Strangers in Neuroscientific Research

On the role of social scientists and ethicists as advisors in ethical, legal and social aspects of the Human Brain Project

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Overview

The Human Brain Project

- Institutional background of the HBP
- Major goals
- Recent controversies

Ethical Issues of Big Neuroscience

- Structural Features
- Technological Features

The Role of Ethical Advisors in the HBP

- Informational Challenges
- Organizational Challenges
- Expectation Challenges

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The Human Brain Project

Institutional background of the Human Brain Project

- The Human Brain Project is a so-called "**Flagship**" of the European Commission's Future and Emerging Technologies Programme (FET) that aims to "*provide a strong and broad basis for future technological innovation and economic exploitation*". → **Technological Focus**
- The Flagship programme started in July 2010; 6 pilot projects were chosen for the so-called preparatory actions in 2011. Those were evaluated 2012 and two winning projects were announced on 28th January 2013. Official launch of the HBP was **October 2013**. → **Bottom-up competition**
- Flagships are supported over a total period of **10 years**, but are subject of regular evaluation that could lead to an early abortion of the Flagship.
  → **Long-term orientation without guarantees**
- Funding of Flagships is in the order of 1 Billion Euros for 10 years, whereas **half of the money** is expected to come from outside of the EC.
  → **Instable, potentially conflicting funding**

Major goals of the Human Brain Project

Goal description based on the HBP Report 2012: *"The goal is to*

*"lay the foundations for a new model of **ICT-based brain research**",*

*"driving **integration** between data and knowledge from different disciplines",*

"and catalyzing a community effort to achieve:
*- a new **understanding** of the brain,*
*- new **treatments** for brain disease*
*- and new brain-like computing **technologies**"*

The idea of "simulating the brain" had an ambiguous role when communicating the goals of the HBP:

- In "official documents", the role of simulations was not put in the forefront.
- Nevertheless, "simulating the brain in order to understand it" became a cornerstone in the public appearance of the project.

Recent controversies regarding the HBP

In 2014, a debate emerged in the project in reaction to the **repositioning of cognitive and systems neuroscience** from the Core Project in the ramp-up phase to Partnering Projects.

The debate rapidly spread in the neuroscience community, escalated and then culminated in July 2014 in an **Open Letter** to the European Commission co-signed by several hundred scientists. The letter included critique regarding:

- Governance
- Scientific approach

This lead to a **mediation process** initiated by the HBP, whose results have been published in March 2015:

- Five recommendations address the scientific programme
- Four recommendations address governance

Although made independently from ELSA, several recommendations align with own assessments and experiences made within the HBP.

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Ethical issues of Big Neuroscience

Characteristics of “Big Neuroscience”

Large, structured and formalized collaborations between scientists are a rather recent phenomenon in the history of science, partly related to the increasing importance of science for the military (e.g. Manhattan Project), but also because some research questions require large research infrastructures (e.g. CERN facilities).

We propose that the following aspects characterize “Big Neuroscience”:

- The challenge to organize, coordinate and manage a large number of **researchers** and research **data** in a way that **accountability** towards the funding organizations can be realized
- The important role of **advanced ICT** serving as a structuring principle for the research carried out.

In two words: it is about structure and technology.

Characteristics of “Big Neuroscience”: Structure (1)

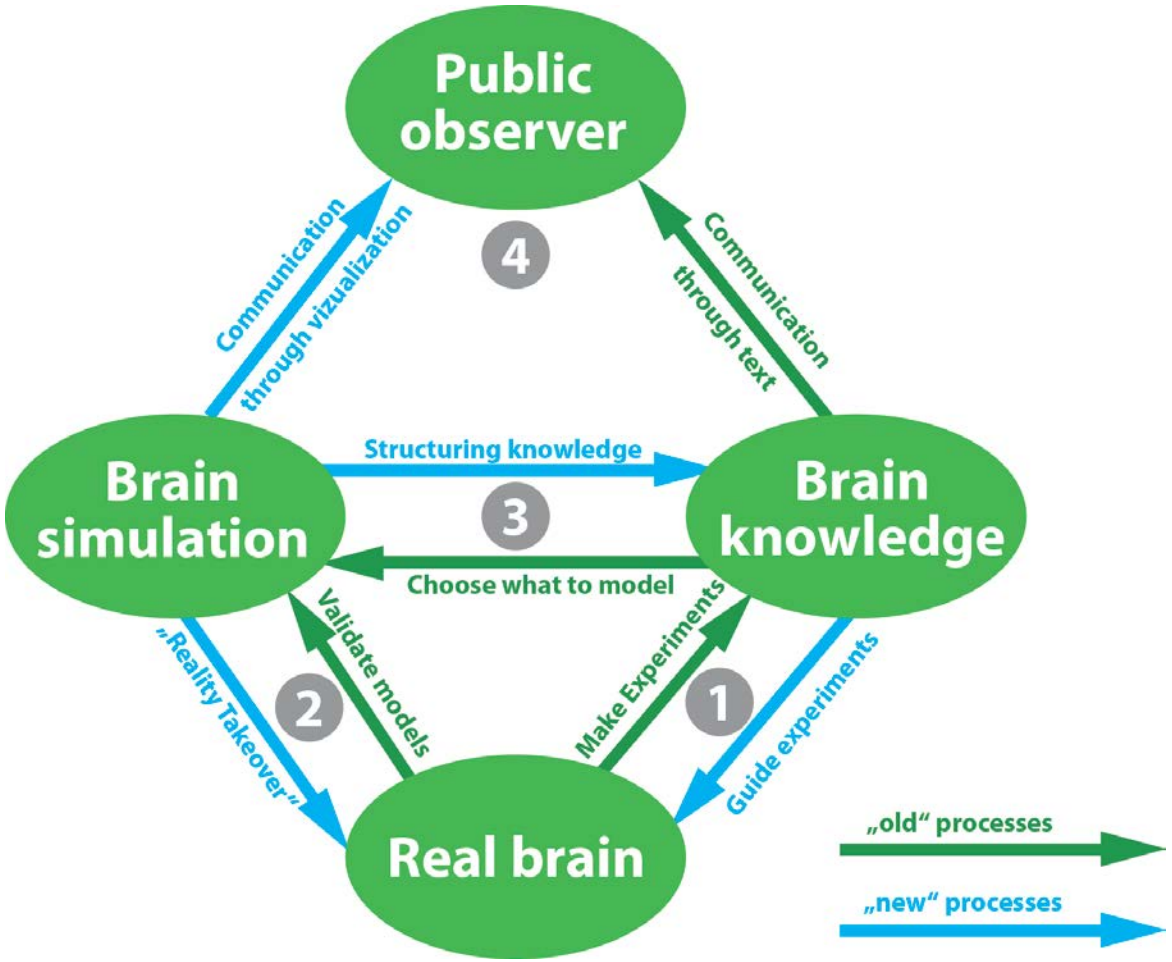
Structural features of “Big Neuroscience”:

- **Big Number**: One big organizational unit with top-down defined patterns of collaboration instead of many small groups as independent units, organized mainly in a “bottom-up” way.
- **Big Data**: Large and heterogeneous data sets emerging from coordinated research actions instead of data mining and pattern recognition in existing data bases (“classical Big Data”).
- **Big Money**: Connection to a large public funding body that commits itself to the project, creating a special kind of interdependence.

Characteristics of “Big Neuroscience”: Structure (2)

	Ethical risks	Ethical benefits
Big Number	- Conflict with “bottom-up” work ethics of scientific cooperation. - Sub-optimal investment of research money in terms of productivity.	- More effective ethical oversight to prevent publication bias and research fraud.
Big Data	- Data security and privacy issues across countries. - Informed consent procedures across different cultures. - Failure because of complexity and/or regulatory issues.	- Larger data base will yield more power and reliability. - Data sharing as a scientific virtue or even duty. - Maximization of data collection to contribute to human welfare.
Big Money	- Big promises that undermine research credibility. - “Too big to fail” problem.	- Increased pressure for accountability regarding use of public money for research

Characteristics of “Big Neuroscience”: Technology (1)



Characteristics of "Big Neuroscience": Technology (2)

	Ethical risks	Ethical benefits
Trust	- Interference with the ethos of free and open science (also due to pushing efficiency)	- More efficient empirical research that minimizes the use of resources (in particular: animals)
Community	- "Fortress mentality" and alienation phenomena	- Increased incentive for interdisciplinary collaboration
Truth	- Ignorance of conflicts in data/ knowledge - Missing peer-review culture	- Better awareness for conflicting findings due to systematic mining of available knowledge
Credibility	- Lacking standards regarding visualization blur the boundary between reality and simulation	- Novel ways to communicate complex phenomena increase public understanding of neuroscience

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The role of ethical advisors in the HBP

Informational Challenges

Two committees (ELSA/REC) have been established as **independent bodies** to "*adopt an advisory role […] and provide strategic guidance on issues […] that may have long-term ethical, legal, philosophical and social implications*" (ELSA) and to "*ensure that HBP research meets the highest possible ethical standards*" in particular in fields that lack legal frameworks/guidelines (REC).

As ELSA/REC members were not involved in setting up the Flagship, the following "information gaps" had to be addressed by us:

- **Science:** what is the HBPs scientific mission and methodology beyond what has been communicated in general/scientific media?
  → **Published information is insufficient for closing this gap**
- **Organization:** What are the "inner mechanisms" of HBP governance and internal communication?
  → **This point turned out to be relevant aspect regarding setting up an advisory function within the HBP.**

Organizational Challenges

There is no “standard procedure” for establishing an advisory role for an external committee of large-scale scientific projects.

Therefore, we were confronted with the organizational challenge of **integrating our committee** into the organizational structure of the HBP (i.e. we “had to found our role partly by ourselves”).

Our “tools” we (ELSA/REC) have established so far:

- **Interviews:** Meeting scientists of HBP sub-projects for in-depth interviews in order to get a closer understanding of goals and methodologies.
- **Joint writing** of papers together with HBP members.
- **Ethics Rapporteurs:** Contact persons within the sub-projects that inform us about ethical issues emerging in the projects.

Furthermore, we made proposals to improve ethical governance within the HBP, e.g. for setting up an “ombudsperson” for (a proposal made by the REC).

Expectation Challenges

Finally, we were confronted with an expectation challenge: What are the expectations towards such a committee with respect to its advisory role both from the perspective of the HBP and the European Commission?

- **HBP:** From the side of the HBP we were assured to have full access to any relevant activities & information that happen within the HPB – but initial expectation remained vague or unrealistic (in particular regarding REC).
- **EC:** In the first ethics review of the HBP in January 2015, the EC considered us to be “allies” regarding the evaluation of the project.

An important challenge in that respect concerns independence on the one hand (i.e.: volunteering, no funding beside expenses), and the amount of work needed to actually be effective on the other hand.

Current situation and future issues

The mediation report made several important recommendations that are currently under evaluation (we were not involved in the mediation process).

One recommendation involves the merger of the two committees that is now likely to take place and that will serve two main functions:

- **Compliance:** Assessment of ethical issues that do not fall under national legislations and for which no clear guidelines are available (e.g.: data sharing with countries that do not comply to EU guidelines regarding animal or clinical research)
- **Foresight:** Identification and normative assessment of long-term issues related to the HBP (e.g.: how to give credits to researchers that collaborate in large research networks).

We look forward to establish additional "communication lines" to the community of researchers that deal with ethical, social and legal issues related to (Big) neuroscience.