



Privacy in the Human Brain Project

The Perspective of Ethics Management

Bernd Carsten Stahl
www.stahl.org.uk



The Centre for Computing and Social Responsibility



De Montfort University, Leicester, UK

Facts and Figures:

- Established 1996
- Staff
 - 10 Research active members
 - 15+ visiting profs and research associates
- ETHICOMP conference series
- Journal of Information, Ethics and Communication in Society
- ~8 live projects, EU, EPSRC, ESRC

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The Human Brain Project

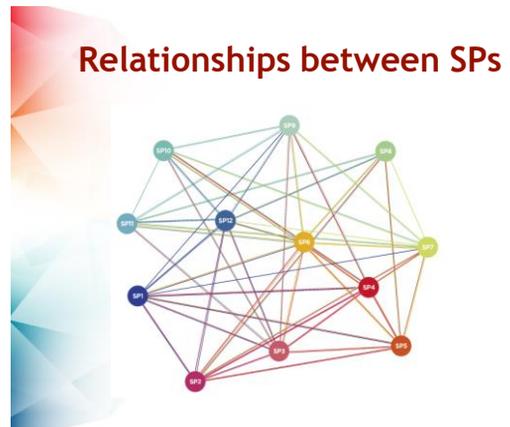
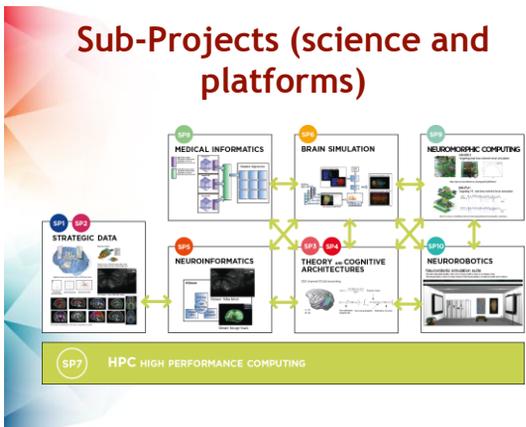
HBP is a European, Flagship initiative that facilitates and supports a global, united effort to understand the brain by providing platforms and tools along with neuroscientific and medical data, to study the brain, its diseases and to catalyze new brain-inspired technologies.

www.humanbrainproject.eu

Ramp-up (10/2013 – 03/2016)	SGA1 (04/2016 – 03/2018)	Overall project (2013-2023)
€50 million	€89 million	€500 million core funding
About 120 partner organisations	120 partner organisations plus partnering projects	120 partner organisations & ?? Partnering projects
	6 cross-cutting co-design projects.	

The Human Brain Project

- HBP aims to create and operate a European scientific research infrastructure for brain research, cognitive neuroscience and other brain-inspired sciences.
- HBP is gathering, organizing and disseminating data describing the brain and its diseases.
- **HBP is dedicated to responsible and ethical research.**
- HBP is an extensive collaboration between scientists, researchers and institutions around the world.
- HBP is an open-science initiative.
- HBP is developing Information Communication (ICT) Tools that have applications in neuroscience, medicine and computing



HBP Members

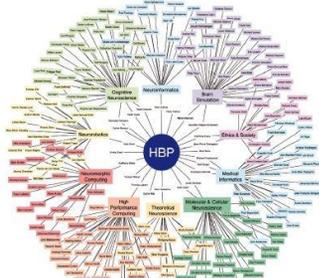
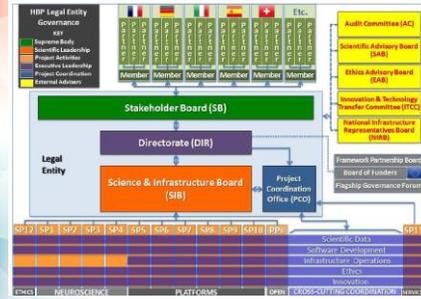
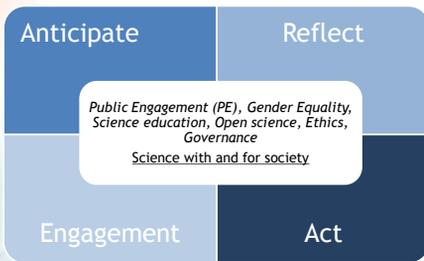


Figure 16. Scientists identified to participate in the HBP. The available data have been aggregated to contribute to the HBP. It is approved as a PDF. <https://eportfolio.pace.edu/view/view.php?id=151358>

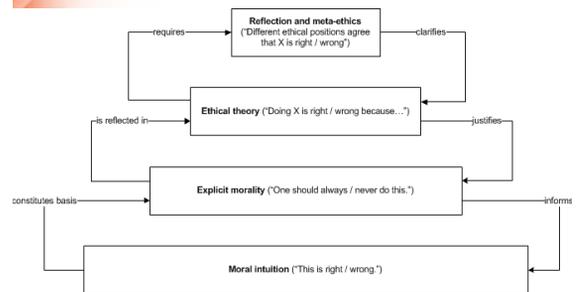
Complexity (organisational)



Responsible Research and Innovation



The Concept of Ethics



Ethics and the HBP

- Ethics of understanding the brain
- Ethics of doing research
- Ethical consequences of research
- Society and Ethics Sub-Project
 - Foresight
 - Conceptual and philosophical analysis
 - Public engagement
 - Ethics Management

Ethics Management, Principles

- Modelled on H2020 Ethics guidance
- Principles:
 - Responsibility rests with PI / task leader
 - EM engages with all parts of HBP
 - Collects approvals where appropriate
 - EM does not approve or give permissions
 - Works with PIs to overcome issues
 - Translates research insights into practice
- HBP EM seeks to develop good practice for managing ethics in large data-drive biomedical research

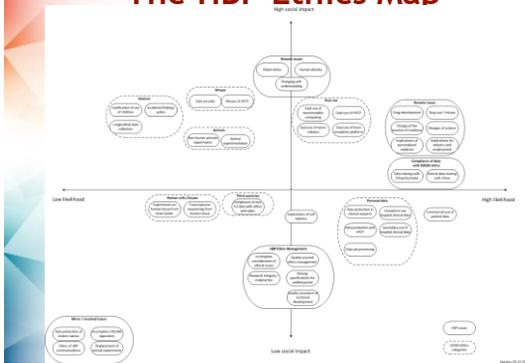
Activities of Ethics Management

- Principles and Implementation of Ethics Management
 - HBP Ethics Map
 - Ethics Issue Action Plans
- Standard Operating Procedures
- Identification and management triage of ethical issues (PORE)
 - Ethics Compliance
 - HBP Ethics Registry
- Interface with the European Commission
- Management and Support of the Rapporteur Programme
- Management and Support of the Ethics Advisory Board
 - Ombudsperson

Input into HBP Ethics



The HBP Ethics Map

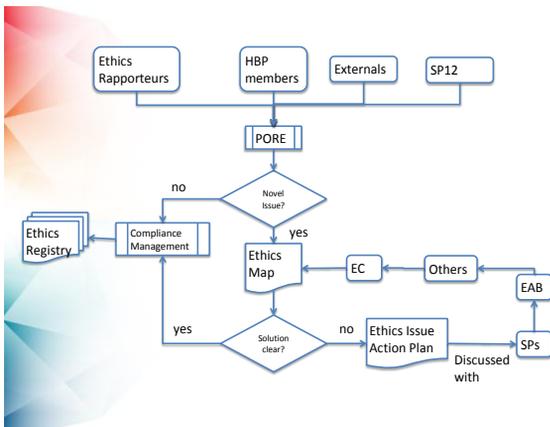


Ethics Issue Action Plans



Compliance Management

- Collection of all ethics approvals from the ramp-up 46 entries
- In H2020 ethics categories
 - 19 "animals"
 - 25 "Humans"
 - 1 "Human Cells / tissues"
 - 1 "None" (retained because of general relevance)
- Human / patient data issues are included in "human"
- During ramp-up no HBP-wide data transfer issues arose. This will happen in the SGA1 phase
 - > Privacy



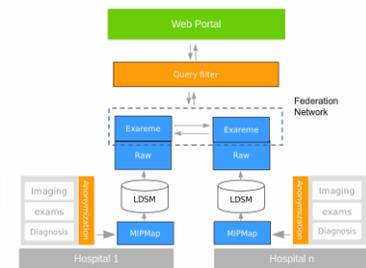
Data Protection Opinion

- Privacy and data protection in ethics review
- SP12 work on data protection
 - Future medicine report
 - Citizen engagement
 - Philosophical reflection
- EAB expertise
- ->Combine all this in one document

Concerns - MIP

- Federate clinical data,
- including genetics and imaging,
- currently locked in hospital
- research records and files with a view to identifying biological signatures of diseases.

Concerns - MIP



Other Privacy Concerns

- Data protection in human neuroscience
 - EEG and fMRI data as basis of models
 - Possibility of anonymisation
 - Informed consent
- High performance computing / modelling
 - Could be misused to deduce identities
 - Info on individuals from models
- Incidental findings
- Use of personal data for commercial purposes

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

Recommendations

- Encourage use of appropriate methodologies
- Explore tools for privacy and consent management
- Explore possibility of broad consent in light of GDPR
- Promote trust and transparency
- Develop resilient data protection processes
- Re-evaluate solutions regularly

Lessons (to be) learned

- Data protection is one issue among many others
- Ethical, social, legal issues are difficult to distinguish
- Defining issues is not trivial
- Data protection is not (only) a technical problem
- Trade-offs are unavoidable
- We WILL go wrong - how can we make sure we learn from that?



References, Papers

- [HBP Ethics and Society Opinion on Data Protection](#)
- Stahl, Bernd Carsten (2012): "[Morality, Ethics and Reflection: A categorisation of Normative IS Research](#)" In: *Journal of the Association for Information Systems* (13:8), 636-656
- Stahl, Bernd Carsten, Mittelstadt, Brent Daniel & Timmermans, Job (2016): "The Ethics of Computing: A Survey of the Computing-Oriented Literature" In: *ACM Computing Surveys* (48:4), Article 55, DOI: <http://dx.doi.org/10.1145/2871196>
- Stahl, Bernd Carsten; Jirotko, Marina, Eden, Grace & Coeckelbergh, Mark (2014): "[From Computer Ethics to Responsible Research and Innovation in ICT: The transition of reference discourses informing ethics-related research in IS](#)" In: *Information & Management*, (51), 810-818,

References Websites / Projects

- HBP Ethics Management: <https://www.humanbrainproject.eu/ethics-management>
- ETICA project: www.etica-project.eu
- Observatory / Framework for RRI in ICT: www.responsible-innovation.org.uk
- Responsible-Industry: www.responsible-industry.eu