



HAL
open science

Privacy in the Human Brain Project: The Perspective of Ethics Management

Bernd Carsten Stahl

► **To cite this version:**

Bernd Carsten Stahl. Privacy in the Human Brain Project: The Perspective of Ethics Management. Anja Lehmann; Diane Whitehouse; Simone Fischer-Hübner; Lothar Fritsch; Charles Raab. Privacy and Identity Management. Facing up to Next Steps: 11th IFIP WG 9.2, 9.5, 9.6/11.7, 11.4, 11.6/SIG 9.2.2 International Summer School, Karlstad, Sweden, August 21-26, 2016, Revised Selected Papers, AICT-498, Springer International Publishing, pp.52-55, 2016, IFIP Advances in Information and Communication Technology, 978-3-319-55782-3. 10.1007/978-3-319-55783-0_5 . hal-01629169

HAL Id: hal-01629169

<https://inria.hal.science/hal-01629169>

Submitted on 6 Nov 2017

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution 4.0 International License

Privacy in the Human Brain Project : The Perspective of Ethics Management

Bernd Carsten Stahl

De Montfort University, Leicester, UK
bstahl@dmu.ac.uk

Abstract. The paper describes the ethics management function of the human brain project. It highlights some of the specific privacy-related issues of the project and the strategies that ethics management uses to address these.

Keywords: Human Brain Project, neuroinformatics, data protection, privacy, ethics management

The Human Brain Project (HBP; www.humanbrainproject.eu) is a European, Flagship initiative that facilitates and supports a global, united effort to understand the brain by providing platforms and tools along with neuroscientific and medical data, to study the brain, its diseases and to catalyze new brain-inspired technologies [1].

The HBP aims to create and operate a European scientific research infrastructure for brain research, cognitive neuroscience and other brain-inspired sciences. It gathers, organizes and disseminates data describing the brain and its diseases. Of particular importance for us is the stated aim that the **HBP is dedicated to responsible and ethical research**. In addition, the HBP is an extensive collaboration between scientists, researchers and institutions around the world. This includes its nature as an open-science initiative. The HBP is developing Information Communication (ICT) Tools that have applications in neuroscience, medicine and computing

It is important to underline that the focus on responsible research and innovation (RRI) figures prominently among the aims of the project. This is explained by the fact that the project's funder, the European Commission, is keen to promote RRI in research [2–4]. At the same time, the HBP raises a number of potential ethical and issues, ranging from the immediate and practical, like the approval of research protocols, to the more general and philosophical, like the possibility of machine consciousness or novel approaches to artificial intelligence (AI).

In order to address these issues, the HBP has a sub-project dedicated to ethics and society. The overall HBP is split in 12 sub-projects which are the organizational home to scientific, technical and administrative activities. The society and ethics sub-project, the home of RRI in the project, is divided into four sections which look at foresight research, conceptual and philosophical analysis, public engagement and ethics management [5]. This abstract highlights the role of privacy and data protection in ethics management.

Ethics management is broken down into several tasks. It covers principles and implementation of ethics management, which includes the development and maintenance of an overview of ethical issues called the HBP Ethics Map (<https://www.humanbrainproject.eu/ethics-management>). Working with other sections of the society and ethics sub-project as well as the scientists of the scientific and technical sub-projects, the ethics management team develops bespoke ethics issue action plans. It develops Standard Operating Procedures (SOPs) and undertakes the identification and management triage of ethical issues. In order to ensure that all work in the HBP happens in accordance with laws and regulations, the ethics compliance task maintains an HBP Ethics Registry which contains an overview of the ethical issues of all other tasks and a collection of ethics approvals of those tasks that require them. Ethics management communicates with the European Commission and its ethics reviewers in the context of regular ethics reviews. In order to have an understanding of specific issues, the ethics management group manages a so-called Rapporteur Programme which includes representatives of all other 11 sub-projects. These rapporteurs are scientists from all areas of the HBP who spend a portion of their time working on issues of RRI. This includes physical meetings, teleconferences and interaction with members of the Ethics Advisory Board, which made up of independent experts who provide advice to the HBP.

Privacy is a key issue that the HBP has to address. There are different types of human data that are potentially affected by data protection regulation and therefore subject to scrutiny during ethics review. This refers to research data that was collected from human volunteers as well as patient data. For volunteer data the processes of collecting informed consent are fairly well established which links to the possibility of using the data for research purposes. The use of patient data raises bigger obstacles. The medical informatics platform, one of the HBP subprojects which aims to gain neuroscientific insights by mining patient data has therefore developed a complex process to allow querying patient data which is held by partner hospitals. This includes several steps of de-identification, anonymisation and aggregation of the data in order to ensure that no personally identifiable information is used. While these aspects are concerned with complying with data protection legislation, including the incoming European data protection regulation, privacy concerns in the HBP go beyond such reactive measures. The HBP strives to establish good practice in the data governance of big neuroscience and aims to put in place ideas of broader data stewardship. The ethics management function plays a central role in this.

Ethics management operates according to the principle of subsidiarity, which means that the responsibility for appropriately dealing with ethical issues remains with the local Principal Investigator. Ethics management supports these PIs and collects approvals. Most importantly, ethics management works with all stakeholders involved (researchers, ethics reviewers, EC, Ethics Advisory Board) to find ways of appropriate dealing with ethical issues. In this way ethics management seeks to develop good practice for managing ethics in large data-drive biomedical research.

Compliance management follows categorisation of ethical issues as described the Horizon 2020 ethics self-assessment manual. During the ramp-up phase, the first phase of the project which lasted from October 2013 to March 2016 the following approvals

were collected: 19 “animals” 25 “Humans”, 1 “Human Cells / tissues”, 1 “None” (retained because of general relevance). It was interesting that no issue was collected under the heading of “privacy”. This is not because of a lack of privacy-related issues, but because they generally fell under human research with privacy being only one aspect of the complex ethical issues.

In fact, privacy was recognised as a key issue in the HBP and, as a consequence, the ethics and society sub-project, together with the Ethics Advisory Board wrote an Opinion on Data Protection¹. This was based on work undertaken in all sections of ethics and society as well as prior work of several EAB members. This Opinion made the following recommendations.

- Create coherent data governance
 - Nominate individual responsible for data
 - Set up data governance committee
 - Include stakeholders and general public
 - Establish PIA and data audit
 - Ensure data stewardship
- Adopt privacy model

The ethics management team is in the process of turning these recommendations into practice. Due to the size and complexity of the project this is not a trivial exercise. The chosen approach is therefore to develop what we call an ethics issue action plan. This is a document that lists all the requirements and suggest possible ways of addressing them. It is developed by the ethics management team and then discussed with the various stakeholders. At the time of writing (January 2017) an internal meeting is being planned to discuss the different measures which include technical measures, implementation of privacy impact assessments, the appointment of a data protection officer and stakeholder engagement with a view to ensuring that the measures are consistent, realistic and fit for purpose.

Ethics management is well placed for such a task, given its prior engagement with all HBP stakeholders. One key insight arising from this work is that privacy and data protection is an important issue, but it is by no means the only one. Different ethical and social issues intersect and privacy issues tend to overlap with other issues in a complex mixture of interests. It is important to create structures that can deal with these issues and that have the potential to react to external developments and learn from mistakes. Ethics management is one such structure that will help the HBP successfully deal with privacy and data protection.

Acknowledgements. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 720270 (HBP SGA1).

¹ Available at: <https://www.humanbrainproject.eu/documents/10180/1384155/EthicsandSocietyOpinionDataProtectionandPrivacy.pdf/3612d948-fc33-4e57-baf3-a9cfe2cd673c>, accessed 10.01.2017

References

1. Amunts, K., Ebell, C., Muller, J., Telefont, M., Knoll, A., Lippert, T.: The Human Brain Project: Creating a European Research Infrastructure to Decode the Human Brain. *Neuron*. 92, 574–581 (2016).
2. European Commission: Responsible Research and Innovation - Europe's ability to respond to societal challenges. European Commission, Publications Office, Brussels (2012).
3. Owen, R., Heintz, M., Bessant, J. eds: Responsible Innovation. Wiley (2013).
4. Stilgoe, J., Owen, R., Macnaghten, P.: Developing a framework for responsible innovation. *Research Policy*. 42, 1568–1580 (2013).
5. Evers, K.: The contribution of neuroethics to international brain research initiatives. *Nat Rev Neurosci*. advance online publication, (2016).