

2nd Report SP12-SGA2:  
Lessons from stakeholder engagement and dialogue  
(D12.3.2 - SGA2)

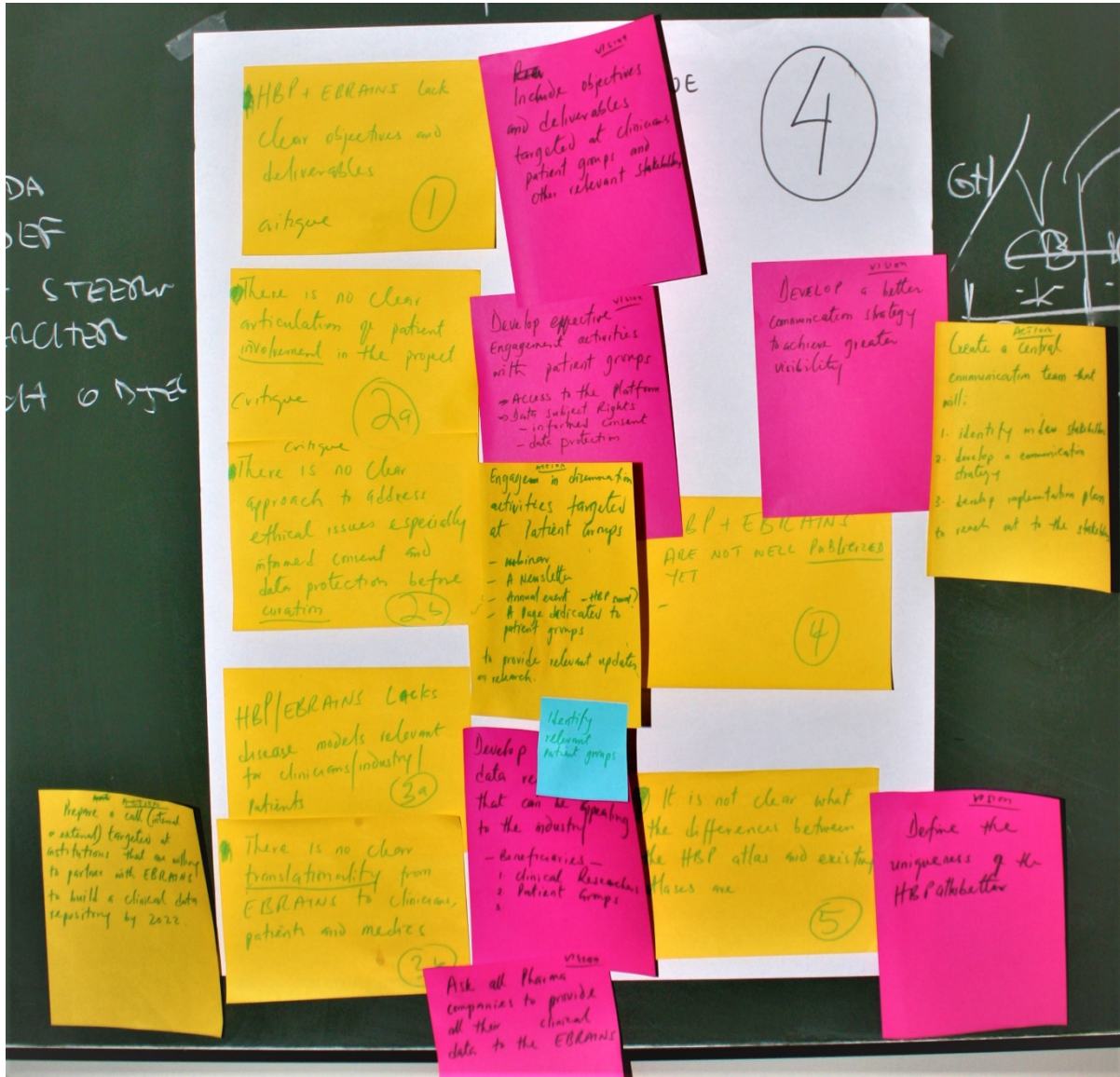


Figure 1: Cover image reflecting some of the results from our first EBRAINS community building workshop

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<b>Description in GA:</b>	<p>The report collects up on the lessons learned from stakeholder dialogue and engagement in the Human Brain Project, from the ramp-up to the end of the SGA2 phase, and it develops foundation for stakeholder engagement in the final phases of the Human Brain Project.</p>		
<b>Abstract:</b>	<p>This report collects up on the Ethics and Society activities on engagement of stakeholders and the European public in the Human Brain project (HBP). The report covers the period from start of the HBP in October 2013 to the end of the third funding period in March 2020. The activities described in this report were carried out by the Danish Board of Technology Foundation. Overall, we have worked with four main themes: data protection and privacy, potential political, security, intelligence or military (PSIM) uses or research, artificial intelligence (AI), and inclusive community building.</p> <p>In the final phase of the HBP grant period priorities could include:</p> <ul style="list-style-type: none"> <li>• Validating the HBP information material on data collection, use, policies, procedures and consent with citizens and other external audiences for e.g. in relation to ease of understanding and transparency on what how and why data is used in the HBP</li> <li>• Investigating and developing step-by-step approaches to support researchers in anticipating societal and ethical issues</li> <li>• Engaging with professional stakeholders, publics, researchers and other brain projects in international debate on neuroethical issues, including issues related to dual use research of concern and AI to stimulate debate, trust, mutual understanding and collaboration.</li> </ul>		

	<ul style="list-style-type: none"> <li>• Supporting education on societal and ethical issues of research in the HBP. In SGA3, we contribute to activities in works package nine (WP9) to develop a training programme in responsible research and innovation for EBRAINS</li> <li>• Supporting the exploration and development of an HBP strategy for commercial exploitation of its work, and assist with the citizen and stakeholder's perspectives and input on the strategy</li> </ul>
Keywords:	Engagement of Publics, public engagement, Stakeholder involvement, Data protection, privacy, disease signature, Community building, Research Infrastructure, Dual use, Neuroethics.
Target Users/Readers:	Funders, general public, HPC community, neuroinformaticians, neuroscientific community, neuroscientists, EBRAINS users, policymakers, researchers, scientific community, students.

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## History of Changes made to this Deliverable (post Submission)

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# 1. Introduction

This report collects up on the Ethics and Society activities on engagement of stakeholders and the European public in the Human Brain project (HBP). The report covers the period from start of the HBP in October 2013 to the end of the third funding period in March 2020. The activities described in this report were carried out by the Danish Board of Technology Foundation. Overall, we have worked with four main themes: data protection and privacy, potential political, security, intelligence or military (PSIM) uses or research, artificial intelligence (AI), and inclusive community building.

In this report, we give brief introductions to the work we did, and we end the report with an outline of possible priorities and lessons on organisation of stakeholder and public engagement work in the last funding round of the HBP from April 1, 2020 to March 31, 2023 (SGA3).

## 2. Engaging publics and stakeholders on data protection, privacy and disease signatures (2014-2019)

In the Ramp-up phase (RUP) of the Human Brain Project (HBP), the Danish Board of Technology Foundation (DBT) engaged stakeholders and the public on issues of data protection, privacy and disease signatures. At the time, the HBP Subprojects (SPs) were focused under the headings "Future Medicine", "Future of Neuroscience", and "Future ICT and robotics". The Ethics & Society work was structured to engage with issues under each of these headings in three cycles of activities. Stakeholder and public engagement activities were organised in Work Package (WP) WP12.3, Task T12.3.1, online engagement of citizens in Europe; T12.3.2, EU wide citizen dialogues; and T12.3.3, stakeholder engagement. The present text describes the activities under Task T12.3.2 and T12.3.3 in RUP, that were led by the DBT, and focused under the theme of "Future medicine".

In 2013, when the HBP began its work, privacy and data protection in research projects had not yet received the great attention that would soon erupt on the proposal and acceptance of the EU GDPR law. However, due to the ambitious plans on the HBP Medical Information Platform (MIP) to federate data from European hospitals, the Ethics & Society group decided to focus on these issues. The aim was to assist the Project with an increased understanding of the issues of data protection and privacy related to such an aim, and to raise awareness on possible future societal and individual level impacts of new disease signatures. The hope was that such work, could make the HBP stand out as a research project with a state-of-the-art infrastructure for data and privacy protection.

### 2.1 Initial plans on data federation and disease signatures in the Human Brain Project

In the Ramp-up phase, the plan for the Human Brain Project (HBP) Medical Informatics Platform (MIP), was to provide tools for data mining and rule-based clustering of the clinical data<sup>1</sup>. The Medical Informatics Platform would become 1) A service for clinicians for objective diagnoses and treatment of brain disease, 2) a tool for neuroscientists to apply, test and input new models and methods and 3) a tool for pharmaceutical and biotech companies for disease target discovery.

The first goal of the Medical Informatics Platform Subproject 8 (SP8) was to federate hospital and other clinical data on all brain diseases and across multiple levels of biology. The data would then be used for data mining and rule-based cluster analysis in order to derive unique objective biological signatures of brain disease. The brain signatures would then be used for diagnosis, more accurate prognosis and new types of drug discovery pathways for the development of new medicines.

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<sup>1</sup> Please note the plans for the MIP were continuously adjusted as the HBP progressed in its work.

## 2.2 Engaging stakeholders on data protection and privacy<sup>2</sup>

During 2014, the Danish Board of Technology Foundation organised two stakeholder forums for researchers in the Human Brain Project's SP8, to discuss these issues with experts from law, social science and the humanities, data protection and the medical profession<sup>3</sup>.

The first event saw experts meet for four hours of online discussion. The discussion was organised on 1) Multi-level brain data federation and protection, and 2) Development of 'disease signatures' and personalised medicine. The second event was a two-day seminar organised on these themes as well. For 2) the questions under discussion centred on the potential for new forms of stigmatisation, and the (mis)fit between clinical practice, new ways of categorising and understanding mental disease and the potential for collaborating with patient organisations.

In the run up to the seminar, the HBP received its first ethics review. The ethics review pin-pointed critical questions on data protection and privacy, and so those questions rose to the top of the agenda for the seminar. That spring (April 2014), the 'Article 29 EU Data Protection Working Party' sent out an opinion 05/2014 on Anonymisation Techniques, and together with the ethics review, the on-going discussion and uncertainty on the next GDPR-under-development formed the context for the event.

The two events ended up producing a set of recommendations for the HBP to take further. They were:

- Clarify responsibilities: Who is responsible for data protection and security?
- Perform privacy impact assessment
- Follow 'good anonymisation practices' as laid out in EU Opinion 05/2014 on Anonymisation Techniques
- Make sure subcontractors follow good anonymisation techniques. Even better: avoid subcontracting
- Stamp data with the type of consent given
- Develop a Partnering Project on the privacy concerns in the Core Project
- Seek informed consent where at all possible
- Improve transparency and trust by:
  - Engaging in collaboration and dialogue with patient associations and external experts
  - Manage expectations by being realistic about outcomes and the research process to patients, medical professionals and the public
  - Listen to concerns and adapt accordingly

Eventually, the recommendations from these two events, together with findings and recommendations from the rest of the Ethics & Society group, made its way into the Ethics & Society Opinion on data protection and privacy<sup>4</sup>.

That opinion in turn, supported efforts of establishing the HBP "Data governance working group (DGWG)" that has since coordinated the HBPs establishment of a Data Protection Officer function

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<sup>2</sup> The newsletter from the event is available here: [http://tekno.dk/wp-content/uploads/2016/04/HBP\\_Privacy\\_informed-consent\\_Policy-Options\\_01.pdf](http://tekno.dk/wp-content/uploads/2016/04/HBP_Privacy_informed-consent_Policy-Options_01.pdf)

<sup>3</sup> The stakeholder forums were organised in collaboration with the HBP Foresight Lab at King's College London.

<sup>4</sup> The Ethics and Society Opinion on Data protection and Privacy is online here: [https://sos-ch-dk-2.exo.io/public-website-production/filer\\_public/24/0e/240e2eaa-8a10-4a17-87bc-b056a3f0cc8c/opinion\\_on\\_data\\_protection\\_and\\_privacy\\_done\\_01.pdf](https://sos-ch-dk-2.exo.io/public-website-production/filer_public/24/0e/240e2eaa-8a10-4a17-87bc-b056a3f0cc8c/opinion_on_data_protection_and_privacy_done_01.pdf)

within the HBP, and support an infrastructure for data protection and management together with the HBP Ethics Support team.

## 2.3 Webinar and Stakeholder Forums on Privacy and Informed Consent (2017)

Informed consent emerged as a central concern and issue to find good solutions for work with health data in the Human Brain Project in the future. Therefore, activities continued to better understand the concept in the context of the HBP's data federation plans. Medical research depends to a large extent on peoples' health data, but these data are often particularly sensitive in nature. For this reason, medical research operates with the principle of informed consent which dictates individuals' absolute right not to be involved in medical research, unless they have given their informed consent to participation. In addition, the sensitive nature of the data makes data protection and privacy essential elements, especially when designing ICT research infrastructures like the medical informatics platform, which intends to federate data.

Therefore, on February 6, 2017 the Danish Board of Technology hosted a stakeholder webinar to open a discussion on the ethical and legal principles on informed consent in the Human Brain Project.

Four guest speakers were invited for a two-hour webinar to present their views on how to tackle the ethical and legal principles of informed consent in The Human Brain Project. Stakeholders and everyone else interested in the subject were encouraged to join the discussion<sup>5</sup>.

Since the HBP involves large datasets, aggregated forms, and has goals that reach far into the future, the right to know what your data is being used for, and the right to withdraw from HBP research is not straight forward. Looking at different aspects of informed consent, the guest speakers gave their recommendations on how to ensure sufficiently informed consent while still being able to conduct good research.

Recommendations:

- Researchers should always when possible get informed consent from data subjects, to which end they need to build trust through being transparent in their communication.
- A failure to seek informed consent, where at all possible, will most likely result in a serious public backlash to the HBP as well.
- A privacy impact assessment of personal data used in research was strongly recommended
- The participants pointed to a need for a HBP privacy officer (DPO). The DPO position was established at the start of SGA2 (March 2016)
- The importance of also considering two other basic principles related to informed consent, namely the use of data for the good of the individual versus data as a potential public good.
- Active involvement and targeted communication would, according to a representative from Alzheimer Europe, help to support the empowerment of vulnerable people such as people with dementia

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<sup>5</sup> Video from the webinars and with the speakers can be found at:

- Prof. Søren HOLM, Professor in Bioethics at University of Manchester (<https://www.youtube.com/watch?v=0414ijZCLWw>)
- Dr Daniela OVADIA, director of the neuro psychology department at the Niguarda Hospital (<https://www.youtube.com/watch?v=Px-aj-vbJWM>)
- [Dr Stephen RAINEY from HBP Ethics Management, De Montfort University](https://www.youtube.com/watch?v=2QoxGGowzi8) (<https://www.youtube.com/watch?v=2QoxGGowzi8>)
- Dr Dianne GOVE, Director of Project, Alzheimer Europe (<https://www.youtube.com/watch?v=uSqwKdsxEnc>)

- Rather than focusing on how people could withdraw from research it is important to build a framework that strengthens the acceptance by involving people in the research and communicating with them in a language they understand.
- The essence of all the above is that informed consent does not solve all problems, but that the researchers themselves also bear a large responsibility.

## 2.4 Engaging stakeholders on implications and possibilities of included 'self-tracked' health data from mobile devices in HBP data sets (2017)

In addition to in-depth exploration of the topic 'informed consent', we developed a collaboration with SP8 on the role of self-tracking practices for the HBP. The idea and motivation came from collaboration with SP8 on the MIP. Stakeholders outside the HBP were invited to join a two-hour webinar on April 20, 2017, on Self-Tracking in the Human Brain Project. At the time, there was interest among the participants to explore the options for mobile health in relation to the MIP to empower people. If HBP consider options for self-tracking however, researchers should be aware of privacy implications, risks of stigmatisation and misleading diagnoses<sup>6</sup>.

## 2.5 Stakeholder dialogues for implementing the medical informatics platform in a Danish context

Having explored issues on data protection, privacy and informed consent, the stakeholder engagement activities focused on exploring compliance issues and opportunities for implementation of the MIP in the Danish context.

### 2.5.1 *Identifying barriers for engagement in the Medical Informatics Platform (2017)*

The MIP integrates data from (University) hospitals and is a major research initiative in Traumatic Brain Injury. The Stakeholder Forums explored options for expanding the HBP user community to researchers and clinicians federating brain-related data through the MIP. Since health data are regulated differently from country to country, the focus was initially on Hospitals in Denmark: firstly, because Denmark has a long tradition in neuroscience and for collecting patient data, and secondly because as organising party, the Danish Board of Technology has a better understanding of the healthcare system in Denmark.

We initially interviewed several health professionals (including representatives from hospitals, Danish Ministry of Health and the Danish National Biobank) to ensure that there was interest from a Danish perspective. Secondly, a workshop was held with Danish brain researchers and clinicians to

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<sup>6</sup> Presentations from participants can be found on YouTube:

- [https://www.youtube.com/watch?v=Y32exJ6LnTk&feature=youtu.be&list=PLJEjgXhD0rY\\_pwyAixvLiXvqmrWtU25ME](https://www.youtube.com/watch?v=Y32exJ6LnTk&feature=youtu.be&list=PLJEjgXhD0rY_pwyAixvLiXvqmrWtU25ME)
- [https://www.youtube.com/watch?v=ePXfwA6pe5g&feature=youtu.be&list=PLJEjgXhD0rY\\_pwyAixvLiXvqmrWtU25ME](https://www.youtube.com/watch?v=ePXfwA6pe5g&feature=youtu.be&list=PLJEjgXhD0rY_pwyAixvLiXvqmrWtU25ME)
- [https://www.youtube.com/watch?v=zabeOwJ33u8&feature=youtu.be&list=PLJEjgXhD0rY\\_pwyAixvLiXvqmrWtU25ME](https://www.youtube.com/watch?v=zabeOwJ33u8&feature=youtu.be&list=PLJEjgXhD0rY_pwyAixvLiXvqmrWtU25ME)
- [https://www.youtube.com/watch?v=nYCz6bWRvE4&feature=youtu.be&list=PLJEjgXhD0rY\\_pwyAixvLiXvqmrWtU25ME](https://www.youtube.com/watch?v=nYCz6bWRvE4&feature=youtu.be&list=PLJEjgXhD0rY_pwyAixvLiXvqmrWtU25ME)
- [https://www.youtube.com/watch?v=O-WOKYhhXa8&feature=youtu.be&list=PLJEjgXhD0rY\\_pwyAixvLiXvqmrWtU25ME](https://www.youtube.com/watch?v=O-WOKYhhXa8&feature=youtu.be&list=PLJEjgXhD0rY_pwyAixvLiXvqmrWtU25ME)



present the MIP and discuss which ethical, legal and practical issues that should be solved before they could join<sup>7</sup>.

The recommendations on implementation in the Danish context were<sup>8</sup>:

- Clarify who, among Danish healthcare actors, can make the decision about joining the MIP and engage clinicians as early in the process as possible.
- Develop precise standard procedures on how to collect clinical data and which datasets should be included in the MIP in order to ensure a high quality of data.
- Establishment of national working groups consisting of representatives from hospitals including clinicians, neuroscientists and technicians.
- Develop clear-cut information material targeting the users and changing the terminology from sharing data to 'sharing data analysis' or 'sharing data aggregates'.
- Send a data governance support person physically to the hospitals when introducing the MIP.

Furthermore, a central outcome of the workshop and interviews was establishment of good contact with the Danish National Hospital (Rigshospitalet). The contact proved the gateway to the first installation of the MIP in Denmark.

## 2.5.2 *Implementing the Medical Informatics Platform (MIP) at the Danish National Hospital (2019)*

The first step in the implementation of the MIP in Denmark was a teleconference about the development of a partnership between the Neuroscience Centre (NRU) at the Danish National hospital (Rigshospitalet) and the Human Brain Project (HBP).

Questions discussed during the teleconference included:

- Who will benefit from a partnership with the HBP?
- What are the possible obstacles for developing a partnership?
- What will be the next step(s)?

The teleconference took place in February 2019 and allowed the NRU to get familiar with the MIP and its functionalities before deciding to move to the stage of data sharing, and it resulted in NRU taking action to install the local MIP at the Danish national hospital. A local MIP was installed at the Danish National Hospital.

The MIP<sup>9</sup> provides the unique capacity to perform federated analysis of data distributed across several hospitals, without moving out, uploading or copying these data. The latter always stay in their hospital of origin, exclusively. In addition, federated analyses are performed on fully anonymised data, and only provide aggregated results (no individual finding), thus offering the highest level of data privacy and security according to GDPR standards.

As detailed below in Figure 2, the installation and running of the MIP include several steps. The first step consists of establishing a partnership between the user and the HBP and installing a "MIP local" which is not connected to any other MIP or networks, and thus does not enable data sharing. The aim of the conference was to inform about HBP in general and the MIP in particular.

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<sup>7</sup> More on the workshop here: <http://hbp.tekno.dk/events/workshop-using-big-data-to-understand-the-human-brain-and-its-diseases/>

<sup>8</sup> Newsletter from the workshop: [https://tekno.dk/wp-content/uploads/2016/04/Newsletter\\_Directions\\_federated\\_data\\_HBP\\_01.pdf](https://tekno.dk/wp-content/uploads/2016/04/Newsletter_Directions_federated_data_HBP_01.pdf)

<sup>9</sup> A number of other relevant documents describing the MIP are available at <https://hbpmmedical.github.io/deployment-pack/> including Ethics considerations, IT requirements and instructions on how to install the MIP, the user manual, and the detailed IT description of the MIP components.

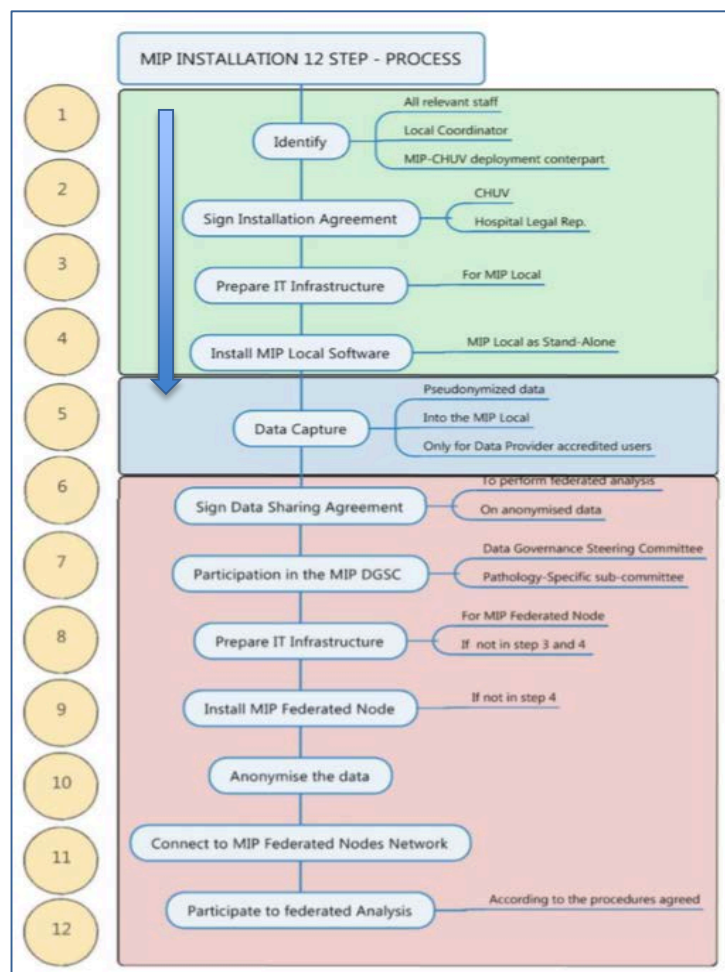


Figure 2: MIP installation steps

The blue arrow indicates where the Danish National hospital is in this process.

## 2.6 Engaging European publics on data protection and privacy in research projects (2016)

In addition to engaging experts, the DBT also coordinated the first EU-wide dialogue of the HBP with lay citizens<sup>10</sup>. The dialogues took place in Austria, Bulgaria, Poland, Portugal, the Netherlands and Sweden, and engaged 123 citizens for a 3-hour meeting<sup>11</sup>. Before the meeting, the citizens were given information material on key questions in their local language<sup>12</sup>.

The meetings produced six main recommendations for the HBP:

- There should be transparency on who uses personal data in the HBP, as well as how the data is being used
- Communication should be clear, detailed and honest
- Citizens would like to know about control measures taken for protection of data
- The HBP should explain the approach taken to get consent for the use of data

<sup>10</sup> The newsletter from those meetings can be found here: [http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter\\_Citizenmeeting2016.pdf](http://www.tekno.dk/wp-content/uploads/2016/04/Newsletter_Citizenmeeting2016.pdf)

<sup>11</sup> The standard programme can be found here: [http://hbp.tekno.dk/wp-content/uploads/2017/08/Short\\_Program\\_HBP\\_citizenMeetings\\_.pdf](http://hbp.tekno.dk/wp-content/uploads/2017/08/Short_Program_HBP_citizenMeetings_.pdf)

<sup>12</sup> The standard in English can be found here: [http://hbp.tekno.dk/wp-content/uploads/2017/08/HBP\\_Cit\\_meetings\\_informationleaflet.pdf](http://hbp.tekno.dk/wp-content/uploads/2017/08/HBP_Cit_meetings_informationleaflet.pdf)

- Data from citizens should be safeguarded from use by for-profit third parties
- 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

Questions on privacy and data protection continued as focal points under the next two rounds of citizen engagement in the HBP. They focused on dual use and AI (see 3.2 and 5.2). In the final phase of the HBP (SGA3), questions on data protection and privacy are again relevant, and in chapter 7, we collect what was learned, and how we are planning to take those lessons into the work for the period April 2020 to March 2023.

## 2.7 Data protection and privacy in the final period of the Human Brain Project (HBP)

The themes on data protection and privacy continue to be relevant for the HBP. With the February 19, 2020 launch of the EC strategy for “Shaping Europe’s digital Future”, they are joined by additional issues on the responsible development of AI and AI technologies. Presently, there is therefore intense focus and awareness on privacy and other fundamental human rights in relation to development of AI or machine learning systems and artificial neural networks. That focus is not likely to decrease over the next years. Machine learning and neuromorphic computing are central technologies and scientific approaches within the HBP efforts of realising a European Research Infrastructure for Brain research. Therefore, the topic of privacy and data protection remain of key importance to the HBP, and the insights and lessons learned on this topic are foundational to the work with dual use, artificial intelligence undertaken in following SGAs, and continued in SGA3 with neuroethics, AI, dual use and community-building.

## 3. Dual use of neuroscience and ICT research in HBP (2016 - 2018)

Research in brain sciences increase capabilities to access, assess and affect thought, emotion and behaviour. While much of this research and development is directed towards clinical use, it also has applications in other settings, notably in the political, security, intelligence and military (PSIM) domains. This is often referred to in terms of ‘Dual Use’ or ‘Dual use of concern’, the latter, is the term used by the HBP’s Ethics and Society group in its opinion on Dual use.

In the first ethics reviews and conversations with HBP’s Ethics Advisory Board (EAB), it became clear the research taking place in the Project could be developing insights and technologies raising potential dual use issues of concern, and in order to better understand what those issues could be, stakeholders and European publics were consulted during SGA1

### 3.1 Future of ICT and Robotics - Dual use (2016)

As part of the future of ICT and robotics focus of SP12 during the Ramp Up Phase (RUP), Task T12.3.3 organised a seminar and a webinar<sup>13</sup> which focused on potential for dual use of the research being carried out in the HBP<sup>14</sup>, and experts expectations to future computing and development of increasingly intelligent machines. The seminar aimed to develop a dialogue on dual use issues and risks, and participants included HBP researchers and experts in issues of dual use of science and technology. The workshop focused on what the key dual uses of concern were for the research and

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<sup>13</sup> The webinar is online here: <http://hbp.tekno.dk/events/webinar-the-future-computing-and-robotics/>

<sup>14</sup> More on the workshop here: <http://hbp.tekno.dk/events/seminar-dual-use-future-computing-neurorobotics-in-the-human-brain-project/>

development carried out in the HBP, what the social and ethical implications might be, and how various stakeholders could influence possible military applications of this research.

Historically, research has often drifted between the civilian and military spheres, and at the workshop several research areas of the HBP were considered to be of great relevance to the battlefield of the future. Recommendations included fostering a culture of responsibility and awareness in the HBP, by developing education and by continuing the system for access limitation to the ICT platforms. On top of this, was the recommendation that an international discussion was necessary on use and misuse of research like that being undertaken in the HBP.

The findings of the workshop were summarised in a newsletter<sup>15</sup>, and it framed the discussion of a meeting on Dual Use held at the HBP Summit, Florence 2016<sup>16</sup>. The RUP work on dual use helped determine the focus for the SP12 work on dual use in SGA1 and SGA2 and the result of the engagement activities on dual use, were summarised in the Dual Use background report which was integrated in the Dual Use Opinion Report and the draft Dual Use Action Plan for SGA2 (SGA1 Deliverable D12.5.4 (D70.4, D39))<sup>17</sup>.

Lessons learned:

- HBP research is of great relevance to military and other dual use actors
- Need for HBP internal training and education to foster responsibility
- Need for international discussion of how to handle dual use potential in neuroscience research that is combined with future computing technologies like neuromorphic computing

## 3.2 Online and Face to Face Citizen Engagement on Dual Use of Neuroscience Research (2017)

Picking up on the output from the Future of ICT and Robotics workshop and webinar, SP12.3.1 in SGA1 organised citizen engagement on the topic of dual use of neuroscience research. To this end, a dual methodology was adopted, carrying out an online survey in 10 EU countries (Belgium, Bulgaria, Denmark, France, Germany, Italy, Lithuania, Malta, Portugal and Slovakia) engaging 2048 people<sup>18</sup>, and citizens workshops in 8 European countries (Denmark, England, Germany, Italy, Lithuania, Malta, Portugal and Slovakia) engaging 241 people<sup>19</sup>. In both cases, recruitment was efforts sought to approximate the participants to the demographic composition of each of the respective countries. The focus of both activities was to investigate what Europeans think about the possibility that civilian research could be used for political, security, intelligence or military (PSIM) purposes.

Recommendations:

- Even though citizens support research, even if it has PSIM potential, they do express concern about this. Particularly regarding surveillance, privacy and hacking, AI, social and political control as well as manipulation.
- Citizens also were in favour of openness about research and results, also for research that has potential PSIM use. In fact, they called for more openness and better communication from researchers.

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<sup>15</sup> Newsletter is online here: [https://tekno.dk/wp-content/uploads/2016/04/HBP\\_Newsletter\\_DualUse\\_Final\\_01.pdf](https://tekno.dk/wp-content/uploads/2016/04/HBP_Newsletter_DualUse_Final_01.pdf)

<sup>16</sup> Description of that event can be found here: <http://hbp.tekno.dk/events/workshop-sp12-eab-and-ethics-rapporteurs-joint-workshop-on-dual-use/>

<sup>17</sup> The Opinion is online here: [https://sos-ch-dk-2.exo.io/public-website-production/filer\\_public/77/61/7761fdcd-b0a0-40a2-a6bd-904d68d52b87/opinion\\_dual\\_use\\_hbp\\_ethicsociety.pdf](https://sos-ch-dk-2.exo.io/public-website-production/filer_public/77/61/7761fdcd-b0a0-40a2-a6bd-904d68d52b87/opinion_dual_use_hbp_ethicsociety.pdf)

<sup>18</sup> More on the online survey here: <http://hbp.tekno.dk/events/online-survey-dual-use-of-human-brain-projects-research/>

<sup>19</sup> More on the citizen workshops and their results: <http://hbp.tekno.dk/events/citizen-workshop-dual-use-of-human-brain-projects-research/>

- Citizens called for international regulation and ethics guidelines, as well as accompanying monitoring and enforcing bodies.
- In general, the citizens called for debate about what research should be publicly funded, whose interests it should serve and what it should be used for.

Overall, the citizens expressed a need for more dialogue on dual use and PSIM issues, more information on research where such issues play a role, as well as involvement in priority-setting on types of research where these issues are present.

### 3.3 International Policy Seminar on Dual use of Neuroscience and ICT research (2018)

Task T12.3.2 in SGA1 organised a policy seminar held March 22, 2018 in Brussels<sup>20</sup>. Policy advisers including Project Officers from the European Commission as well as military professionals and a number of dual use experts joined the seminar. The seminar was the culmination of the SP12 work on dual use, which was initiated in the RUP, with the workshop and webinar on Future of ICT and Robotics. The aim of the seminar was to bring awareness to the draft SP12 Opinion on Responsible Dual Use and to discuss and collect feedback on the draft Opinion. In addition, the seminar collected feedback on the HBP's 'Dual Use Action Plan', which set forth how HBP would continue to address dual use. The seminar was co-organised by SGA1 WP12.1 and WP12.4.<sup>21</sup> Importantly, a working group was set up in the HBP to continue to address dual use issues and implement the recommendations from the Ethics and Society Opinion.

## 4. Public engagement and stakeholder involvement efforts on artificial intelligence

In the third HBP funding phase (SGA2), artificial intelligence (ai), its potential and its relation to the HBP emerged as pressing issues. The Ethics and Society group decided to prioritise an exploration of the relevance of general ethical and societal questions asked on AI to the HBP. The stakeholder and public engagement activities developed by the Danish Board of Technology Foundation set out to explore the breath of issues raised by AI from politics, human rights and law to the economy, education and healthcare. A two-step process was planned, where 1) Experts were invited to the AI 360 workshop in Copenhagen in March 2019. They included recognised experts in human rights, ethics, law, social science, culture, politics and economy. During two days they went through a systematic process of deliberation about the multi-dimensional and thorough treatment of AI and its implications for our future societies. Then, during the fall of 2019 and the early months of 2020, EuropeSay citizen meetings took place across Europe engaging more than 900 European citizens in 156 separate events.

### 4.1 Artificial intelligence - AI360 I COPENHAGEN (2019)

The public engagement contribution to the SP12 efforts concerning artificial intelligence were initiated with the AI360 I COPENHAGEN - a multi-disciplinary expert and stakeholder workshop.

The AI360 methodology was developed specifically for this workshop. The methodology is a multi-criteria analysis where participants alternate between being in competence-specific groups

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<sup>20</sup> More information on the policy seminar: <http://hbp.tekno.dk/events/seminar-on-dual-use-and-research-policy/>

<sup>21</sup> The Ethics and Society Opinion on Dual Use is online here: [https://sos-ch-dk-2.exo.io/public-website-production/filer\\_public/77/61/7761fdcd-b0a0-40a2-a6bd-904d68d52b87/opinion\\_dual\\_use\\_hbp\\_ethicsociety.pdf](https://sos-ch-dk-2.exo.io/public-website-production/filer_public/77/61/7761fdcd-b0a0-40a2-a6bd-904d68d52b87/opinion_dual_use_hbp_ethicsociety.pdf)

addressing aspects that fall within one specific dimension of society which matches their professional competences, and reviewing the input developed in the other dimension groups.

The dimensions cover all aspects of society and thus the outcome of the workshop is a holistic 360-degree assessment of how artificial intelligence affects society.

The AI360 I COPENHAGEN event was followed-up by the EuropeSay on AI citizen engagement, as described below. The conclusions and recommendations from both will continue to be addressed by WP9 in SGA3.

Recommendations:

- There is still time to act to ensure the positive potentials of AI can be realised
- However, there are some fundamental negative consequences of AI which do not currently have any solutions. These include the expected unequal distribution of costs and benefits related to the implementation of AI, as well as the massive potential for manipulative and abusive uses of AI technology

## 4.2 Citizen Engagement on Societal Implications of Artificial Intelligence - EuropeSay on AI (2019-2020)

The next step in SP12's public engagement efforts on artificial intelligence was to use the outcomes of AI360 I COPENHAGEN as input to a Europe-wide citizen engagement process, EuropeSay on AI.

To this end, DBT developed a new methodology, GlobalSay, making use of the online engagement tool, EngageSuite. The GlobalSay methodology enables any citizen to set up meetings anywhere, at any time and with anyone. This means that the consultation is designed to consist of multiple small scale meetings. Each meeting is supported by an online platform guiding participants through the process, providing information and questions for discussion before posing questions for individual voting.

EuropeSay on AI had 156 events across 13 European countries with 928 participants.

Recommendations:

- Participants were generally positive towards AI, but also have significant concerns about its potential uses. Concerns included what combining seemingly disparate data could tell about an individual, they were concerned about what it could tell about philosophical views, their mental and physical health and their economic standing. At the same time, participants were concerned about what data was collected and available on them, but they did not feel that they had any control over this data or its collection.
- The second overall message was that there should be human involvement in AI decisions. While AI is acceptable, it should primarily act to support decision making, not oversee it. This also means that the people operating it should be able to understand the recommendation or conclusion, what it is based on and what data is used to make that decision. Black box AI is not acceptable.
- The third message, which was very clear, was that AI should be regulated. Only 3% of participants were not in favour of regulating AI. The type of regulation that was voted for the most was a case-by-case certification of every AI system being used, along the lines of how genetic technology and chemicals are regulated today.

## 5. Exploring international collaboration on developing public engagement for addressing neuroethical questions (2019-)

During 2019, we engaged with the Neuroethics working group of the International Brain Initiative (IBI). The IBI itself was established in 2017, and founding members include the Australian Brain Alliance, Japan Brain/MINDS Project, Korea Brain Initiative, the E.U. Human Brain Project and the U.S. BRAIN Initiative. The IBI has two running working group and three additional working groups in the making. The two established working groups include: Global Inventory of Brain Projects and Global Neuroethics.

The Global Neuroethics Working group had defined public engagement as a key priority for its work in 2019. Building on the 5 neuroethics questions developed during its first year of operation, the groups wanted to investigate the need and potential of meaningful and successful public engagement with issues in neuroethics. Therefore, there was a need for researching strategies and creating best practices for public engagement in a variety of cultural and geographic settings. The group had set up a multi-step approach towards this aim. The first step was smaller 1.5-day Global Neuroethics Pre-Summit Workshop<sup>22</sup>. The workshop was held in Uppsala, Sweden in May 2019, co-hosted by the HBP<sup>23</sup>. The second step was a 2-day Global Neuroethics Summit in Daegu, Republic of Korea in September 2019 that coincided with the 2019 International Brain Research Organization Congress.

From these meetings it became clear that there are significant differences to how the World's brain projects understand public engagement and the neuroethical issues of importance. Cultural context could be an interesting topic for further exploration in moving forward on the understanding of neuroethical questions and advancing international collaboration. The workshops also resulted in work on a joint publication that is under development with the neuroethics group of the IBI.

In SGA3, we take the network and insights from these two events into a development of a concept for global public engagement on neuroethical questions and test it in Europe. The aim being to increase and deepen our understanding of the ethical issues, the cultural aspect that influence our understanding of the issues, and the possibilities for moving forward in advancing international collaboration.

## 6. Inclusive Community Building for a European Neuroscience Research infrastructure (2015-2020)

### 6.1 Community building efforts on theory and data for advancing future neuroscience and the Human Brain Project

The first stakeholder workshop on community building was organised by the Danish Board of Technology Foundation as part of its work in the HBP Ethics and Society group. The workshop focused on community-building and was organised in May 2015. The seminar came at the heel of a mediation

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<sup>22</sup> The summary report of the workshop can be accessed here:

<https://emdesk.humanbrainproject.eu/shared/5e7cd4078fa6e-4e62dc7665ab7b0c300173e984407563>

<sup>23</sup> The background setting for the Uppsala Workshop: [http://hbp.tekno.dk/wp-content/uploads/2019/05/Background-Packet\\_Uppsala-Neuroethics-Workshop\\_May-2019\\_email-version-1.pdf](http://hbp.tekno.dk/wp-content/uploads/2019/05/Background-Packet_Uppsala-Neuroethics-Workshop_May-2019_email-version-1.pdf)

The background setting for the Daegu meeting: <https://globalneuroethicssummit.com/>

process in the HBP. The outcome of that process were recommendations for an extensive restructuring of the Project. From the mediation report<sup>24</sup>, the workshop focused on two recommendations made in the executive summary:

- The HBP should define a unique set of concrete and achievable long-term objectives, which can be realized within the projected timeframe and with the financial resources available. To this end, it is recommended that the scientific program be carefully re-evaluated. Concentration on a smaller number of properly prioritized activities will be required. *Research activities should focus on the development of a set of models that complement each other and integrate multiple scales and perspectives, together with the specification, design, implementation and testing of IT platforms enabling and exploiting these models. The HBP should provide access to existing experimental neuroscientific data. It should not attempt to fill all the gaps in structural and functional data, but should rather focus on dedicated and targeted experiments, which will be required for the development and provisioning of the IT platforms.*
- *Cognitive and systems neurosciences should be (re-)integrated by means of a new subproject comprising at least 3-4 work packages. These should cut across, and thereby link, the existing subprojects. The crosscutting activities should demonstrate the value that the evolving IT platforms can add to the solutions of concrete and ambitious problems in cognitive and systems neuroscience in an interdisciplinary research approach.* These crosscutting activities should be substantially funded by a reallocation of the budget based on an assessment of the scientific quality and programmatic fit of the work planned in the subprojects.

The seminar therefore brought together HBP researchers with cognitive neuroscientists from outside of the HBP. At the seminar researchers from the HBP gave the audience insight in the work with different aspects of building the ICT infrastructure and the aim with building such facilities.<sup>25</sup>

Recommendations coming from the seminar were:

- Communicate more about the research being done in the subprojects
- The Project should still have several objectives, e.g.:
  - assist in understanding how brains fail
  - take a particular disease or drug design as a starting point
  - network building between internal and external researchers could be a success in itself
- Develop plans for how the horizontal integration should take place. It will not 'just happen'. Find a point of connection between bottom-up and top-down approaches and create a bridge between the molecular and the cognitive level (multi-level integration)
- Prioritise building in plasticity and neuro modulation in the ICT brain models
- Set up a 'brainstorming structure mechanism' where crazy ideas can develop and be tested.

## 6.2 Investigating frameworks and models for research infrastructures (2018)

SGA1 Task T12.3.2 organised a webinar with The European Research Infrastructure Consortium (ERIC) and the European Strategy Forum on Research Infrastructures (ESFRI). The aim was to explore the options for developing the HBP Research Infrastructure (RI), and the role of the DBT was to facilitate an open forum for questions and discussion. The representatives from ERIC and ESFRI provided

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<sup>24</sup> The 2015 Mediation report is online here: [https://www.fz-juelich.de/SharedDocs/Downloads/PORTAL/DE/pressedownloads/2015/15-03-19hbp-recommendations.pdf?\\_\\_blob=publicationFile](https://www.fz-juelich.de/SharedDocs/Downloads/PORTAL/DE/pressedownloads/2015/15-03-19hbp-recommendations.pdf?__blob=publicationFile)

<sup>25</sup> The newsletter from that seminar can be found here: [http://tekno.dk/wp-content/uploads/2016/04/Newsletter\\_FutureNeuroscience\\_Community\\_HBP\\_01.pdf](http://tekno.dk/wp-content/uploads/2016/04/Newsletter_FutureNeuroscience_Community_HBP_01.pdf)



information on legal and financial frameworks for the establishment and operation of research infrastructures in Europe.

The objective of this webinar was informing about the organisation of ERIC and ESFRI and discussing the perspectives and alternatives to these frameworks in relation to the HBP.

Question that was discussed during the webinar<sup>26</sup>:

- What kind of Research Infrastructure do we want?
- What kind of Research Infrastructure frameworks exist?
- How does the HBP fit with ESFRI and ERIC?
- What is needed to be successful with an ERIC solution?
- What alternatives exist?

Recommendation:

- ESFRI differs between *single site* and *distributed* RI. The HBP is characterised as a distributed RI that is connected through a Central Hub. The development of a successful governance and management infrastructure in a distributed RI, like the HBP, is of higher complexity than is often the case for the single-site RI. This also means that it can be difficult to gather the relevant people and to make the governance and management transparent.

## 6.3 Open Research Agenda Setting in HBP and EBRAINS (2018)

During SGA2, Task T12.3.2 (Stakeholder Forums) organised a webinar with experts on open research agenda setting. This, in order to inform about how this can be utilised to improve research and innovation, in relation to the Human Brain Project<sup>27</sup>.

Furthermore, the webinar meant to highlight major advantages of involving citizens and multi-stakeholders in research and innovation (R&I), the distinctive features of the concepts Responsible Research and Innovation (RRI), Open Science and Open Research agenda setting with talks from experienced researchers utilising these methodologies.

In order to inform the HBP and briefly presents the concepts, as well as the potential benefits that may arise from a broader implementation of Open Research Agenda Setting within the HBP, a news brief on ORAS for community building with recommendations for how to implement this in HBP SGA3 Community building was also written.

The news brief was envisioned to support the implementation of ORAS in SGA3. However, since ORAS was already mid 2019 accepted to be part of the community engagement in SGA3, the document has, instead, been produced as a note to the community building strategy, describing how ORAS will be implemented<sup>28</sup>. The strategy will be finalised by the Community Building Working Group in SGA3.

## 6.4 Developing the EBRAINS Community (2019)

In Late 2019, an EBRAINS community Building workshop was organised in Brussels by SGA2 Task T12.3.2 (Stakeholder Forums). The results from the workshop fed into the preparation of the community building efforts in SGA3, WP4, T4.14 (Inclusive Community Building).

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<sup>26</sup> More information on the webinar here: <http://hbp.tekno.dk/events/webinar-frameworks-for-research-infrastructures-in-europe/>

<sup>27</sup> Video recordings from the webinar can be found at: <http://hbp.tekno.dk/events/webinar-on-open-research-agenda-setting-and-the-human-brain-project/> and is public available on YouTube.

<sup>28</sup> The note is produced as a confidential project document.

The workshop was one of the first steps in building a community around the EBRAINS Platform and the results of the workshop will be fed directly into the making of a community building strategy.

The first EBRAINS Community Building Workshop was designed to achieve a better understanding of the wishes and needs of industry and patient associations for being part of and benefitting from an inclusive EBRAINS community. Participants representing neuroscience associations and participants with a clinical background were also welcomed. Different aspects of the EBRAINS Platform and general HBP research were presented to the participants at the EBRAINS community building workshop.

The workshop served as a first glance into the wishes and needs of potential members of the future inclusive EBRAINS community. The participants represented a broad stakeholder group which illustrates how far EBRAINS and its community might reach in the future. While there was much support and interest in the future EBRAINS community, the results of the workshop also illustrated how much effort is still needed to develop the Platform and increase communication efforts.

Lesson learned and primary actions we will take in SGA3:

- Establishment of Community Building Work group,
- Assign Community Managers and define tasks and objectives,
- Formulation of strategy and timeline for CBWG work (Community Building Roadmap),
- Clearly formulated value proposition and pitch for EBRAINS to be used internally and externally,
- Further value propositions for service categories,
- Definition of stakeholders and strategies for targeted communication and engagement,
- Strategy for user recruitment and engagement,
- Strategy for broad stakeholder and non-user engagement.

In chapter 7, we collect the lessons learned on the themes and recommendations of importance to professional and public stakeholders of the Human Brain Project, and we provide an outline for our work in the SGA3 phase of the HBP.

## 7. Wrapping up and looking forward

The Human Brain Project, as the only major strategic research project of the European Commission made responsible research and innovation (RRI), a key ambition from the very beginning. In the ‘Description of Work (DoW)’ for the ramp-up phase, the Project committed to “[...]follow a policy of Responsible Innovation, providing effective governance of ethical issues arising within the project including issues arising from research itself (experimentation with human volunteers, use of data in clinical archives, animal experimentation, ownership, allocation of public spending), its potential applications (new techniques for diagnosing and treating brain disease, new classes of computing systems and intelligent machines, potential military applications), and its philosophical and conceptual implications. As part of this policy the project will set up and manage a large-scale Ethics and Society Programme (see section 1.3.2.12), which will absorb approximately 3% of the total project budget.”<sup>29</sup>

The public and stakeholder engagement activities were a central part of the commitment to responsible innovation by providing insight into points of views of public and private stakeholders, identifying emerging controversies and providing the Project with recommendations on how to take into account any issues or concerns raised its work.

Looking across the themes and recommendations emerging from our work with stakeholder and public engagement, several issues cut across all themes. They include:

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<sup>29</sup> Page 204 in “Part B - Narrative Information” in Annex 1 “Description of Work” of the Grant Agreement 604102 for the Human Brain Project.

A) Transparency, clear, detailed, honest, easy-to-understand as well as easy-to-find information on:

- Data use, data policies, procedures and control measures
- Beneficiaries collecting data and for what purposes
- Implementation of informed consent
- Policies on collaboration with third parties and commercial exploitation of HBP work
- Clear information material on implementing the Medical Informatics Platform (MIP)

B) Education and debate:

- Education of researchers on the possible societal and ethical implications of their work
  - E.g. public and professionals are concerned about the potential for abuse and manipulation, and lack of clarity on e.g. accountability and liability
- Increased debate on prioritisation of research funds and who the beneficiaries of research are
- Visible initiatives by researchers/research project in the international debate on dual use research of concern and social and ethical issues raised by the combination of neuroscience and new computing technologies and techniques

C) Inclusive community building involving e.g. clinicians, patient organisations, humanities and social sciences:

- Communicate continuously on research in the HBP and the possibilities to become involved
- Have a specific disease or drug design as a starting point for making a difference
- Develop strategic plans for community building and organise the Project to allow for networks and for collaboration across the Subprojects to develop
- Set up informal 'brainstorming structure mechanism' where crazy ideas can develop and be tested

Of the above issues many of them were identified in the very first years of the Project, and therefore have been addressed through various measures. E.g. the Data Governance Working Group (DGWG)<sup>30</sup>, has developed policies, and procedures to address items on data use, policies, procedures and control measure, data collection, purposes and informed consent. Information material on the MIP have also been developed<sup>31</sup>. For the issues under B), The HBP education programme, has also hosted several workshops on ethical and societal issues related to HBP work. Finally, for C), we, and other partners in the Ethics and Society group, have worked extensively to understand needs of stakeholders and mechanisms of community building.

Still, the issues and recommendations under A), B) and C) provide insight into items of continuous public and stakeholder interest and concern. They also inspire areas work for increased refinement and impact of our work with public and professional stakeholders within the HBP. In the final phase of the HBP, SGA3, priorities could include:

- Validating the HBP information material on data collection, use, policies, procedures and consent with citizens and other external audiences for e.g. in relation to ease of understanding and transparency on what how and why data is used in the HBP
- Investigating and developing step-by-step approaches to support researchers in anticipating societal and ethical issues
- Engaging with professional stakeholders, publics, researchers and other brain projects in an international debate on neuroethical issues, including issues related to dual use research of concern and AI, to stimulate debate, trust, mutual understanding and collaboration.

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<sup>30</sup> Work of the DGWG can be found here: <https://www.humanbrainproject.eu/en/social-ethical-reflective/dgwg/>

<sup>31</sup> <https://hbpmmedical.github.io/deployment-pack/>

- Supporting education on societal and ethical issues of research in the HBP. In SGA3, we contribute to activities in WP9 to develop a training programme in responsible research and innovation for EBRAINS
- Supporting the exploration and development of an HBP strategy for commercial exploitation of its work, and assist with the citizen and stakeholder's perspectives and input on the strategy

Finally, we have learned the value of dialogue and collaboration for our own work in the Human Brain Project. The implementation of RRI in the HBP was a major ambition. It involved introducing ideas, questions, concepts and ways of working unfamiliar to many researchers in the HBP. In order to succeed, relationship building within the Project has been a major factor and effort. The fruits of which are beginning to clearly show with e.g. the inclusion of Open Research Agenda setting approaches in the EBRAINS infrastructure Work Package 4 in SGA3 (Task T4.14), and the collaboration on MIP implementation in Denmark.

In SGA3, we will build our work on the collaborations already established in the HBP, and work with the HBP researchers to develop our content and questions (as much as possible) to align with where they see a potential for enhancing e.g. international collaboration by addressing e.g. neuroethical issues. Unlike any other of the World's Brain Projects, the HBP has committed itself to better understanding societal needs and values. Because of this, the Project is in a unique position to develop an EBRAINS infrastructure that is aligned with European values, developed and supported by society and professional user communities.