEWS ABOUT PRIVACY AND RESEARCH

When asked about what privacy meant to them the three most common responses from the delegates mentioned the reassurance that private interests would not profit from their data, the ability to choose when and how to share data and transparency when it comes to what data is shared and under what circumstances.

A majority of delegates, when asked whether they saw research as more important than privacy or the other way around, responded that that research is more important than privacy. However this view was not universal and some participants contextualized their comments.



“I think that protection of my privacy and integrity is more important than ‘Research’ (which risks corruption). But I consider ‘pure’ research to be more important to ‘society’ than the feeling of individual security”

When it came to rating their own understanding of how much they knew about data handling the delegates gave mixed responses, however, the great majority agreed that they did not know where to go to get more information about how their data is currently used.

“I think there is too little information about how data can be used for other purposes. People have very little knowledge about this.”

The questionnaire also asked the participants to define what they viewed as private data. The most common definitions included social activities, political views and a wide ‘all of the above’ definition.

2.2 VIEWS ABOUT ANONYMISATION & SAFEGUARDS

One of the strongest findings from the questionnaire is that most of our participants did not view anonymisation alone as sufficient protection for their data in most cases. When given a number of options no one solution gained widespread support. The participants expressed support for a wide range of options.

“More than anonymisation is needed”

The participants were asked what their expectations of professionals who handle their data is. The three most common responses were: “I expect they will be able to keep my data private.”, “I expect that they will not use of my data for any other research than what I have agreed to” and “I expect them to inform me, if they find information about possible illness(es)”.

“In the anonymization process the data should we divide it into degrees of ‘sensitivity’? It should be harder to access to data in certain areas.”

The participants’ most common view was that they wanted to give consent for research if their data had not been anonymised. Some participants expressly supported broad and dynamic consent.



“If anonymised an ethical committee can decide, in each research project (option C). If not anonymised I want to be asked in each individual case and if it is ok it happens through dynamic consent.”

“The answer is completely dependent on the purpose of the research. Research with a purpose which benefits society a lot and where anonymization is very hard are absolutely fine. They can be decided by an ethical committee. If the data is NOT anonymised it should be decided by the individual in each separate case.”

2.3 VIEWS ABOUT WHO SHOULD BE ABLE TO ACCESS DATA

The questionnaire also asked who the participants were happy to have access to their data. Some participants only wanted public institutions to have access (under strict controls), however the majority view was one that accepted use of data by private actors, but with controls with regards to anonymization standards and ethics.

Public institutions were the type of institutions that most participants felt comfortable with using data but some participants expressly supported the use of data by companies.

“It is important that important data and conclusions of the material cannot be privatised. (Creative commons - share alike)”

“Who gathers the data is not important to me, what is important is the purpose and the benefit to society and how data is managed. It must be ethical, regulated and transparent.”

2.4 FEARS AROUND HEALTH DATA

When asked which was their largest fear when it came to data usage the most common response from the participants was “I worry about my data being used for personal or financial gains instead of scientific progress”, followed by “I wonder whether the outcomes of the research will actually be beneficial to society” and “I worry about where my data will end up”.

“At the moment, but in the future I am unsure what can happen and who will have access to my data.”



The participants felt that others could potentially be affected by the use of their data.

“Depends if the data which is used can have a negative impact on me. Otherwise I am happy to help.”

There were mixed views on anonymization, and it was clear that the majority of participants did not think it was enough on its own. They expressed fears of hacking of data and the impact of profit motives.

“I am not worried about any of this. I have confidence in the current legislation around e.g. decisions of ethical committees work for my and society's best interests.”

“The assumption is that consequences will be negative, and in the question about the ‘biggest issues around my health data’ the options assume that I am worried. There is also an assumption that private companies are only motivated by profit. Private companies can also contribute to great social benefit.”



3 THEMES FROM THE GROUP INTERVIEWS

In the group interviews the following questions were developed and asked by the participants themselves:

- When do people get to make profit / privatize conclusions about health data? If it is not ok, how do we avoid this? What are the risks of privatization?
- Is health data more sensitive for certain groups than others? How do you handle this discrepancy in this case?
- How should we as a society handle the case of Henrietta Lacks if it happened today?
- Do we think it is a good idea to reward those who provide health data with personal medical information in exchange for their participation?
- What are your thoughts about anonymisation?
- A pharmaceutical company makes money, but can also contribute to society. Should pharmaceutical companies have access to health data?
- Are you aware of how much personal data you provide about yourself? For example, through social media? How do you feel about this in light of what we discussed today?
- If a close relative would be able to recover from a serious illness if there had been access to health data, would this affect your opinions about data sharing and anonymisation?
- Do you know enough on how your data can be used in the future to make a decision today?

Common themes which emerged from both groups were the role of private sector entities in data and research, the degree to which individuals are aware of how much data they share,



and the issue of whether individuals should benefit personally from sharing data. These themes also appear in the responses to the questionnaires.

3.1 THE MEANING OF PRIVACY

Clearly privacy matters a great deal to the participants of the Malmö event. Many participants felt that they had not discussed or reflected on these issues in much detail before and appreciated the opportunity to do so in the meeting.

3.1.1 What is personal data

The questions allowed the participants to explore what they defined as private or personal data. Many participants felt that they did not have a good sense of what data they currently shared, or how it was used currently. This made it difficult for them to assess what personal data is at a time when social networks gather and store a lot of data. One participant remarked that most people “don’t actually read the terms and services” when they sign up and therefore have little sense of what they shared.

Another common view was that just because personal data is safely stored today it is hard to say what will happen with it in the future. The fact that data is often stored in multiple places and abroad also was a cause for concern.

When we were discussing personal data and sharing on social networks as opposed to research data one participant felt that there is a big difference between social networks where people sign up freely and cases where data is shared without the person choosing to do so.

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

There was widespread worry about misuse, especially since the data lives on and can be combined with other data and/or de-anonymised using new technology. Several participants remarked on the difficulty of making an informed assessment of the risks as the field is developing so quickly. Many remarked that they maybe don’t know the consequence of their current data sharing, they mentioned online ads influenced by shared data for example, with one person worrying that this might inadvertently share health facts that an individual might wish to keep secret: “Will you get Viagra advertising if you have erectile dysfunction? It is unclear how it all works.” Some participants felt that the fact that their personal data was “hidden in the crowd” of everyone else’s data was a comfort, but other participants felt that it



if someone wanted to find their data they would be able to.

There was also a discussion about whether the consequences of releasing data would be higher for certain groups and if this meant that they needed extra protection. Two possible groups mentioned in these discussions were celebrities (who might be blackmailed) or individuals with particularly stigmatized diseases. However several participants remarked that the act of tracking these groups with special need for protection would create sensitive data which needs protecting. Who would decide this? They felt that a better option would be to have high protection standards for everyone. This would also be fairer for everyone.

3.2 PROTECTION OF PERSONAL DATA

The participants felt that the protection of data in research was important, however the balance of protecting data and encouraging research was a difficult one for many of them to make.

3.2.1 Views on anonymisation

Several participants expressed the view that it is doubtful whether there really is something that is really anonymised for good. Data which is impossible to attribute today might not be so in the future. There was a view that data of different levels of sensitivity needed to be treated differently, depending on the impact of releasing the information.

A couple of participants felt very strongly that part of the answer would be to remove the human factor from managing data. Insecure systems were caused by people and so data systems should be automated as far as possible. Other participants felt that this was unrealistic.

3.2.2 Perspectives on consent

The participants agreed that consent was very important. However they did not agree on how it should be created and affirmed. For many of the participants ethics committees were a vital part of the picture in regulating the use of personal data. Many participants were surprised by the fact that new technology meant that previously anonymised data might not be so in the



future. For some of them dynamic consent was seen as positive because it would allow data protection to be upgraded continuously and would keep them in the loop.

3.3 ACCESS AND USE OF PERSONAL DATA IN RESEARCH PROJECTS

On a theoretical level the participants were very supportive of research. However, there were many questions about who has a legitimate right to use data and under which circumstances.

3.3.1 Attitudes towards the use of private data

The use of personal data in research by private companies was very controversial among the Swedish participants. Many participants felt it was especially important for ethics committees to closely scrutinize the pharmaceutical companies' benefit, to society, and that they didn't profit unduly from restrictive patents. There was concern that private companies might benefit from public data without contributing much financially and that they might lock in benefits from the research through patents or trademarks. It was felt that it was important that the benefits of research should be available to all.

There was also a lively debate about whether private individuals should be allowed to benefit from the use of their data. Some participants felt that part of the reason people felt uncomfortable about sharing their data was that they didn't see any benefit to themselves, only risks. If people were offered benefits for sharing data (financial compensation, recognition or access to detailed updates on their own personal health data were mentioned as possible benefits) people might feel more inclined to share data. Other participants were very much against the idea of compensation for individuals. Some participants felt that recognition is one thing, money another. Some people felt that it shouldn't be relatives of someone who can give consent, this the role of individual. There was however a view among many participants that while anonymity is important there should be a cut off point after which data became available after someone's death. One suggestion was 15-20 years after death.

There was also a lively debate about whether researchers should tell people if they found health problems when reviewing their health data. Some participants felt that they would want to know, whereas others felt that it would be presumptuous to assume that everyone wants to know. One participant suggested that there might be an age difference whereby older people



might be less interested in knowing. One possibility discussed was having a box that a participant could check if they wanted researchers to tell them if they found something. One fear with letting people know was that this would mean designing anonymisation systems which could be re-identified by design.

3.3.2 Perspectives on consent

Consent was seen as important but also very difficult. There is a lot of data and the participants felt very ill-informed about risks of sharing data. Some found solace in the fact that there is so much data that they felt they disappeared in it all, whereas other did not feel comforted by this. Several participants stated explicitly that they felt safe with the current consent regimes in place in Sweden. There was widespread agreement that it is the individual who needs to have a say in what is personal data. These issues were seen to becoming more important as healthcare is digitalized, for example online clinics which are being trialed in Sweden. One participant pointed out that this could mean that recordings of communication between doctors and patients might be stored on a server. Many participants felt that data was at risk.

3.3.3 Who may have access to personal data

As mentioned the issue of private sector companies was controversial. Some participants strongly supported the right of private companies to carry out research with data whereas other participants questions the right of private companies to make profits of public data. Many participants wanted to see that the research contributed to something genuinely beneficial for society. When challenged on what this would be one participant mentioned cosmetic research as an area which didn't benefit society enough to warrant data sharing. One participant phrased it as a question of "Give and take". Another participant wanted the right for companies to profit from public data to be linked to a requirement to share data with other. "If you gain from a project you have to give back" Corporate secrecy should not prevent continued research in this perspective. The role of ethics Committees was mentioned by several participants when it came to private sector work. Some participants felt that transparency towards the whole population was especially important when it came to the private sector. Generally speaking Universities and government access to the data did not evoke as strong a reaction as private sector actors. However, as stated



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previously several participants made it very clear that they were not particularly worried by private sector access as they felt the current regime was robust.



4 RECOMMENDATIONS

Due to the small group size at the Swedish event recommendations were developed by the group as a whole.

One area of concern was ensuring long term protection of data in the light of new technological developments, which risks leaving citizens vulnerable to sudden and unexpected improvements in re-identification technology. The group struggled to come up with a recommendation but made it clear 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.

A recommendation was to inform citizens about how Patient records and other health data (both anonymised and non-anonymised) is currently shared between countries – (within the EU and outside the EU). An area that was raised here was Cloud services where technical uncertainty needs to be addressed to keep public trust.

A further recommendation as to explore was of providing citizens with a “Private key” to access their data and to allow sharing of this. This system would need to be safe from outside intrusion. Better locked personal information was seen as worth the cost of investment.

A discussion followed about how research and data sharing is never risk free. For the public a good understanding of the value and risk of research was seen as important. When we discussed the material used in the dialogue the view was that it was too focussed on risk, too little on the value of research through data sharing. The recommendation was to provide more balanced information for future dialogues when it came to the benefits, including successful projects in the past, making risks and opportunities clear to participants and a little more training in the beginning.

Finally the view of the group was to affirm the right of individuals to take the decision whether to share data.



5 CONCLUSIONS

During the Swedish HBP deliberation event we had a wide ranging conversation about the issues surrounding the use of personal data in research.

The role of private companies and interests in research was controversial. The majority of participants that accepted use of data by private actors, but with controls with regards to anonymization standards and ethics. The participants felt more comfortable with the use of data by public institutions. Regardless of user, it was felt that it was important that the benefits of research should be available to all and that the research contributed to something genuinely beneficial for society. There was also a lively debate about whether private individuals should be allowed to benefit from the use of their data. The most common view was that recognition for sharing data might be appropriate whereas monetary benefit would be inappropriate.

A great majority of participants did not know how their data is currently used and did not know how to find out. The majority of participants did not view anonymisation on its own as sufficient protection for their data in most cases. There was widespread worry that data lives on and can be combined with other data and/or de-anonymised using new technology. Solutions that the participants mentioned being comfortable with included ethics committees, and dynamic consent, which was seen as positive because it would allow data protection to be upgraded continuously and would keep them in the loop.

There was widespread agreement that it is the individual who needs to have a say in what is personal data. For the public a frank conversation about the values and risks of data sharing in research was seen as important.