
Ethical Reflections of Human Brain Research and Smart Information Systems

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Abstract: This case study explores ethical issues that relate to the use of Smart Information Systems (SIS) in human brain research. The case study is based on the Human Brain Project (HBP), which is a European Union funded project. The project uses SIS to build a research infrastructure aimed at the advancement of neuroscience, medicine and computing. The case study was conducted to assess how the HBP recognises and deal with ethical concerns relating to the use of SIS in human brain research. To understand some of the ethical implications of using SIS in human brain research, data was collected through a document review and three semi-structured interviews with participants from the HBP. Results from the case study indicate that the main ethical concerns with the use of SIS in human brain research include privacy and confidentiality, the security of personal data, discrimination that arises from bias and access to the SIS and their outcomes.

Furthermore, there is an issue with the transparency of the processes that are involved in human brain research. In response to these issues, the HBP has put in place different mechanisms to ensure responsible research and innovation through a dedicated program. The paper provides lessons for the responsible implementation of SIS in research, including human brain research and extends some of the mechanisms that could be employed by researchers and developers of SIS for research in addressing such issues.

Keywords: Smart Information Systems, Ethics, Human Brain Research

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Introduction

Considerable research is undertaken on the use of innovative computer technologies in understanding the human brain (Goertzel et al., 2010; Shapshak, 2018). One example of such research is the Human Brain Project (HBP), a ten-year scientific research project that aims to build an ICT infrastructure for neuroscientific research. Various components of this large and complex project involve Artificial Intelligence (AI) and Big Data (Smart Information Systems - SIS). The HBP aims to build a collaborative ICT-based scientific research infrastructure to allow researchers across Europe to advance knowledge in the fields of neuroscience, computing, and brain-related medicine (Human Brain Project, 2018).

In general, the use of such SIS raises ethical concerns relating to autonomy, trust, consent, identification, inclusion and digital divides, security, harm, misuse, and deception, to name just a few (Stahl & Wright, 2018). Drawing from the research in the HBP, this paper presents an analysis of ethical issues arising from the use of SIS in human brain research. Using a case study of the HBP, it covers insights from the project to reinforce the comprehension of well-known ethical issues and possibly those that are not well known. In so doing, the case study addresses the research question: **how do organisations perceive ethical concerns related to SIS and in what ways do they deal with them?** To address the research question, data was collected through a document review and semi-structured interviews with three participants from the HBP. The structure of the paper is as follows:

- Firstly, the paper presents a review of the current use of SIS in human brain research focussing on the types of SIS technologies being used.
- Secondly, the paper highlights a range of ethical issues surrounding the use and implementation of SIS in human brain research that are drawn from the literature.
- Thirdly, the paper describes the HBP case. It outlines the SIS that are being used in the HBP and the aims of their use. Further, the paper discusses the effectiveness of the SIS used in the HBP.
- Fourthly, the paper presents the ethical issues that arise when using SIS technologies in HBP. This is followed by a discussion of the mechanisms that are used in the HBP to recognise and address ethical issues.

The paper contributes to knowledge about the ethical use of SIS in human brain research. It also contributes to practice by looking at how SIS could be effectively and ethically implemented in human brain research. Thus, the paper has implications on the formulation of policies to ensure that ethical and legal implementation of SIS in human brain research.

The use of SIS in Human Brain Research

Research on the human brain has a long history. Humans have tried to understand what it is to remember, to reason and to know for a long time (Arbib, 1975). Today, this quest includes research to understand the human brain using computer technologies. The human brain is a

complex organ. Due to its complexity, scientists are trying to use the capabilities of some advanced SIS to discover and develop systems that can advance knowledge in the fields of neuroscience, computing, and brain-related medicine. Research into the brain is partly motivated by the rise in brain diseases as people have longer lifespans, and at the same time have to adapt to an ever more complex society. These changes in society and life have provided new reasons to study the brain, and more scientists are now keen to research and develop technologies that can support brain research (Goertzel, Lian, Arel, de Garis, & Chen, 2010).

Given that, there is ongoing research that uses science and technology based on a comprehensive understanding of the structure and behaviour of matter from the Nano-scale up to the most complex system yet discovered, the human brain (Shapshak, 2018). Part of that research has seen concerted efforts to bring together information technology with new technologies based on cognitive science to understand how the brain functions. The benefits of such convergence have the potential to improve a better examination of biological intelligence and understand how the brain functions (Hassabis, Kumaran, Summerfield, & Botvinick, 2017).

The use of technologies such as SIS in human brain research has been going on for many years. Many studies have been conducted to develop technologies that help in delving deep into the functions of the brain and learn the principles that are fundamental to its design and operation (Huerta, Koslow, & Leshner, 1993; Shepherd et al., 1998). Neuroinformatics¹, which allows scientists to collect and organise huge volumes of data on the brain, has been a catalyst of a rise in the use of SIS in human brain research (Alexiou, Theocharopoulou, & Vlamos, 2013; INCF, 2018). The use of SIS in this regard is aimed at exposing correlations and other patterns in data and in extracting general organising principles. Examples of such use can be seen in initiatives such as the International Neuroinformatics Coordinating Facility (INCF)², The Human Connectome Project³, and The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative⁴.

In most research initiatives on the human brain, there is the use of new enabling technologies such as modern High-Performance Computing (HPC) and simulation-based science (Reger, Fleming, Sanguineti, Alford, & Mussa-Ivaldi, 2000), which are now combined with Big Data analytics and AI to provide powerful SIS. Over the years the use of SIS in human brain research has progressed (Goertzel et al., 2010; Prieto et al., 2016; Reger et al., 2000), and recent advanced SIS systems have been used to model and simulate brain processes and thus reveal the complex chains of causation leading from cells and connections, to behaviour and cognition (Shapshak, 2018).

¹A research field concerned with the manipulation of neuroscience data through the use of computational models and analytical tools.

² INCF, Advancing data reuse and reproducibility in global brain research. <https://www.incf.org/about>

³ The Human Connectome Project (HCP). <http://www.humanconnectomeproject.org/about/>

⁴ What is the brain initiative? <https://www.braininitiative.nih.gov/>



With the use of SIS, brain simulations can organise data and knowledge to allow researchers to address the ultimate questions concerning the origins of cognition and behaviour. As SIS advance, they will continue to be a key enabling technology for new approaches to brain research, and the knowledge that results from their use will promote a completely new class of information systems.

At the heart of these new information systems is the influence of neuroscience on SIS. Using technologies such as neural networks and deep learning, SIS have been adopted to understand the functions of the brain. AI and Big Data have been revolutionised by remarkable advances in neural network or deep learning methods (LeCun, Bengio, & Hinton, 2015; Prieto et al., 2016). Core to such an understanding are the insights that are cultivated from neuroscience. Neuroscience provides a rich source of inspiration for new types of algorithms and architectures, independent of and complementary to the mathematical and logic-based methods and ideas that have largely dominated traditional approaches to AI (Hassabis et al., 2017).

Although this sounds promising, there are ethical issues related to the use of SIS in human brain research. These are covered in the following section.

Ethical Issues with SIS in Human Brain Research

The use of SIS in human brain research raises several ethical issues. During background research into the ethical issues of using SIS in human brain research, a number of sources were used. These sources included journals such as IEEE Security Privacy, Neuron, and The Journal of Supercomputing. Also, insights were derived from Artificial Intelligence Applications and Innovations (AIAI) international conference proceedings to further understand the ethical issues with SIS technologies. In coming up with relevant literature, a broad search of keywords using different variations was conducted in databases such as Google Scholar and Scopus. After reviewing these articles, a number of ethical issues with respect to the use of SIS in brain research such as privacy, data ownership, accountability and trust were realised (See Figure 1).



Figure 1: Ethical Issues with the SIS use in Human Brain research from the Literature

Privacy

In brain research, SIS pose a risk of violating privacy through the actions and rules that define who has access to certain types of information. There is also a risk of discovering the data providers' identity, or disclosure of sensitive information. For instance, there is wide use of global repositories that are populated by data and protocols which are prone to the risk of intrinsic and consequential harm of the data owners or research participants (Stahl and Wright, 2018). The repositories contain data that could be re-identified to the primary source and violate their privacy. Although this is not straightforward, with advanced data aggregation and mining techniques, there is the possibility of re-identification of the data subjects (Rommelfanger et al., 2018).

Data ownership

There is a possibility that the data that are being used for research could be commercialised and shared with third parties for other purposes. This raises issues relating to data ownership and intellectual property rights. Since human brain research involves massive unstructured data which are collected, stored and processed by the SIS used in the research, it involves complex ethical considerations because the big datasets may consist of a variety of intellectual properties, such as research results, copyrights, trademarks, and patents (Alexiou et al., 2013; Anagnostopoulos, Zeadally, & Exposito, 2016). The use of SIS in human brain research also raises the question of equitable access to the benefits of applications for the data subjects, such as patients, beyond the research itself (Rommelfanger et al., 2018).

Trust and Accountability

Another ethical issue relating to the use of SIS in brain research is that of trust and accountability. Trust of all the stakeholders in the use of SIS in brain research is important. There is a requirement of accountability that should be upheld by the researchers and other stakeholders, particularly when it comes to data manipulation, sharing, access to data, allocation of rights and ownership. Relatedly, the use of SIS also brings with it issues of algorithmic bias and the transparency of the decisions that are made by artificial intelligence within the SIS (Stahl and Wright, 2018). In the case of human brain research, the use of Big Data poses ethical and policy-related issues concerning the governance and regulation of data content, access to and use of databases or datasets (Anagnostopoulos et al., 2016).

So far, the paper has indicated that the use of SIS in brain research is not a new thing. Advanced technologies such as SIS are used to conduct research relating to the brain, and the use of AI and big data open new capabilities in trying to understand how the brain functions. Moving on, the next section will describe HBP, which implements and uses SIS in human brain research.

Human Brain Project: A Case of a project that uses SIS in Brain Research

The Human Brain Project (HBP) is building research infrastructure to help advance neuroscience, medicine and computing. The HBP is a 10-year project that is funded by the European Union, which began in 2013. The project directly employs more than 800 people in over 100 universities, teaching hospitals and research centres in 20 countries around Europe. The HBP aims to develop an ICT infrastructure for neuroscience (Amunts et al., 2016). It is a cutting-edge SIS project in several ways. It uses massive amounts of neuroscientific data and AI for the generation of new insights into the brain, and is developing novel computational architectures based on neuroscience that may overcome some of the limitations of current AI.

The HBP is structured around a unified agenda to gather and analyse data on the brain, derive organising principles and build brain models with as much biological detail as technically possible (Human Brain Project, 2018). The HBP will use the advancement of brain science and medicine to accelerate our understanding of the brain and its diseases. Such models represent extreme applications that will shape the future of supercomputing and provide the technologies to create realistic simulations of life processes. Combined with high-level mathematical theories of brain function, the HBP uses SIS in its quest to build a new class of brain-like hardware devices and computer architectures that may result in the next generation of AI and data analytics. However, the use of SIS in the HBP has ethical implications, and it is important to understand these.

To understand some of the ethical issues with the use of SIS in human brain research, background research about the use of SIS in human brain research and its ethical implications was conducted. The results were presented above. Also, three interviews with members of the HBP were conducted to gain an in-depth understanding of their interactions with SIS and

their views of the most fundamental ethical issues relating to the use of SIS in the project. The interviews were conducted between August and December 2018.

The data collected were analysed using a thematic data analysis technique which was both deductive and inductive. The deductive themes were derived from the interview questions to begin the analysis process. Using Nvivo qualitative data analysis software, categories were established into different nodes during a two-day SHERPA consortium workshop. Consequently, inductive themes emerged from the interview transcripts to inform this case study paper.

Individuals Interviewed

To get an in-depth understanding of the ethical issues related to the use of SIS in the HBP, three individuals were interviewed. The roles of the individuals interviewed ranged from ethics and data governance to the technical management of the SIS. For instance, one of the individuals was involved with cataloguing the ethical issues that could result from the use of algorithms and machine learning related analytical tools within the HBP. In summary, Table 1 below shows the interviewees and their roles.

Interviewee	Role in the HBP	Date of Interview
Interviewee 1	Ethic rapporteur	23.08.2018
Interviewee 2	Ethics and data governance	02.10.2018
Interviewee 3	Technical management	19.10.2018

Table 1: Interviewee roles in HBP

The SIS being used by the Human Brain Project

The SIS being used in different parts of the HBP involve, at a minimum, three dozen separate algorithms and machine learning techniques. These techniques are used in a joint platform (Figure 2 below) that unifies SIS tools to build a research infrastructure for neurosciences.

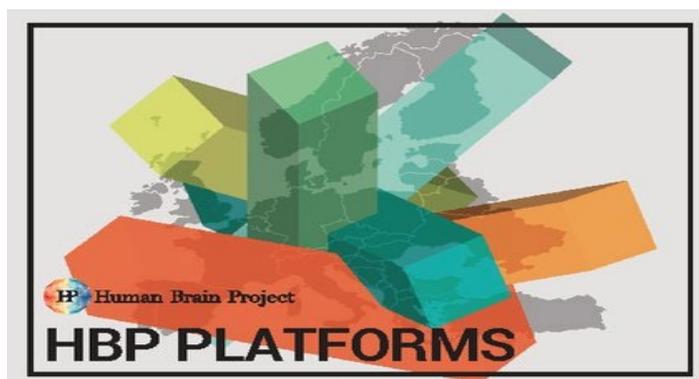


Figure 2: Human Brain Project Platforms
(Source www.humanbrainproject.eu)

The joint platforms involve neuro-robotic simulations and high-



performance computing kernels to support brain simulations. These SIS are used in the project's joint platforms, including Neuro-informatics, Brain Simulation, High-Performance Analytics and Computing, Medical Informatics, Neuromorphic Computing, and Neurorobotics. These platforms are described in Table 2 below.



Platform	Description
Neuroinformatics Platform	The Neuroinformatics Platform involves collecting, organising and making available a range of brain data. It provides services to search and access neuroscience data, data models and other resources through multi-level brain atlases. The platform manages the curation process and data registration of different kinds of data from humans and animals.
Brain Simulation Platform	The Brain Simulation Platform provides tools and models to facilitate the convergence between different modelling tasks. This supports a further understanding of brain structure and function. It is an accessible platform designed to reconstruct the brain through simulation, with a whole suite of software tools and workflows for collaborative brain research. The platform allows researchers to simulate models of the brain at multiple levels on supercomputers.
High-Performance Analytics and Computing Platform	The High-Performance Analytics and Computing (HPAC) Platform builds, integrates and operates the hardware and software components of the project's supercomputing, data and visualisation infrastructure, providing the necessary computing and storage resources for neuroscientific research. The HPAC has very high computational power to run large-scale simulation involving the large amounts of data produced.
Medical Informatics Platform	The Medical Informatics Platform (MIP) gives researchers the ability to access and analyse large amounts of clinical data. The data provide patterns which are used to develop new hypotheses about brain diseases. Also, the platform is used for developing an understanding of disease clusters and their signatures. Early achievements using the MIP include the identification of new subtypes of dementia and the first biological signatures for that disease, which allows a prognosis to be established before the onset of disease symptoms.
Neuromorphic Computing Platform	The idea behind the Neuromorphic Computing Platform is to make computers that use similar architecture to that inspired by the human brain, which would make some computationally difficult energy-intensive tasks more accessible. This involves a remotely accessible large-scale neuromorphic computing system. The computing systems are built from fast, energy-efficient devices that imitate the brain's physical process.
Neurorobotics Platform	The Neurorobotics Platform involves virtual and real robots and environments for testing brain simulations. In the platform, its users can plan, run and evaluate neuroscience experiments that use a public online research interface that involves using virtual robots connected to simulated brains.

Table 2: A Summary of Platforms that use SIS in HBP



The aims of the HBP in using SIS

Data manipulation

Scientists require the support of enormous computing power and information systems that can manipulate the huge datasets that human brain research involves. As pointed out by Interviewee 2, part of the reason for the platforms' existence in the HBP is to make a unified system that collects and builds complex data-driven brain models based on huge datasets. SIS are also used by neuroscientists to collect data, then develop brain models based on these data, and simulate these models (Amunts et al., 2016; Human Brain Project, 2018).

Virtualisation

SIS are used to develop virtual brain models which are used in real or simulated robot bodies. The Neurorobotics Platform gives any simulated brain model its virtual or real "body" and explores how it controls movement, reacts to stimuli, and learns in a virtual environment. According to Interviewee 3, the idea of some of the systems, such as the Neurorobotic Platform, is:

'to have an accessible platform designed to reconstruct the brain through simulation involving simulating brain models with a whole suite of software tools and workflows for collaborative brain research. The important thing about this is that it will allow, in theory, researchers to simulate models of the brain at multiple levels'.

Also, the SIS are used to link a simulated brain to a robotic body to provide a powerful mechanism for testing the fidelity of the brain simulation.

Data exploitation

The HBP's Medical Informatics Platform (MIP) is intended to advance brain medicine by using computer science to allow researchers around the world to exploit medical data, regardless of where the data may be stored, and to create machine-learning tools that can search these data for new insights into brain-related diseases. Huge volumes of data are shared across thousands of hospitals around the world. Although medical researchers can access data in their hospital relatively easily, normally access to data in other hospitals is much more difficult, as patient confidentiality, data protection and the incompatibility of Information Communication and Technology (ICT) systems become major considera-



tions (Human Brain Project, 2018). The MIP offers ICT solutions which overcome these constraints while maintaining the confidentiality that is so important to the medical profession and the patients through data curation. To support this, Interviewee 3 pointed out that:

'it is quite an expensive process to extract information in a manual form, a manual approach. Therefore, they used SIS trained to understand and facilitate the automatic classification and extraction of structured metadata records.'

Also, machine learning applied to huge data sets offers the possibility of identifying new “disease signatures”. These are based on a broad range of factors, from the molecular level to the whole brain, and observable disorders of cognition and behaviour, which should pave the way for improved diagnosis and hence better treatment outcomes. This involves:

'a lot of separate algorithms and machine learning techniques that are being used in different parts of the HBP' (Interviewee 2).

The Effectiveness and Impact of the SIS

At the time of writing the case study, the use of SIS in the HBP was showing some effectiveness towards the reduction of labour hours. Interviewee 3 stated that the use of SIS in the HBP is

'meant to reduce the amount of labour required to share data, to make it a more streamlined process and more efficient'.

For instance, the interviewee said that the data curation process is quite expensive because it requires relatively a lot of time and energy and discussion between people to make things work. However, with the use of SIS, some of the issues have been drastically minimised. One constraint that was mentioned that affects its effectiveness is bias. Interviewee 3 suggested that bias can affect the quality of the outputs being carried out by the SIS.

In terms of impact, the SIS has demonstrated long-term global impacts:

'with global users of the infrastructure, and global contributors of data to various activities in the infrastructure. And the data is expected to potentially be used by people outside of Europe' (Interviewee 3).



It is clear that the impact of the SIS will go beyond the lifespan of the project, as suggested by Interviewee 2 who mentioned that the infrastructure for neuroscience innovation that is used in the project is visionary and will be used in the future. The SIS in the HBP will allow a lot more open science through sharing metadata across the globe.

However, although there is potential impact of the SIS use in the HBP, some of the platforms are yet to show their full potential. An example was given for the MIP, in which Interviewee 1 stated that:

'the impact is still quite small because we are still developing the platform, but the first steps we've made have allowed some promising results in terms of identifying some subpopulations of people with the same disease [...]because of availability and sharing of data that is more complex and huge than what would have been accessed by institutions individually' (Interviewee 1).

As the project progresses, there is an expectation of some large-scale effects when more hospitals are using the platform and sharing data.

Despite the impacts of SIS in the HBP, some limitations and constraints affect its use. For example, Interviewee 3 mentioned that the MIP works in some cases but not in others. This is put down to the fact that it has not been widely deployed and the project has only carried out a proof of concept to test the functionality of the SIS at this point. Interviewee 3 further said that one constraint that could affect how the SIS will work beyond the proof of concept stage would be the availability of the resources needed to continue.

Another limitation is related to the quality of the input data set. The effectiveness of the SIS in doing their job will be affected by the quality of data input. For instance, Interviewee 1 stated:

'if you have a bias in the input dataset you expect to see biased classification'.

This is very important since the use of one of the platforms (MIP) is sorting, organising and sharing data for papering, which calls for efficiency in the process to ensure quality outputs.

However, despite these limitations, the work of the SIS in HBP is promising. As Interviewee 1 pointed out, they:



'can expect that the more metadata we collect, the better data the systems will have to learn from when they go to do their classification process in the future. So, it should get better with time and type of scenario.'

With time, the SIS will mature and improve as has been seen in some areas of the MIP. With MIP, the SIS use of deep learning is maturing, particularly the part that is being used for text classification and automatic semantic tagging.

Lastly, the SIS used in the HBP has a long-term impact on different stakeholders, including scientists, medical professionals, patients and the public, because it facilitates a better and improved understanding of the brain, which will lead to improved medication and science that is geared towards addressing health problems related to the brain. As confirmed by Interviewee 1, the SIS provide ways about:

'how we can improve the healthcare system and make it more efficient and more patient-oriented, moving towards precision medicine'.

Ethical Issues with the use of the SIS

From the three interviews that were conducted in this case study, the ethical issues that were established resonate with those in the literature. There is a broad intersection between the ethical issues that are covered in the literature and those that emerged from the interviews. The ethical issues with the use of SIS in the HBP included privacy and confidentiality, personal data and security, discrimination and bias and finally, transparency (see Figure 3).

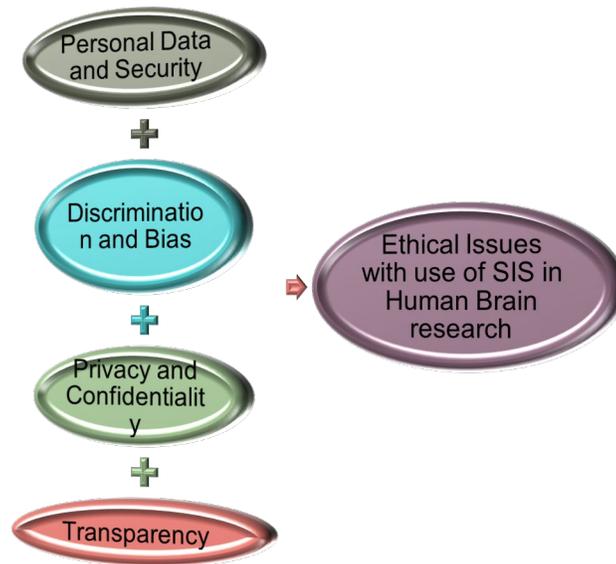


Figure 3: Ethical Issues with the SIS use in Human Brain research from the Interviews

These ethical issues illustrated in Figure 3 are discussed below.

Privacy and Confidentiality

One of the issues with the use of SIS in the HBP relates to privacy. Since the SIS collect personal data, all three interviewees stated that there is a risk of violating the privacy of the *'data subjects'*. For instance, Interviewee 2 mentioned that depending on the type of SIS, there were different levels of risk to privacy, with some of them presenting higher degrees than others. The interviewee gave an example of the Neurorobotics Platform, which is extremely unlikely to cause problems with privacy, compared to the MIP. The interviewee mentioned that the risk to privacy causes tension between innovation and privacy' because everybody has to worry about user and staff data, and 'despite good funding in the HBP not everybody was necessarily budgeting for massive encrypted servers back in 2012 when the project was conceptualised initially.

Similarly, Interviewee 1 mentioned that the risk of identifying patients will remain because there is always the possibility of hackers accessing the data. One thing that could be done is continuously keeping in mind the priority to protect patients' data and empowering people with their data. The interviewee further said that this would involve explaining to patients the value of data, how to handle it, protect or share data.

Despite the doubts on the ethical implications relating to privacy and the General Data Protection Regulation (GDPR), Interviewee 3 stated that one idea to address the issue of privacy would be:

‘to have a federated sort of platform where people can query it without violating the GDPR [...] without posing any risk to patient confidentiality, data security, or any other privacy aspects’.

There is also an ethical concern relating to violation of group privacy through the possibility of considering specific algorithms, as the origins of the data sources include heritage or biography. According to Interviewee 2, this is worrying because there could be *‘ways in which different sets of data can potentially be recombined to [...] identify groups’*. Despite this concern, the interviewee mentioned that as a project, the HBP has an ethical imperative to research with veracity, and there are some legal frameworks around the use of the SIS that could be used to mitigate against loss of integrity.

Personal Data and Security

Related to the issue of privacy in the HBP is the use of personal data. Interviewee 2 pointed out that the use of personal data and the:

‘potential use of big data analytics, present concerns about group-level harms and the privacy of users. The big issue with the use of SIS is to figure out how to find the right balance between sharing (personal) data for research and to have enough usability of this data, respecting the patients’ and the citizens’ privacy’.

In addition to this concern, there are issues of using anonymisation as one of the techniques to secure the data from being misused. Interviewee 2 stated that the project goes:

‘all the way to anonymisation, which then probably renders the data not usable. So, one way to avoid this is by using a lot of information, which then presents a big risk of re-identifying patients’ (Interviewee 2).

As a result, there is a risk of some researchers trying to *‘find out a way to de-anonymise data’* (Interviewee 2) because there is a push to innovate more and more, which is of concern when it comes to the ethical use of the SIS. Reflecting on this issue, Interviewee 2 said that the HBP tries:



'to find the right balance between protecting and using the data for progress'.

Parallel to the use of personal data is the issue of security. Interviewee 2 stated that there is always an issue of security at the software level because the SIS is using the internet. With the use of the internet, the systems are opening ports into hospitals, which means that there should be a lot of safeguards for specific parts of a specific server. The interviewee acknowledged that:

'some technologies might feel very helpful, but maybe they are too open to hacking and penetration'.

Interviewee 2 stated that *'guaranteeing 100% that there will be absolutely no way to re-identify a patient is not possible'*. But, he further said that the risk of hacking the SIS is low because if someone was interested in identifiable data, they would be better off accessing it on the hospital servers compared to the MIP. This reinforces the fact that the data used in the MIP are:

'a result of aggregated analysis rather than raw data, which poses a very low risk' (Interviewee 2).

Having said that, there is an acknowledgement that all the SIS platforms present various security risks. However, as pointed out in the interviews, the levels of risks vary in that some platforms. For instance, Neurorobotics platforms are extremely unlikely to cause problems with privacy compared to other platforms due the type of data used, although they could be prone to hacking.

In connection with personal data, there is also an issue of informed consent. Since the use of SIS in the project involves collection and manipulation of personal data, a question was raised on informed consent. Interviewee 3 stated that they assume that there is implied consent from some data subjects because:

'researchers involved in the production of the data have chosen to be involved in the curation process'.

However, this is not the case with each person individually because they may have been implicitly involved when someone shared the dataset, therefore *'their attachment to the dataset would require consent'*. Despite making these two suggestions, the interviewee added that they could not tell whether this was acceptable, only acknowledge that there was a potential issue with informed consent.

Discrimination and Bias

Issues surrounding discrimination and bias are important when it comes to the use of SIS in general. This was also unveiled as a potential issue with the use of SIS in the HBP. Interviewee 2 showed concern over bias and digital division that would result in the use of SIS in the project. The interviewee's concern was connected to the availability of resources across that project, which could result in a digital divide between those who have the resources to use most of the platforms and those who cannot. Also, this was something that would result from the different platforms not being joined up as would have been expected. Therefore, with the lack of integration:

'there is a lack of fairness regarding who fully utilises the SIS and who does not' (Interviewee 2).

There is also potential to discriminate by drawing on datasets that are non-representative of particular stakeholders when using the SIS. This was suggested by Interviewee 2, who said that there is *'a potential to miss out on neuro-diverse people'* because of where the data are being drawn from. As a result, there could be some stakeholders who are left out and are not represented or included. One of the ways of tackling the issue of discrimination, according to the interviewee, is perhaps to reflect on the *'algorithms or machine learning procedures'* that are being used in the project. This is also related to having open and transparent processes where people can ask questions around data sources and intentions with the aim to identify areas that are being overlooked.

Transparency

The SIS in the project uses several algorithms, but due to the nature of the project:

'it's very difficult to pin down the person responsible for the development of an algorithm or find out where they got it, or any of those things, and then figure out how it was designed' (Interviewee 2).

It is also difficult to track the kind of metadata that is used in some of the techniques that are employed in the SIS. The problem is that a:

'a lot of the researchers do not even know where their data or their algorithms come from because there is open source stuff' (Interviewee 2).

This interviewee further said that it is concerning that there is very little transparency in the processes. Despite having people responsible for looking at ethical issues such as



transparency, the landscape in which the technologies are used in the project does not provide enough opportunities for transparency. Interviewee 2 also mentioned that it could be *'more difficult to try to figure out the nature of the technology [being used] and where do all of the constituent parts come from'*. A different view, however, was given by Interviewee 3, who specifically referred to MIP and the way that it is planned to be used in the first phase. Interviewee 3 mentioned that there is transparency in the use of MIP, as a specific SIS platform, because it is a semi-automated process that guards against lack of openness in the processes by design.

Despite the concerns with transparency issues, there are mechanisms put in place to try and encourage transparency within the processes. For instance, although not always effective, there is a push towards engaging with both internal and external users of the technologies to keep them open and useable. An example of such initiatives to promote transparency is a product called Knowledge Graph that is currently being developed. The Knowledge Graph:

'will be a publicly accessible, quite transparent interface where people can look at HBP data and can perform their own research there' (Interviewee 2).

This is something that will hopefully address the digital division and transparency issues that are encountered in the use of SIS.

Mechanisms to address Ethical Issues

As seen from the discussion above, the use of SIS in human brain research raises ethical concerns. To address these concerns, some policies govern the use of SIS, specifically related to the ethical implications of the use of SIS in the HBP. However, Interviewee 2 pointed out that there was a lack of overarching policies around the use of SIS in the HBP. To address this, the interviewee suggested that:

'there needs to be conversation [...] because there isn't a blanket policy that will cover all of the many and varied possibilities for the HBP'.

One of the reasons for not having a blanket policy was down to the fact that the work with SIS in the HBP involves a wide range of disciplines, and therefore, some people would not:

'have the appropriate knowledge to think about how the development of specific algorithms should be governed, and they may not have the back-



ground to do a forensic examination of the tools they're using. So, it's immensely complex'.

Despite such limitations, there are specific policies on the principles and processes that govern the work in HBP, including the use of SIS. For instance, the policies cover issues related to confidentiality, informed consent, and licensing

In addition, the project has a dedicated program to provide mechanisms to ensure Responsible Research and Innovation⁵. This dedicated program covers the eight main components that are shown in Table 3 below.

⁵an approach that anticipates and assesses potential implications and societal expectations with regard to research and innovation, with the aim to foster the design of inclusive and sustainable research and innovation(European Commission, 2012)



Mechanism	Brief description
Foresight Lab	<ul style="list-style-type: none"> • Investigates possible outcomes and consequences of the work undertaken by the HBP • Focuses on identifying and evaluating the future impact of new knowledge and technologies generated by the HBP using a range of methods including action research, interviews, participant observation, literature reviews, questionnaire surveys and expert workshops
Ethics Support (ES)	<ul style="list-style-type: none"> • Provides administration of ethics-related issues. This includes the support of additional structures that help with ethics-related issues and structures • Manages compliance with EU research ethics principles. • Supports an external Ethics Advisory Board • Leads a cross-HBP Data Governance Working Group
Ethics Rapporteur Programme (part of ES)	<ul style="list-style-type: none"> • Deepens understanding of potential ethical and social implications of research and other work in all the HBP Subprojects • Establishes communication links that help HBP achieve and maintain Responsible Research and Innovation goals
Data Protection Officer (DPO) (part of ES)	<ul style="list-style-type: none"> • The DPO is a professional in the field of data protection and works with HBP partners to facilitate compliance with the GDPR. The role of the DPO includes consultation on data processing activities and providing advice and recommendations on compliance with applicable laws
Public Engagement	<ul style="list-style-type: none"> • Reaches out to stakeholders and the general public to discuss issues of relevance to the HBP and the public • Activities include public meetings, online consultations and stakeholder forums
Neuroethical Reflection	<ul style="list-style-type: none"> • Focusses on conceptual ethical and regulatory issues, from potential privacy threats to understanding consciousness and the meaning of human and personal identity
Ethics Advisory Board	<ul style="list-style-type: none"> • This an independent body that advises on specific ethical, regulatory issues raised by research undertaken or planned under the HBP
Data Governance Working Group	<ul style="list-style-type: none"> • It is involved with the overall management of the usability, integrity and security of data used in the HBP

Table 3: Mechanisms to deal with ethical issues in HBP



Conclusion

The use of SIS is making strides in human brain research geared towards understanding the complex functions of the brain and treatments of some challenging brain diseases. This case study showed how SIS is being used in one such research initiative that is taking place to understand the complex functions of the human brain. Three interviews were conducted to explore different perspectives on the use of SIS in human brain research, and which ethical issues arise from the use of SIS in human brain research.

The ethical issues that emerge from the case study resonate with issues in the literature such as privacy and confidentiality, security of personal data as well as trust and accountability by the researchers and other stakeholders, particularly when it comes to data manipulation. From the interviews, additional ethical issues were established including discrimination resulting from bias and access to the SIS and their outcomes, and transparency of the processes that are involved in human brain research due to the complexity of the technology used.

Also, of interest were the different views expressed by the interviewees, who had different roles in the research, on ethical issues with the SIS. There was a difference in perspectives between those that deal with the ethical governance of the research compared with those who are responsible with the technical side of the research and therefore, the implementation of the SIS. Despite the differences in perspectives across the roles, holistically there is recognition of the ethical implications that relate to the use of SIS in their research activities, and therefore the project has put in place mechanisms to safeguard against some of the consequences that could result from the use of SIS. Some of the mechanisms include dedicated ethics support, policies and guidelines as well as public engagement.

Limitations

While the HBP appears to be tackling some of the ethical issues relating to the use of SIS, some other areas need to be considered. For instance, it would be ideal if there could be an exploration of how the different views on the ethical issues across the multiple roles involved in different SIS platforms could be harmonised.

Regarding the use of the SIS, despite great efforts being made in the use of different SIS across platforms, there are still limitations relating to resources and capacity that are required for the integration of the complex systems. Also, there are differences in the progress of SIS implementation across the platforms, which sometimes affects the effective-



ness of the SIS used in the project. However, this is something that will be addressed if the necessary resources are put in place.

Contribution and Implication of this Case study

While there is literature on the ethics of SIS and particularly the use of AI and Big Data in human brain research, there is still room to build on existing literature on assessing the ethical issues of implementing SIS in human brain research. To that effect, this case study contributes to knowledge around the use of SIS in human brain research. It highlights ethical issues that relate to the use of SIS in human brain research and at the same time signposts how the ethical issues could be addressed through some mechanisms used in the HBP such as Data Governance Working Groups, Neuroethical Reflection and Foresight Labs. In so doing, learning from the steps undertaken in the HBP, the case study contributes to practice by highlighting some of the practical measures that are vital in the ethical implementation of SIS.

The case study has implications for policy formulation around the ethical use of SIS in human brain research. There is little guidance on how the use of SIS can be effectively and ethically implemented in human brain research within policy frameworks. Most of the existing frameworks offer general guidelines on the ethical implementation of SIS in research, but there is a need to have guidelines that focus and directly relate to the specific issues with the use of AI and Big data in human brain research. It is hoped that this paper will encourage the assessment of ethical SIS use in current and future human brain research.

Further Research

The use of SIS in human research, as is in the case of the HBP, may lead to the next generation of SIS. At this point, it is not clear whether such new SIS will raise the same or other ethical issues because it is not yet clear what their capabilities will be. While this paper offers a review of some of the notable ethical issues with the use of SIS in human brain research, there may be additional foci that need to be evaluated in the future to uncover additional issues in this emergent field. It is fair to say that this case study does not answer every question on the topic, but it lays a basis for further research in the field that could enhance our understanding of ethical issues and how to address them in emerging SIS.

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