

# **Citizen's view on data protections and privacy in research projects The Netherlands**



Human Brain Project

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## **EXECUTIVE SUMMARY (1/2 PAGE)**

This report reflects the outcomes of a citizen-participation meeting concerning privacy and data protection in relation to medical data such as potentially used in the Human Brain Project. The meeting was held on the 20<sup>th</sup> of February from 10.00 to 14.30 at the MOTI museum, Breda, The Netherlands. 28 participants, reflecting different Dutch demographic parts of society, were invited to partake in this workshop, in which:

- Informed consent was asked of the participants to use their data for this report
- Information was provided via a lecture on the issue surrounding privacy and data protection in the use of medical health data and the concept and workings of anonymisation were explained
- A questionnaire was filled out concerning questions of privacy and data protection in relation to medical health data
- Interviews were devised and conducted by the participants in an interactive session, in which the main concerns surrounding privacy and data protection were discussed
- A plenary meeting was held to discuss and summarize main points that emerged from both the questionnaire and the interviews.

The report reflects the main outcomes and relevant points raised by the participants – detailed data can be found in the annexes.



## 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 the Netherlands, before proceeding to the results.

### 1.1 THE NETHERLANDS

The aim of this report is to analyse citizen's perception of data protection and privacy issues in research projects. The goal is to provide HBP researchers and management with input that can use to plan the design of data collection and processing procedures in the HBP.

We will begin with providing some basic information about the Netherlands, and subsequently continue the paragraph with basic information (about R&D).

#### 1.1.1 Basic Information

The Netherlands is a small, low lying, densely populated country (408 people per km<sup>2</sup>), located in Western Europe (but having three island territories in the Caribbean; being Bonaire, St. Eustasius and Saba). The Netherlands borders with Germany, Belgium, and the North Sea (sharing nautical borders with Belgium, the United Kingdom and Germany).

The largest and cities in the Netherlands are Amsterdam, The Hague and Rotterdam.

The most significant sectors of the Dutch economy in 2014 were public administration, defense, education, human health and social work activities, wholesale and retail trade, transport, accommodation and food services, and industry. The Dutch main export partners are Germany, Belgium and the UK, while its main import partners are Germany, China and Belgium.<sup>1</sup>

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<sup>1</sup> European Union, *Member Countries: The Netherlands*, ([http://europa.eu/geninfo/query/index.do?filterNum=11&queryText=the+netherlands&summary=summary&more\\_options\\_source=global&more\\_options\\_date=\\*%&more\\_options\\_date\\_from=&more\\_options\\_date\\_to=&more\\_options\\_language=en&more\\_options\\_f\\_formats=.htm&swlang=en](http://europa.eu/geninfo/query/index.do?filterNum=11&queryText=the+netherlands&summary=summary&more_options_source=global&more_options_date=*%&more_options_date_from=&more_options_date_to=&more_options_language=en&more_options_f_formats=.htm&swlang=en)).



### **1.1.2 Basic Information about R&D<sup>2</sup>**

- Capital: Amsterdam
- GDP (national currency): 642 929.00 (2011)
- Number of Inhabitants: 16.947.904 (2015)
- Official Languages: Dutch, Frisian, Papiamentu (Bonaire), English (Saba and St. Eustasius)
- Form of Government: Constitutional monarchy with a parliamentary system
- Major Economic Sector: Services (78%)
- R&D expenditure as a percentage of GDP: 1.90
- Percentages of R&D expenditure financed by the government: 33.94
- Percentages of R&D expenditure financed by the industry: 51.12
- Percentages of R&D expenditure financed by other domestic sources: 3,62
- Percentages of R&D expenditure financed by sources abroad: 11.32
- Percentages of R&D funding performed by the business enterprise sector: 56.57
- Percentages of R&D funding performed by the higher education sector: 32.64
- Percentages of R&D funding performed by the government sector: 10.78
- Percentages of R&D funding performed by and the private non-profit sector: included elsewhere

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<sup>2</sup> OECD MSTI database, 2011 figures.



## **2 RESULTS FROM THE QUESTIONNAIRE**

### **2.1 GENERAL (ANNEX 1)**

In the Dutch citizen meeting, we welcomed a great diversity of people. The questionnaire was filled in by 28 people, out of which 14 were male and 14 female, meaning that in that respect it was a very balanced group. Also with regard to the occupation of the attendees, there was a large variety: 12 participants are unemployed or now unemployed (e.g. retired or student), 2 indicated to be a student, 3 work in the health sector, 2 in ICT, 2 do not wish to answer, and the rest of participants have employments in either the energy sector, financial sector, public sector, insurance, mail service, marketing, or science. 6 people belong to the age group 0-25, as do also 6 to the age group of 66-75. 1 person belongs to the age group 76-100. 7 people are of the age 56-65, 5 people 46-55, and 3 fall in the category 26-35. For most of the participants (11 to be exact) the motivation to join the citizen meeting can be found in their conviction that the meeting was a good occasion to learn more about data protection and privacy issues in research. 5 people have or had issues of privacy and data protection, potentially playing a role in their own life, 5 are “simply” worried about privacy and data protection, and 2 liked the opportunity to have their voice heard in a European Union research project. For 1 person, the motivation came from following news on privacy and data protection. Next to that, one person indicated to be worried about privacy and data protection, and to have issues of privacy and data protection that plays a role his or her own life. The last persons’ motivation arose from liking both the subject and the opportunity to have its voice heard in a European Union research project.

### **2.2 ORGANISATION AND CONTENT OF THE CITIZEN MEETING (ANNEX 2 AND 3)**

Two questions in the questionnaire dealt with the purpose of finding out participants’ opinions with regard to the organisation and content of the meeting. This is meaningful with a view to future citizen meetings, and the usefulness of the results of this one.

To the question what people thought of the information booklet, most people (8 to be more precise) answered that it gave a good overview of issues related to data protection and privacy in research. 6 had the same opinion, but added to the foregoing that it was easy to understand too. 8 only answered that the information booklet was easy to understand. However, 2 people thought the booklet was hard to understand, 1 person concluded that the booklet gave a distorted overview of issues related to data protection and privacy in research, 1 reply



mentioned that the booklet was a little abstract, and 2 attendees stated that they did not read the booklet at all.

Regarding the question of what people thought of the questionnaire, the responses were extremely diverse. At a glance: there was a majority (12 people) who thought that the questions matched well with the information booklet. 1 person found the questions are clearly defined; they fit well with the provided information, and are easy enough to understand. 2 people made known to find the questions too hard. Remarkable is that one of those 2 was also the one who indicated to find the booklet hard to understand. But the other person who was of the opinion that the questionnaire was too hard to understand, indicated that the information booklet gave a good overview of issues related to data protection and privacy in research. This could mean that the questionnaire was of a more difficult level than the information booklet. To resume, few people (4) argued to find there was too little nuance in the answers to choose. 1 person thought the questions were too easy. 3 people thought the questions were biased (and one of them even found them ambiguous). Some answers (3) showed indistinctness (e.g. about the possibility to provide just one or more answers).

### **2.3 PRIVACY AND PRIVATE DATA (ANNEX 4 AND 5)**

To half of the group (14 people) privacy means the ability choose what information about them is shared with third parties. 1 person was of similar opinion, but added that privacy also means certainty that an employer cannot access an employee's health data, and certainty that insurance companies cannot access this health data, and certainty or guarantees that personal data is not used for profit purposes by for example companies. Another participant added to that the ability to choose what information is shared with third parties, mentioning that privacy is transparency in how information is being used. Another participant added that privacy means the certainty that his or her employer cannot access his or her health data. 6 other persons stated that privacy means the transparency in how information being used, to which another person added that privacy means certainty that insurance companies cannot access health data. 3 attendees indicated that privacy is the certainty that personal data is not used for profit purposes by for example companies. 1 recipient implied that privacy means that the data subject decides what or what not to share with others (government, friends, companies, etcetera), regardless of whether it was their request to share information or not. The last person does not have a specific idea of what privacy is.

Focusing on different kinds of information, one question was: what do you consider private data about yourself? The answer options were: data about activities (sports, bar visits,



smoking status), data about political views, data about religious views, information about health status, information about who friends are, and the content of correspondence with others. The majority of the group (19, not being the same majority as mentioned earlier in this subsection however), considered all of the options above being private data. Some of the attendees saw private data more narrow (e.g. seeing only content of correspondence with others, or health status as private).

## 2.4 PROTECTION (ANNEX 6 AND 7)

The citizens were asked how they would like to see their personal data protected. 11 of them think that they should be asked for their informed consent every time researchers would like to use their data, **also** if their data has been anonymised. 1 person agrees, but to be specific adds that anonymised means to him or her that an ethical commission (existing of capable, well-selected members) decides whether the data are adequately protected or not. 6 people would like to be asked for their informed consent, **except** if their data has been anonymised. 4 people state that they think their data should be in any case be anonymised, and they think an ethics - committee should also review data use, even if data protection is adequate. Striking is that 1 person states that his or her data does not have to be protected. This is one of the people whose motivation to join the meeting was to learn more about data protection and privacy issues in research, so maybe he or she has a different opinion after providing this answer. 4 people would like to be asked for their broad consent, **even** if their data is anonymised, and 1 last person thinks that ethics committees can decide if his or her data is adequately protected. There is just 1 person that thinks that anonymization is an adequate form of data protection. This same person however, worries about data brokers who live off selling data-sets, and what they might do with data. The adequateness of protection is therefore also immediately questioned. For the rest of the group it holds that 12 people worry about new technological developments like for instance super computers that can break anonymization procedures, with some of them also worrying about e.g. data brokers who live off selling data-sets, and/ or misuse by insurance companies, and/ or hackers breaking the anonymization of data). 9 people are not sure about the adequateness of anonymization for protection, with some of them also worrying about e.g. misuse by insurance companies, and/ or data brokers who live off selling data-sets, and/ or hackers breaking the anonymization of data). In this context of anonymization, 2 persons “just” worry about data brokers who live off selling data-sets, and what they might do with data, 1 person worries about what kind of research data is being used for, and 1 person “just” worries about hackers breaking the anonymization of data. There are



only 2 persons that think that anonymization is absolutely and clearly not an adequate form of data protection.

## **2.5 PRIVACY AND RESEARCH (8, 9 AND 10)**

We put the question to the participants on how the trade-off between the level of privacy protection and the value of research data should be solved. After all, the less information on people is provided to researchers, the better their privacy is protected, but also the less useful the information is for research. 15 people answered that according to them, only for some types of data researchers should require high levels of protection. This would mean that the other, less (but probably still) protected types of data would be more (or the most) useful for research. No one specified for what kind of types of data exactly researchers should require high levels of protection. 5 people are in favour of privacy protection over research; they think that the protection of their privacy is more important than research in any circumstance, and the same amount of people think the opposite: research is more important than the protection of privacy. 1 person maintains the dilemma, stating that both protection of privacy and scientific medical research are important. 2 persons argue that there is a dilemma, since they do not feel personal data needs specific protection (one of them is the same person that stated that his or her personal data does not need to be protected, as set forth in subsection 2.4).

As for the main concern regarding the use of data for research, it is clear that the most people (15) worry the most that their data is used for personal or financial instead of scientific progress, with 1 of them also worrying that his or her data can be used against him or her, and with 1 of them worrying about where his or her data will end up. 3 more persons worry about where their data will end up, 7 people worry that about their data being used against him or her, with one of them in addition worrying that under 'false' pretences of scientific research data can consciously be misused. 4 people wonder whether the outcomes of the research will actually be beneficial to society. Of researchers that use personal data for conducting research, it is expected by 12 citizens that they will not use of that data for any other research than what participants or patients have agreed to, with 1 person not only expecting, but even demanding that. 1 person would like to have a certain benefit him- or herself when his or her data is used by researchers; expecting them to inform him or her if they find information about possible illness(es). 8 people expect that the researchers will be able to keep their data private. 1 person thinks researchers should have had some training in handling personal data. According to 1 attendee researchers should have a strong developed ethical system of norms and values,



and they should at all times be aware of their responsibility. 2 persons indicated to have no exact idea of what qualifications scientists processing personal data should have. As for the rest of the group, opinions range from expecting researchers to keep data subjects informed about their research, to wanting researchers to be screened.

## 2.6 ACCESS, COLLECTION, USE AND INFORMATION (ANNEX 11, 12, 13, 14 AND 15)

To the question who can access their personal data, 13 of the participants stated to think both public organisations as well as private industry can use personal data for research, but that they should be strictly controlled for living up to the latest anonymization standards and an ethics committee should review all procedures. 1 of them states that it is important that the private sector, receiving or collecting data "free of charge", is not going to use the data with a commercial or financial interest at a later stage, selling the data to, for instance, other researchers or third parties. Accordingly, this person was also worrying about data being used for personal or financial gains instead of scientific progresses stated in subsection 2.5. Another interesting point is that one of the 13 people providing this answer was the person who indicated to find anonymization to be absolute no adequate form of protection. 10 answered that only publically funded organisations and institutions may use their data for research, with 8 of them stating that those publically funded organisations and institutions should be strictly controlled for living up to the latest anonymization standards and an ethics committee should review all procedures. In line with the foregoing, 1 person finds that ethical commissions that also have the task to keeping an eye on the common interest may access personal data. 1 person thinks there should not be any restrictions on who has access to his or her data. 1 attendants' opinion is that he or she does not think that anyone should be able to use his or her data for research. This same person indicated that if his or her data is anonymised it may be used for any research project that he or she have agreed to have it used for, which makes it rather contradictory. 2 persons do not think there should **not** be any restrictions on who has access to their data. The last person is not in favour of ethical commissions, stating that ethical commissions are never a good idea ("see the banking sector").

One step further than merely accessing personal data, is the collection of it; the citizens were asked who they think can legitimately collect personal information about people, on which differing answers were given. The answers to these questions are divided between either public institutions for research purposes, or the government (e.g. for security purposes like the



prevention of terrorist attacks). Research is seen as a legitimate aim to collect by 1 attendee as well, but also by researchers working at a University (and not for instance researchers of Monsanto). 2 people are comfortable with the industry collection personal information to develop medication or other health services. 2 attendants have a narrower view: nobody should be able to collect personal information.

Reverting to the concept of anonymization in connection with the use of personal data, it was answered 9 times that if data is anonymised it may be used for any research project agreed to have it used for. 6 people had a likewise answer; stating that if data is anonymised it may be used for all the types of research agreed to have it used for. 7 people have a wider vision: if their data is anonymized it may be used for anything researches deem appropriate. 2 citizens indicated that when their data is not anonymised, they should be asked for permission to use it every time someone wants to use it. 3 of the attending citizens, having a less strict opinions on the use of non-anonymized data, think that if their data is not anonymised, they should be asked for permission once for the types of research someone would like to use it for. For only 1 person, there is no distinction between anonymized or non-anonymized data: it may be used for all types of research, after consent was asked.

Hardly any participant (24) felt well - informed about the use of their personal data by third parties, with 22 of them not knowing where they can get more information about the use of their data if they need it. One person adds to this the example of trackers on the Internet; “many people know so much about me, while I do not know who exactly and what information they have on me.” Only 3 people do feel well informed enough who has access to their data and what it is being used for. However, one of those states that you can never exactly oversee for what exactly approval is given. The last person answered to not yet encountered a situation based on which he or she can answer this question.

## **2.7 IMPLICATIONS FOR OTHER PEOPLE (ANNEX 16)**

Every attending citizen declared to think that when they share their data, it could have implications for other people. Only person adds to that point of view, that this is a difficult question that requires more information.



### **3 THEMES FROM THE GROUP INTERVIEWS**

The participants were asked to come up with 5 questions with regard to privacy, and to ask those questions to other participants as if they were journalists interviewing. In this chapter, the questions (cursive) and answers will be provided. Not (only) the answers are interesting, also the questions that participants came up with give an overview of what people clearly deem important enough to ask.

#### **3.1 GENERAL**

The following 1 question shows the participants' doubt whether they are able to represent the entire Dutch society, and whether the discussion on privacy still makes sense.

*Do you think the group of attendees the citizen meeting on February 20, is representative for the entire Netherlands?*

1. No.
2. No. Our specific interest in this topic and the fact we all live in a same region makes that we cannot represent the rest of the Netherlands.

*Do you think that the discussion on privacy in general makes any sense, since our data is to be found in approximately 30.000 files already?*

1. The discussion makes sense for raising awareness. Several generations do not really see the hazards and risks. It also makes sense in the context of improving laws and rules.
2. Yes, because discussions can generate new rules with regard to protection.

#### **3.2 PRIVACY**

##### **3.2.1 The Meaning of Privacy**

*What does privacy mean to you? N.B. This question was asked twice.*

1. Self-determination with regard to personal data. Autonomy, and the right to not being followed.
2. Privacy means that the data subject decides what is shared with others. It does not only contain personal data but it goes further than that. Privacy also means that when someone shares his/her personal data with others, they are released and yet not private anymore. Also, when people take part in social traffic, personal data is not really protected anymore.
3. That personal data belongs to the data subject and that personal data should be safe.



4. Privacy means that the data subject decides what is shared with others. It does not only contain personal data but it goes further than that. Privacy also means that when someone shares his/her personal data with others, they are released and yet not private anymore. Also, when people take part in social traffic, personal data is not really protected anymore.

### 3.2.2 Hazards

Quite a few questions were asked in the context of (potential) hazards. This shows that with regard to the processing of (sensitive) personal data, people are generally worried and reserved.

*How would you want prevention of misuse of your personal data?*

1. There is a role for the government in this.

*Could you give three examples of hazards of providing personal data?*

1.
  - a. Insurance companies could exclude certain people on the basis of personal data.
  - b. DNA could be placed on a crime scene.
  - c. The government and companies have so much of your personal data that your identity might get lost.
2.
  - a. Hacking.
  - b. Misuse.
  - c. Pursuit of profit.

*How real are those hazards? Could you rate them from 1(not really) to 5(yes, really)?*

1.
  - a. 1:5
  - b. 2:1
  - c. 3:4
2.
  - a. 1:4
  - b. 2:4



c. 3:5

*How do you think that your openness with your personal data could possible work against you?*

1. In the labor market; for instance in case of chronic illnesses. But also, insure premiums could vary. Also in combination with for instance police records, would people with many fines for speeding be treated differently based on that fact?
2. It could lead to rejections on the labor market. It could lead to hazards in taking out insurance (for instance: if you have a certain clinical picture, it can lead to rejection or higher premiums).

*How do you think that your openness with your personal data could possible work against you?*

1. Different situations:
  - a. In the labor market; for instance in case of chronic illnesses.
  - b. Also, insure premiums could vary.
  - c. In combination with for instance police records, would people with many fines for speeding be treated differently based on that fact?
2. Different situations:
  - a. It could lead to rejections on the labor market.
  - b. It could lead to hazards in taking out insurance (for instance: if you have a certain clinical picture, it can lead to rejection or higher premiums).

The answers are much alike.

### **3.2.3 Extent of Processing**

*Do you think that it should be possible to process personal data on a world-wide basis?*

1. Scientific interest comes before keeping personal data to yourself. And also on an international level: medical scientific research is important. So yes, a world-wide basis should be possible but ONLY for medical scientific research and not for commercial interests.
2. No, because there are hazards to be foreseen in the regime it may cause. But also yes, because of an overall cooperation.



*Do you think that all sorts of personal data should be known by your doctor?*

1. No, not all sorts of personal data (e.g. not financial data). However, after being informed about the possible added value of that, the opinion might change.
2. No, because it would cause a high interference with privacy, but also yes because it might help doctors to find out sooner how and in what way to help the patient.

*Do you think that it should be possible to provide people money for the use of their personal data? For instance: someone has a disease on which you want to conduct research, should it be possible to ask that ill person for certain personal data in exchange of money?*

1. Yes.
2. This is different for everyone. It can be asked to people, though, but it should be someones own consideration. On the other hand, providing money for personal data can have the effect that people become reckless with their personal data.

### **3.2.4 Management of Personal Data**

*Who, in your opinion, should be responsible for the management of personal data in the Netherlands and Europe?*

1. As an individual, you are responsible for your own affairs. In the context of medical matters however, a professional should make responsible choices. And it should not have any commercial interest! It should be relevant to use personal data. How more personal data is, the better and more interesting for commercial parties. People probably do not want their personal data used by those commercial parties, but they are not aware of the fact that it happens. There should be an independent institution to supervise research. The independency of the Dutch DPA is questioned, so it is not known whether we already have that in the Netherlands.
2. The Dutch government does not feel responsible, while the government should protect independently. But on the other hand: who is able to master this? Maybe there could be an ethical commission for the entire of Europe?



### **3.3 PRIVACY AND MEDICAL RESEARCH**

#### **3.3.1 The Distinction Between Personal Data & Medical Personal Data**

*Within the notion of privacy: do you make a distinction between personal data in general and medical data? Could you explain your answer?*

1. The distinction is in the purpose: there is a distinction to be made between personal data used for a commercial aim or for research.
2. There is a difference between personal data in general and personal data. But there is also a general and a commercial interest to be distinguished.

*What distinction do you personally make between personal and medical data?*

1. There is no distinction, but medical data should be dealt with more carefully.

#### **3.3.2 Consent**

*In case you give consent for the use of your personal data for medical research, do think it should be possible to except certain parts of that personal data?*

1. Yes, it should be possible to be selective in that.
2. This question was not really answered twice, however it was stated that the storage of personal data should not be forever, and that there should be a limitation period in that.

*Do you think that, in case you gave consent for the use of your personal data for medical research, you should be able to put an end to that consent? How should control and be ensured*

1. Yes, it should be possible to put an end to that consent at all times.
2. The management of personal data should be transparent. Results should only be able to be used by public organisations, and there should be a research protocol.

#### **3.3.3 Transparency**

*In case a data subject provides consent on the use of his/her personal data for medical research, do you think that it is important to make entirely clear whether the data subject understands the aim of the research?*

1. Yes



2. Yes, transparency is very important. However, sometimes it might not be possible or desirable to discuss the aim of a certain research in advance. In that case, the aim of the research should be explained after the research is conducted.

*Do you think that there should be more transparency on medical data and commercial companies, and if yes: who should be responsible for that and how could that transparency be accomplished?*

1. Yes

### **3.3.4 Scientific Research & Society**

*In how far do you think that results of scientific research could damage society (instead of being in favour of society, as is mostly assumed)? → For instance, due to research we can see in an early stage whether a baby will be born with down syndrome. Many people decide to abort such babies. What does this mean to our society?*

1. Yes, this could also harm society.

*Do you think that the sharing of medical data for research enhances or improves society?*

1. Yes, but only for scientific research, not for commercial interests. Also, there should be enough safeguards and control. Correlations on the basis of personal data are never 100% true, this brings hazards in relation to the conclusions that are taken based on those correlations.
2. No, because there is too much known because of medical research.

*What, in your opinion, is more important: medical scientific research (common interest or privacy (individual interest)?*

1. Medical scientific research
2. Both equally important.

*Theorem: it should be possible to share or disseminate my personal data for every research (and thus my personal interest is subservient). Yes or no?*

1. No



### **3.3.5 Social Media**

*What danger do you see in the linking of medical data with social media?*

1. That is not a comforting idea. Social media is not objective.
2. When people make the choice to share information on social media, they should be aware of the fact that there might be consequences.

### **3.4 DEATH & AGE**

*In case there is no last will of a data subject, do you think it should be possible to use personal data of that data subject?*

1. No.
2. No. When there is no last will, it should not be an option. It should work the same as with a donor card.

*Do you think that personal data needs less protection when the data subject gets older?*

1. No. There is no distinction between young or older people.
2. No, because where to draw the line?



#### **4 RECOMMENDATIONS**

The 4 tables discussed themes during the questions. The recommendations, due to time constraints, were summarized in a plenary and summarizing session. The following issues were raised:

What is medical data and what are the boundaries of medical data? Discussions here evolved around the notion of medical data and what should be incorporated in the set of medical data. Does step-counter data count as medical data, for example? Connected to this issue is the discussion surrounding responsabilisation and the limits of individual responsibility in protecting medical, or other data. Several participants pointed out that the act of collecting, storing and sharing (sensitive) data should in the first place be a responsibility of the individual. Others pointed out that this is not so easy since they do not know who has their data or that data can be shared without the subject or individual knowing.

Regarding ethical committees, there were discussions on if and how these ethical committees should be selected, trained and/or informed about state-of-the-art issues surrounding also the technical side of data protection.

Following on that, the issue of monetisation was discussed, asking if and how individuals should benefit from sharing their data, either in the form of monetary compensation or via updates on information and access to the research. Based on this, the question was raised if and whether health data is public data, or privately-owned.

Ownership of data was seen as a difficult and ambiguous topic, following also from questions regarding data responsibility – if data is public, how is responsible for it, hospitals, government(s) or individuals? - but also on data decisions. What is to be done with elder patients who cannot act as fully responsible agents when having to decide about their personal data? How about possibilities for people to opt-out? Will this always be an option, or will data sharing become a demand or prerequisite to partake in a certain medical study or treatment? Finally, the privacy-problem in itself was discussed: is it a main concern and if so, why and how does it weigh to other concerns, such as public health?

Generally, recommendations were not clearly formulated, however, some solution- directions were provided that meant evolved around transparency of research to the public, access control over medical data and some insight into how and why certain data were processed (more clarity on purpose of data use). Concerning data use, recommendations were made to actively inform and involve citizens more in research processes.



## **CONCLUSIONS**

The general conclusions of the meeting can be summarized as follows:

The reasons for participating came partially from concerns over privacy and data protection, partially from curiosity into what this project and this meeting would be about, and to learn about how and why medical research uses personal data. During the questionnaire and the interviews main directions of thought and discussion were the trade-off between data sharing for healthcare purposes and the protection of privacy and personal data. In talking about data ethics, many participants found it hard to think outside concrete examples of how and why personal data aids medical research and how it can or should be protected. The topic of anonymisation was not picked up widely: discussions were mainly directed at types of research and data use, and the limits of medical data once smartphone- and other social-media data start to become part of these types of research as well. Participants stated they learned a lot from discussing privacy and personal data issues with other citizens – and were generally happy with the HBP to conduct such participation meetings as a way to facilitate transparency



## 5 ANNEXES

### ANNEX 1

<b>GENDER</b>	
FEMALE	14
MALE	14
<b>AGE GROUP</b>	
0-25	6
26-35	3
46-55	5
56-65	7
66-75	6
76-100	1
<b>EMPLOYMENT</b>	
(Now) unemployed	12
Do not wish to answer	2
Energy	1
Financial Sector	1
Government/Public	1
Health Care	3
ICT	2
Insurance	1
Mail service	1
Marketing	1
Science	1
Student	2
<b>MOTIVATION</b>	
I am worried about privacy and data protection	5
I follow news on privacy and dataprotection	3
I follow news on privacy and dataprotection. Also, I am worried about privacy and data protection. Also, I have had issues of privacy and data protection play a role in my own life.	1
I have had issues of privacy and data protection play a role in my own life	5
I liked the opportunity to have my voice heard in an EU research project	2
I liked the opportunity to have my voice heard in an EU research project and the subject appeals to me	1
I thought the meetings were a good occasion to learn more about data protection and privacy issues in research	11



ANNEX 2: The information booklet

<b>THE INFORMATION BOOKLET</b>	
A little Abstract	1
I did not read the booklet	2
It gave a good and distorted overview of issues related to dataprotection and privacy in research	1
It gave a good overview of issues related to dataprotection and privacy in research	8
It gave a good overview of issues related to dataprotection and privacy in research and it was easy to understand	6
It was easy to understand	8
It was hard to understand	2



ANNEX 3: The questionnaire

THE QUESTIONNAIRE	
I did not think the questions were very hard to understand, but also not really easy	1
I think there was a limited ability to give nuanced answers	1
I thought the questions matched well with the information booklet	12
I thought the questions were biased	2
I thought the questions were biased and ambiguous	1
I thought the questions were too easy	1
I thought the questions were too hard	2
It is a pity that it was only possible to provide one answer, sometimes the questions were quite hard to understand, the material is hard to understand. It is good however to raise awareness with regard to this topic. Citizens know too little about this. They know too little about what happens with personal data (e.g. the personalized supermarket bonus card, etc.)	1
It requires much time to read it, some answers have little nuance, while sometimes the answers differ significantly from each other	1
It was unclear whether it was possible to provide one or more answers. Also, the questions and answers were unclear in their formulation	1
No answer	1
Questions were not always clear it was a limitation that we were able to give just one answer per question	1
Sometimes, the questions were unclear (probably due to a bad translation)	1
The questions are clearly defined, they fit well with the provided information, and are easy enough to understand	1
There was not enough nuance in the answer-options, which made it hard to choose. For instance because there were possible exceptions to think of with every answer. Also, sometimes, the answers were too different, which made it hard to choose just one answer	1



ANNEX 4

<b>THE MEANING OF PRIVACY</b>	
Certainty that my personal data is not used for profit purposes by for example companies	3
I do not have a specific idea of what privacy is to me	1
My ability choose what information about me is shared with third parties	14
My ability choose what information about me is shared with third parties. Also, certainty that my employeer cannot access my health data. In addition, certainty that insurance companies cannot access my health data. Lastly, certainty that my personal data is not used for profit purposes by for example companies	1
My ability choose what information about me is shared with third parties. Also, transparency in how information about me is being used	1
That I decide what or what not to share with others (government, friends, companies, etcetera), regardless of whether it was their request to share information or not	1
Transparency in how information about me is being used	6
Transparency in how information about me is being used and certainty that insurance companies cannot access my health data	1



ANNEX 5

PRIVATE DATA	
All of the answers (namely, the following I consider as private: data about my activities (sports, bar visits, smoking status), data about my political views, data about my religious views, information about my health status, information about who my friends are, the content of my correspondence with others)	19
I consider data about my activities private (sports, bar visits, smoking status), I consider data about my political views private, I consider data about my religious views private, I consider information about my health status private, I consider the content of my correspondence with others private	1
I consider data about my political views private. I also consider data about my religious views private	1
I consider information about my health status private	2
I consider information about my health status private. Also, I consider the content of my correspondence with others private	1
I consider the content of my correspondence with others private	4



ANNEX 6

<b>PROTECTION</b>	
I think Ethics committees can decide if my data is adequately protected	1
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	2
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	11
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. Anonymised means in this context to me that an ethical commission (existing of capable, well-selected members) decide whether the data are protected adequately or not	1
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	2



ANNEX 7

ANONYMIZATION	
I am not sure	2
I am not sure and I worry about data brokers who live off selling data-sets, and what they might do with my data	2
I am not sure and I worry about hackers breaking the anonymisation of my data	2
I am not sure, and I worry about data brokers who live off selling data-sets, and what they might do with my data	1
I am not sure. Also, I worry about misuse by insurance companies	1
I am not sure. I worry about new technological developments like e.g. super computers that can break anonymisation procedures. Also, I worry about hackers breaking the anonymisation of my data. In addition, I worry about data brokers who live off selling data-sets, and what they might do with my data. I also worry about what kind of research my data is being used for. Lastly, I worry about misuse by insurance companies.	1
I worry about data brokers who live off selling data-sets, and what they might do with my data	2
I worry about hackers breaking the anonymisation of my data	1
I worry about new technological developments like e.g. super computers that can break anonymisation procedures	4
I worry about new technological developments like e.g. super computers that can break anonymisation procedures and I worry about data brokers who live off selling data-sets, and what they might do with my data	2
I worry about new technological developments like e.g. super computers that can break anonymisation procedures I worry about misuse by insurance companies	1
I worry about new technological developments like e.g. super computers that can break anonymisation procedures, and I worry about data brokers who live off selling data-sets, and what they might do with my data	1
I worry about new technological developments like e.g. super computers that can break anonymisation procedures. Also, I worry about data brokers who live off selling data-sets, and what they might do with my data	1
I worry about new technological developments like e.g. super computers that can break anonymisation procedures. Also, I worry about hackers breaking the anonymisation of my data. Also, I worry about data brokers who live off selling data-sets, and what they might do with my data	1
I worry about new technological developments like e.g. super computers that can break anonymisation procedures. Also, I worry about hackers breaking the anonymisation of my data. Also, I worry about data brokers who live off selling data-sets, and what they might do with my data. Also, I worry about what kind of research my data is being used for. Also, I worry about misuse by insurance companies	1
I worry about new technological developments like e.g. super computers that can break anonymisation procedures. I also worry about hackers breaking the anonymisation of my data	1
I worry about what kind of research my data is being used for	1
No	2
Yes, but I worry about data brokers who live off selling data-sets, and what they might do with my data	1



ANNEX 8

<b>HOW TO SOLVE THE TRADE-OFF</b>	
I do not think there is a dilemma, since I do not feel my personal data needs specific protection	2
I think research is more important than the protection of my privacy	5
I think that it are only for some types of data that we should require high levels of protection	15
I think that the protection of my privacy is important, and I also think that scientific medical research is important	1
I think the protection of my privacy is more important than research	5



ANNEX 9

THE MAIN CONCERN & RESEARCH	
I wonder whether the outcomes of the research will actually be beneficial to society	4
I worry about my data being used for personal or financial gains instead of scientific progress	13
I worry about my data being used for personal or financial gains instead of scientific progress. I also worry that my data can be used against me	1
I worry about where my data will end up	2
I worry about where my data will end up, and I worry about my data being used for personal or financial gains instead of scientific progress	1
I worry that my data can be used against me	6
I worry that my data can be used against me. In addition, I am worried that the pretences of scientific research can consciously be misused.	1



ANNEX 10

<b>QUALIFICATIONS OF SCIENTISTS</b>	
I expect that they will not use of my data for any other research than what I have agreed to	11
I expect that they will not use of my data for any other research than what I have agreed to. I actually do not only expect this, I demand this	1
I expect them to inform me, if they find information about possible illness(es)	1
I expect them to keep me updated about their research	1
I expect they will be able to keep my data private	8
I have no idea	1
I think they should have had some training in handling personal data	2
None of the answers. But at the same time, I am not able to provide a solution myself.	1
They should be screened	1
They should have a strong developed ethical system of norms and values, and they should at all times be aware of their responsibility	1



ANNEX 11

<b>WHO CAN HAVE ACCESS</b>	
Ethical commissions is never a good idea (e.g. See the banking sector!). Every information can be accessed by hacking, and yet I do understand that parties use my personal data. In this, I find it very hard to make a distinction between different parties	1
Ethical commissions that also have the task to keeping an eye on the common interest	1
I do not think that anyone should be able to use my data for research	1
I do not think there should not be any restrictions on who has access to my data	2
I think both public organisations as well as private industry can use my data for research, but they should be stricly controlled for living up to the latest anonymisation standards and an ethics committee should review all procedures	12
I think both public organisations as well as private industry can use my data for research, but they should be stricly controlled for living up to the latest anonymisation standards and an ethics committee should review all procedures. To me, it is important that the private sector, receiving or collecting data "free of charge", is not going to use the data with a comercial or financial interest at a later stage, selling the data to, for instance, other researchers	1
I think that only publically funded organisations and institutions may use my data for research	2
I think that only publically funded organisations and institutions may use my data for research, but they should be stricly controlled for living up to the latest anonymisation standards and an ethics committee should review all procedures	8



ANNEX 12

<b>LEGITIMATELY COLLECTING DATA</b>	
A limited group under strict conditions which are fixed per research	1
Industry to develop medication or other health services	2
Nobody	1
Nobody, and if so: consent is always a necessary requirement	1
Public institutions for research purposes	8
Researchers, working at a University (and not for instance researchers of Monsanto).	1
The government	4
The government for security purposes like the prevention of terrorist attacks	7
The government for security purposes like the prevention of terrorist attacks, and also public institutions for research purposes	1
The government for security purposes like the prevention of terrorist attacks. Also, industry to develop medication or other health services	1
The government, and public institutions for research purposes	1



ANNEX 13

USE	
If my data is anonymised it may be used for all the types of research that I have agreed to have it used for	6
If my data is anonymised it may be used for any research project that I have agreed to have it used for	9
If my data is anonymised it may be used for anything researchers deem appropriate	7
If my data is not anonymised, I should be asked for permission once for the types of research someone would like to use it for	3
If my data is not anonymised, I should be asked for permission to use it everytime someone want to use it	2
My data may be used for all types of research, after my consent was asked	1



ANNEX 14

<b>FEELING INFORMED?</b>	
I do not feel informed enough about who has access to my data and what it is being used for	23
I do not feel informed enough about who has access to my data and what it is being used for. For instance, trackers on the Internet; many people know so much about me, while I do not know who exactly and what information they have on me	1
I feel informed enough about who has access to my data and what it is being used for	2
I feel informed enough about who has access to my data and what it is being used for. However, you can never exactly oversee for what exactly you give approval	1
I have not yet encountered a situation based on which I can answer this question.	1
<b>KNOW WHERE TO GET INFORMATION?</b>	
I do not know where I can get more information about the use of my data if I need it	22
I know where I can get more information about the use of my data if I need it	6



ANNEX 15

<b>IMPLICATIONS FOR OTHER PEOPLE?</b>	
Yes, I think others could potentially be affected by the use of my data. For example use of data about genetics could also hold information about my family	27
Yes, I think others could potentially be affected by the use of my data. For example use of data about genetics could also hold information about my family. This is a hard question which deserves, in my opinion, more explanation	1