Neuroethics (2024) 17:23
https://doi.org/10.1007/s12152-024-09558-1

ORIGINAL PAPER

Perceptions on the Ethical and Legal Principles that Influence Global Brain Data Governance

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Received: 15 February 2023 / Accepted: 13 April 2024

Abstract Advances in neuroscience and other disciplines are producing large-scale brain data consisting of datasets from multiple organisms, disciplines, and jurisdictions in different formats. However, due to the lack of an international data governance framework brain data is currently being produced under various contextual ethical and legal principles which may influence key stakeholders involved in the generation, collection, processing and sharing of brain data thereby raising ethical and legal challenges. In addition, despite the demand for a brain data governance framework that accounts for culture, there is a gap in empirical research and actions to understand how key stakeholders around the world view these issues using neuroscientists who are affected by these ethical and legal principles. Therefore, using the research question *how do ethical and legal principles influence data governance in neuroscience?* we attempt to understand the perceptions of key actors on the principles, issues and concerns that can arise from brain data research. We carried out interviews with 21 leading international neuroscientists. The analytical insights revealed key ethical and legal principles, areas of convergence, visibility, and the contextual issues and concerns that arise in brain data research around these principles. These issues and concerns circulate around intimately connected areas which include ethics, human rights, regulations, policies and guidelines, and participatory governance. Also, key contextual insights around animal research and ethics were identified. The research identifies key principles, issues, and concerns that need to be addressed in advancing the development of a framework for global brain data governance. By presenting contextual insights from neuroscientists across regions, the study contributes to informing discussions and shaping policies aimed at promoting responsible and ethical practices in brain data research. The research answers the call for a cross cultural study of global brain data governance and the results of the study will assist in understanding the issues and concerns that arise in brain data governance.

Keywords Neuroethics · Data Governance · Brain Data · Neurodata · Ethical Principles · Legal Principles

Introduction

Neuroscience is currently producing big-brain datasets which are used by various scientists and researchers who exist in various jurisdictions. Despite the geographical and jurisdictional differences, the growing

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need to advance neuroscience research has motivated strategies for more collaborative efforts that have given rise to various large scale brain research projects and data repositories that exist in different geographical regions. This need for coordinated collaboration has also seen various brain research projects coming together to advance neuroscience [1]. While there are significant efforts to advance data sharing and collaboration, there are also concerns around ethical, legal, and cultural hurdles which may arise during data sharing and collaboration among regions due to the diversity in legal and ethical frameworks [2–4]. This has resulted in various calls for the study of brain data governance from a cultural perspective to understand the practices and perceptions of key stakeholders involved in brain research and neuroscience.

Although calls for a culturally informed brain data governance framework have been made, practical steps and studies to understand the global perceptions of key stakeholders, particularly neuroscientists who are influenced by these ethical and legal principles, are currently limited. This creates gaps in the understanding of brain data governance in two dimensions. First it creates gaps in the understanding of the perceptions of those who apply these principles in the collection, processing and sharing of individual level data which directly influences brain data governance. Secondly, it also creates gaps in the understanding of the contextual issues that arise during the application of these principles.

Previously our research provided a conceptual understanding of the ethical and legal principles that exist in the brain data governance landscape [5]. These principles are also codified in international, regional, and national regulations. However, the perceptions around them as conceptualised by key stakeholders involved in the collection, storage, processing and sharing of brain data are still limited. We argue that key actors in brain data research such as neuroscientists can provide an understanding of how these principles are applied and the issues and concerns that arise around their contextual application. Furthermore, due to the lack of a universal framework for the governance of brain data, key stakeholders such as neuroscientists may be influenced by their contextual perceptions, regulations, and ethical principles resulting in challenges in international brain data sharing across borders. These perceptions by those who apply these principles can also provide an understanding on how these principles influence the governance of brain data based on their context. Therefore, this study attempts to understand how ethical and legal principles influence brain data governance by exploring the perceptions of neuroscientist using the following research question *how do ethical and legal principles influence data governance in neuroscience?*

In this paper we lay out the perceptions of neuroscientists in different brain projects. Through interviews with neuroscientists who are key stakeholders in brain data research, the study uncovers key findings such as the level of convergence and prioritisation of principles in different regions (using the level of discussions on particular principles and issues), and the substantive issues and concerns that arise in the application of ethical and legal principles that currently exist in policies, guidelines, and legal frameworks. Other key findings also include the conceptualisation of ethical and legal principles not as two separate concepts but as a unified set of principles that influence the conduct of brain data research. The findings also show that issues and concerns generated in the application of ethical and legal principles cut across four key interconnected areas which include ethics, human rights, regulations, policies and guidelines, and participatory governance. The results of the research raise critical issues and concerns around the best practices that may need to be agreed upon to develop an international data governance framework for brain data.

The research responds to the call for inclusive dialogues among stakeholders from diverse cultural contexts and the acknowledgement of the different sociocultural needs, issues, and concerns that can shape the principles around brain data. The paper also serves as a catalyst in understanding the key issues and concerns from key actors and experts involved in the collection, processing and sharing of brain data globally. The results of the research will inform policymakers, funders, neuroscientists, publishers, and other relevant stakeholders involved in the current discussions around the development of an international data governance framework for brain data.

The paper commences by examining the core concepts essential to the study. It then delves into the importance of ethical and legal principles in governing brain data, emphasising the gaps in understanding their influence on stakeholders and the associated issues and challenges that arise in their application as a result of global diversity. This sheds light on the study's significance. Subsequently, the research design is detailed, followed by the presentation of analysis results. Finally, the paper offers a comprehensive discussion of the key contextual insights and draws conclusions.

Conceptual Background

To provide conceptual clarity, here we present and discuss key concepts and themes that provide a focal lens on the study.

International Brain Data Governance

Data governance provides a framework for the efficient management of data [6] and is influenced by various ethical and legal principles [5, 7]. Some of the principles underline the importance of moral rules and obligations and the importance of identifying general considerations [8] when managing data from collection to deletion. Data governance has often been influenced by information technology or corporate contexts, which focus on the efficient management of data usually in single organisations or within a region. However, in the context of brain research, we emphasise that data governance does not only focus on data management but cuts across several spectrums that must reflect the ethical, legal, and social implications (ELSI) [9] of brain data research. Therefore, we define data governance as the *principles, policies and strategies that define responsibilities of accountable stewardship which include acquiring, aggregating, deidentifying, processing, curation, retention, deletion, use and the overall availability, usability, integrity, security, and privacy of data in alignment with ethical, legal, and social obligations*. This, therefore, means that *international brain data governance has to do with how brain data is processed in accordance with ethical standards, regulations, and data management standards (e.g. FAIRness-Findable, accessible, interoperable, and reusable)* [10] *across different jurisdictions* [3].

While a set of universally acceptable principles would advance the development and understanding of international brain data governance, this has not been the case as data governance principles are deeply rooted in ethics and law [11]. Ethics can have multiple interpretations (ethical pluralism) while law also varies according to jurisdiction. However, understanding the background of these tensions is essential as it creates a focal lens for this study. Therefore, in this section we provide a background on ethics and law which gives an underpinning to data governance. We also provide a background on the relationship between ethical and legal principles, their importance in brain data, and why understanding the gaps in the application of ethical and legal principles is important to advance international brain data governance.

Ethics

Ethics as a branch of philosophy has been a fundamental focal point of discussions spanning over centuries. The conventional philosophical viewpoint of ethics focuses on moral principles and beliefs which guide the actions and judgement of individuals in a society [12]. In general, ethics is considered as a synonym for moral philosophy [13] and stems from the Greek word "ethos" which stands for "custom" or character. Ethics can be broken down into multiple branches which include normative ethics, meta-ethics, applied ethics, and descriptive ethics [14]. This paper uses the term *"ethics" to denote individual rights and the grounds or basis on which moral judgements, actions, reflections, behavioural standards, or statements are made*. These moral judgements provide individual obligations and establishes a framework for societal, moral, and social perceptions. In addition to ethics, the study introduces law which is a major theme in data governance and is highly interdependent on ethics.

Law

Over centuries, law has witnessed multiple definitions and interpretations due to its applicability in various fields, and up till date people still struggle with grasping a simple concept of law [15, 16]. When the question of what law is or what is the essence of law is presented, it always goes beyond common sense to provide an answer and requires knowledge of all the existing conventions overseeing the use of the word "law"; therefore providing a definition of the concept of law is complex [15, 17]. However, for the purpose of this study, we use the term "law" *to denote the body of principles or guidelines that oversee certain kinds of human conduct* *that are no longer optional but obligatory and overseen by a system of societal or governmental rules*. In terms of law, the obligation of human conduct is backed by moral rules, which removes certain areas of conduct and reduces the freedom of an individual to do whatever they like [15, 16].

Exploring the Interplay of Ethical and Legal principles in the Governance of Brain Data: Challenges and Diversity in Global Perspectives

There is a complex relationship between ethics and law, and many social scientists have pointed out that ethics shape laws in different jurisdictions, while laws also complement ethical principles. This means that a system of law can sometimes be constitutive of the average of the ethical systems in society. Therefore the greater the deviation of law from the ethical systems of a group of people upon which the law is to be imposed, the greater the difficulty in the application of law [18]. This is to say that jurisdictions do align their laws to their ethical principles and their legal systems are reflective of their ethical systems to promote applicability in their context. This also affects the way brain data is governed in different jurisdictions as ethics is known to vary among societies.

Discussions around the nature or the essence of law usually point towards a contention that there is no clear direct connection between law and ethics, but there exists a general contention that there is a necessary connection between law and morality [16]. This claim regarding the connection of morality and the law constitutes of multiple variants and lack clarity, especially because the term morality is also characterised by multiple interpretations as associated with ethics. The notion of common morality can be seen in universal and regional guidelines and regulations such as the Universal Declaration of Human Rights (UDHR) [19], the Universal Declaration of Bioethics and Human Rights [20], the EU General Data Protection Regulation (GDPR) and Health Insurance Portability and Accountability Act (HIPAA) [21, 22] reflecting ethical and legal principles such as justice, beneficence and equality. These ethical and legal principles are also important in the field of brain data as they attempt to generalise the universality of practices while promoting human rights for the greater good.

Although these declarations, regulations, and ethical systems exist, they have not been able to provide a robust global governance framework for brain data due to various challenges which stem from the application of ethical and legal principles in the collection, processing, and application of brain data. Our study conceives ethical and legal principles not as immutable principles of conduct or as discoverable by reason, but as expressions of human attitudes to conduct which may vary from society to society. Our study suggests that there is a diversity among moral codes (ethical pluralism) as related to ethical principles which may spring either from the peculiar but real needs of a given society which may influence the key actors (e.g. neuroscientists) involved in brain data research.

Navigating the Ethical Landscape of International Brain Data Governance: Influences, Challenges, and Key Stakeholders

The importance of ethical principles in brain data research can be highlighted by the development of neuroethics [23], which provides a set of ethical, legal and social tools for informing the design and conduct of brain research. The use of ethical principles has also been considered as a core element in promoting data sharing and collaboration especially in large neuroscience projects [11]. This is because ethical principles provide an avenue to navigate the ethical tension and moral hurdles that occurs in brain research. Ethical and legal principles or norms which can be applied in the field of brain research have been codified in various documents such as the Declaration of Helsinki [24], GDPR [25], HIPAA [21], the neuroethics guiding principles for the NIH Brain Initiative [26], and the neuroethics question to guide neuroscience research by the Global Summit Delegates [2], and in international laws and declarations such as the Universal Declaration on Human Rights [19], and the Universal Declaration on Bioethics and Human Rights [20]. General ethical and legal principles or norms include equality, justice, and fairness as these are applied generally in systems all over the world [27].

Although there are international norms on data protection, they are no streamlined data governance frameworks for how researchers need to address some of these principles in brain data research. Also, while these principles have been outlined as guiding principles to oversee brain data research, it is still not clear how these principles influence key stakeholders such as neuroscientist in various regions involved in brain data research with a special focus on the contextual issues that arise with their application. With ethical views varying from one region to another, some of the consequences of this lack of clarity may involve the varying interpretations of ethical principles and guidelines, the underrepresentation of some principles, or lack of application of some principles, and unintended ethical violation of data gotten from another region. Therefore, understanding the ethical and legal principles that influence various key actors in various brain projects is crucial for understanding brain data governance most especially on how key actors in brain data research apply these principles and the issues and concerns that arise around these principles and how they can be addressed to form best practices. We posit that it is through the understanding of the perceptions and views of key stakeholders such as neuroscientists can policy makers, international organisations, funding organisations, scientists discern the issues and concerns that arise around the application of ethical and legal principles in brain data research.

Having provided a background on international brain data governance, ethics and law, the complicated relationship between ethical and legal principles, the importance of ethical and legal principles in brain data governance, and the current gaps in understanding the application of ethical and legal principles by neuroscientists from different brain projects and regions, it is therefore necessary to understand how ethical and legal principles influence key actors and the contextual issues and concerns that arise in order to answer the research question: *how do ethical and legal principles influence data governance in neuroscience?*

Research Design

Prior to this study a scoping review was carried out to identify the key ethical and legal principles in the landscape of brain data governance [5] which was followed by a pilot study. The pilot study was used to test the feasibility of this study and provided results which assisted in making minor adjustments to the interview questions. Therefore, informed by the results of the pilot study this study adopted methods for data collection and analysis that align with contextual, explorative, and descriptive research [28] using a qualitative approach. The underlying rationale for this approach lies in an attempt to explore social reality around the key principles identified in the scoping review as one of the strengths of qualitative research is its ability to explain processes and patterns of human behaviour that can be difficult to quantify [29]. A qualitative approach allows participants themselves to explain how, why, or what they were thinking, feeling, and experiencing at a certain time or during an event of interest which can be important especially around the key ethical and legal principles identified in the scoping review. The research received ethics approval from the De Montfort University's Research Ethics Committee and considered and mitigated identifiable concerns related to participants' informed consent, privacy, and confidentiality.

Sample Selection

For this study, we categorise neuroscientists as key actors or stakeholders in brain data research. This is because neuroscientists are representative of an important stakeholder group who are involved in the collection, processing and sharing of brain data while applying principles that exist in policies, guidelines and regulations that currently depict governance. Neuroscientists usually act as the first point of contact in the data management life cycle as they are responsible for collecting brain data while traversing regulatory and ethical hurdles. They also translate legal principles and make ethical decisions when collecting and processing individual brain data. Therefore, they serve as examples of people who are affected by these principles and can provide an understanding of *how ethical and legal principles influence data governance in neuroscience.*

Currently various research projects exist in various regions, however the IBI according to its vision aims to advance ethical neuroscience through international collaboration by bringing together neuroscientists from regional and national brain research projects. Currently seven national brain projects spanning across four continents form the IBI excluding Africa and Latin America as the only continents without a representation. Therefore, the study used purposive sampling, which is a method used to select information rich cases related to the phenomenon of interest [30] to identify neuroscientists who are mostly Principal Investigators (PIs) from the IBI, LATBrain Initiative, and the Society of Neuroscientists of Africa (SONA).

This resulted in a geographical spread of neuroscientists involved in different brain projects in different regions who were able to provide contextualisation. Table 1 below shows the geographical distribution of participants based on the regions which underpin their contextualisation and where their research projects are situated.

In the research design the use of continents is established to offer a broad overview of regional trends and perceptions. While recognizing that significant variations in perception exist between countries within the same continent, the focus here is to provide a foundational understanding of continental-level patterns. By examining continental trends, we aim to identify overarching themes and tendencies that may influence perceptions across diverse countries within each continent.

Size and Justification

Sample size has been subject to a lot of debate especially when it comes to acceptable principles that should be used in determining the numerical size of participants to be used in qualitative research [30–33]. However, the more useable data is collected from each person in a sample, then the fewer the number of participants required to make the total sample size for the achievement of saturation [34]. Furthermore, the required number to achieve saturation is usually around 12 participants [35].

Table 1 Geographical distribution of research participants based on their brain research projects and contextual underpinnings

Geographical Distribution	Number of Participants
AFRICA	3
LATIN AMERICA	3
EUROPE	4
NORTH AMERICA	7
ASIA	3
AUSTRALIA	1

Interviews

Interviews in research ensure that the relevant context can be brought into focus and then situated knowledge can be produced [28, 36, 37]. The ontological and epistemological position of the research justifies the use of interviews because they do not produce reality, rather they rely on the participants ability to remember, conceptualise, and interact therefore constructing reality which needs interpretation [38]. The study adopted the use of semi-structured one on one interviews which were carried out virtually via Zoom and lasted about 15 to 20 min. The study used open ended questions which focused on the ethical and legal principles or issues that the participants thought could arise from neuroscience research. We also used probing questions to ask participants of their knowledge about neurorights and the principle of retention and destruction of data as these were less visible based on the results of our previous study.

Data Analysis

The transcripts of the interviews were analysed using *Nvivo 12* qualitative data analysis software and thematic analysis [39], and coding was caried out to categorise statements. We analysed and coded the statements by reading and understanding the transcripts to identify which principle in our previous study matches the statements and which themes emerged from the statements. A consistency check was also performed both by reference to our prior study and a process of deliberative mutual adjustment among the general principles and the judgments contained in our prior study, an analytic strategy known as reflective equilibrium [40]. We then used the matrix coding query tool in *Nvivo* to determine the visibility of identified principles or themes under different participants in a region. This assisted the study in determining how many coding references were made to each thematic node under each region.

Results

In this section we provide a detailed analysis of the results. To present key findings we focused mostly on statements related to concerns and issues under the themes identified. We noticed that participants pointed out that ethical and legal principles or issues arising from neuroscience are related and could not conceptualise ethical and legal principles or issues separately when asked about what ethical and legal principles or issues arise from brain data research. Participants also attempted to provide the relationship between the ethical and legal principles which they had previously highlighted, and the analysis deduced that there was majorly an agreement that there is a relationship between ethical and legal principles however the responses by the participants showed the complex and dynamic relationship between the ethical and legal principles and their perceptions around them therefore increasing the need for a data governance framework which will achieve harmonisation and standardisation. This is important because some of these principles having been codified in law and researchers often struggle to distinguish these principles. Although basically, these are fundamental principles with ethical traditions.

The analysis showed that they appear to be some level of convergence around some of the principles as the discussions around the principles were visible across multiple participants from different regions. This is shown in Table 2 below. For example, privacy, confidentiality, and protection discussions were visible across all participants and the legal basis principle which focuses on legal underpinnings as the basis for the collection, processing and management of data was also visible across all the participants. However, there was less convergence around the principle of trust as the discussions around trust was only visible in the conversations of North American and European participants.

Based on the analysis as shown in Table 2 above we deduced high coding references to several principles by using the number of coding reference to a principle. This can also mean that the principles with high discussions are prioritised by a region or by participants over other principles or concerns. The principles with high coding references can also mean that the participants feel that the highlighted principles should be prioritised, or they encounter more issues and concerns around them. For example, the African participants had more coding references under fairness and transparency, proportionality, legal basis and privacy, protection, and confidentiality. While the Latin America participants prioritised integrity and legal basis. North American participants had more priority under consent, responsibility and accountability, integrity, ownership, legal basis, and privacy, confidentiality, and protection. For European participants priority appeared around fairness and transparency, privacy, protection and confidentiality, anti-discrimination and bias. For Asian participants priority

Table 2 Principles mapped to their corresponding regions of visibility

	AFRICA	LATIN AMERICA	NORTH AMERICA	EUROPE	ASIA	AUSTRALIA
Beneficence and Non-Maleficence	*	*	*	*	*	
Privacy, Protection and Confidentiality	**	**	**	**	**	*
Independence and Autonomy	*				*	*
Engagement	*		*	*		
Fairness and Transparency	**		*	**	**	
Legal basis	**	**	**	*	**	*
Ownership	*	*	**			
Proportionality	**		*		*	
Integrity		**	**	*		
Responsibility and Accountability		*	**	*	*	
Anti-Discrimination and Bias			*	**	*	*
Consent			**	*	*	
Trust			*	*		

**Coding reference to a principle*

***high coding references to a principle which signifies prioritisation by participants* existed around privacy, protection and confidentiality, fairness and transparency, and legal basis.

The Figs. 1, 2 below provides a summary of the principles and main issues that emerged from the analysis. Concepts like neurorights and data retention and deletion were not spontaneously mentioned by the participants, but rather they were explicitly asked to give their opinions on them.

In the next sections we provide a detailed analytical evaluation to present the various discussions around the identified principles.

Privacy, Protection, and Confidentiality

Most participants point to the fact that privacy may be the core ethical issue in brain research. Most North American participants used the term "anonymisation" as an essential element of providing privacy and confidentiality, which highlights its prominent use in the North American context, while an African participant (Africa3) used the term "defacing", while a Latin American participant (LatinAmerica2) used the term "coding", and the Australian participant used the word "blinding" to quantify techniques for achieving privacy and confidentiality of data.

This subtle but diverse use of different keywords to quantify privacy and data protection techniques highlights the different practical applications of data protection mechanisms (or privacy enhancing techniques) by different participants and it is not clear if "coded data" is equivalent to "defaced data". While no participant mentioned "pseudonymisation", it is quite clear that in the European context, pseudonymisation and anonymisation are commonly used privacy enhancing techniques [41, 42].

It also appears that in the European context, neuroscientists or data custodians are currently encountering challenges when applying privacy-enhancing techniques which involve the need to provide privacy, security, and protection in infrastructures while retaining the utility of data.

> *"we get collaborators who request things that are so hard to implement, so, so complicated that they become useless, right? there is a point where there is a threshold, where you say, okay, I really might want to make this useful and secure and this is as secure as I can give you without making it almost impossible to use"* (Europe3).

Fig. 1 Overview of ethical and legal principles and key areas of issues and concerns

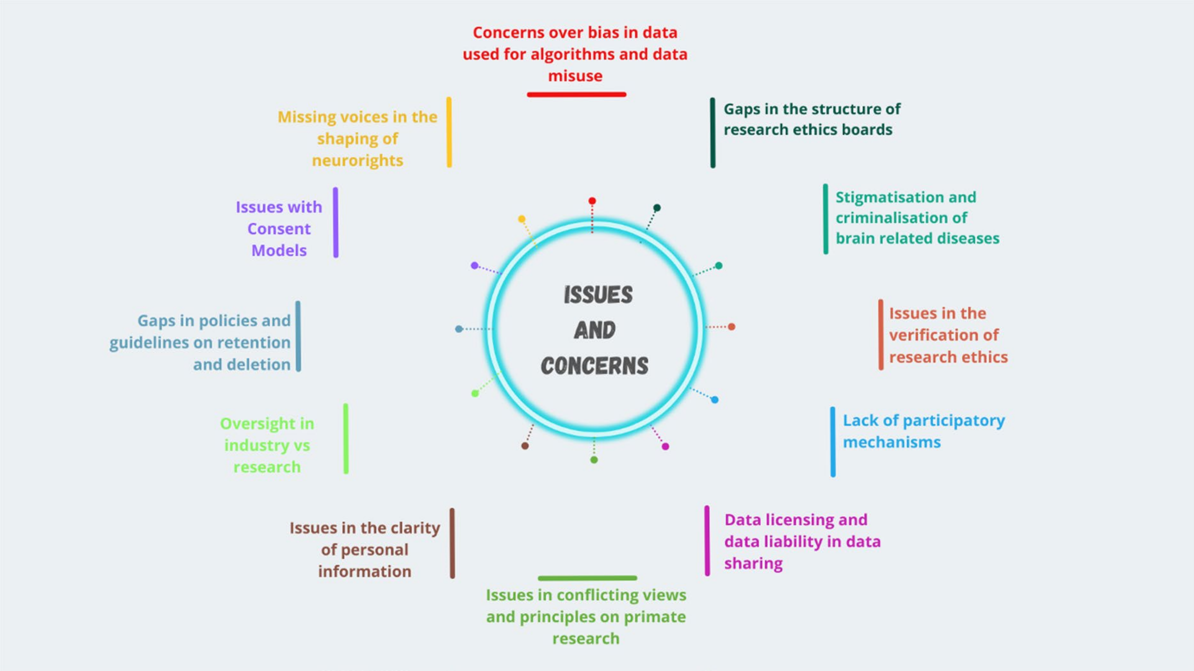

Fig. 2 Contextual principles, issues and concerns arising from brain research

While in the European context, there are concerns about the utility of data due to privacy and data protection techniques, in the North American context some participants appear to be more concerned around the efficiency of current privacy and data protection techniques with statements highlighting the inadequacies of anonymisation. Perceptions show that anonymisation may not be sufficient as a privacy enhancing technique.

> *"as soon as we share subject identifiers, even anonymized ones there is a risk of re identification"* (NorthAmerica1).

Also, in the use of personalised medicine through modelling, some participants from North America believe that an individual can be identified through the model because models are now created using human imaging data.

In the Asian context, the application of privacy and data protection and their inadequacies appears to align more with the lack of clarity of what is categorised as personal information, and one Asian participant appeared to highlight the contextual meaning of personal information which influences how mechanisms are applied to attain confidentiality, privacy, and data protection. This lack of clarity in the definition of personal information was mainly attributed to sharing brain data and is illustrated below.

> *"one possibility is shape of the brain could be a kind of personal information, because as you know, the brain has a very complex shape different people have different gyral patterns or sulcal patterns. So that is kind of a fingerprint. So, its maybe possible to identify a person from his MRI data that is possible"* (Asia2).

The statement above was further bolstered by the participant pointing out that considerations are ongoing around the sharing of facial data together with brain imaging data.

Participants from the African and Latin American region appear to be influenced more by the need to provide clarity in terms of data protection mechanisms. For example, participants pointed out the need for data management, control, and protection of research participants and data. This shows that while in the European context clear mechanisms exist it might not be the same for these regions.

The statements and perceptions above also show the varying practices and concerns faced by neuroscientist when applying privacy, confidentiality, and data protection and can influence the sharing, processing, and storage of brain data.

The misuse of brain data is also considered as one of the most important issues of privacy and data protection by participants and is also linked to the violation of human rights which was highlighted by the Australian participant. The potential misuse of data is also expressed in terms of the reuse of data to provide big data insights, especially with regards to broad reuse as this may affect the privacy of the individual as highlighted by American participants.

Consent

North American participants expressed strong views on need to always explain what the potential downstream uses of the data are to the subject as there is a perception that the potential downstream uses of data which has been acquired cannot be pre-empted therefore resulting in a lack of control of the downstream uses of data. This shows that in the application of consent, there is a perceived lack of adequate models. This relates to the potential misuse of data and shows that although neuroscientist and researchers obtain consent for research, there is a level of uncertainty that consent may not be valid for all uses of data. This uncertainty around consent is also grounded in the use of invasive technologies as highlighted by another participant who questioned the validity of consent in such technologies that can alter the brain chemistry over long periods.

There were strong views from North American participant about consent as a tool for research subjects to have control over their data and to control privacy risks as owners of private data thereby leading to a trade-off between privacy and utility. A North American participant also argued that consent influences sharing as the research subjects cannot completely understand the implications of data sharing therefore consent should be limited by law.

> *“I don’t think it’s entirely possible, I think people can’t completely understand what could be the implications of sharing, and that this consent should also be limited by law. So, it shouldn’t be possible to consent to anything”* (NorthAmerica1).

This appears to be reflected by an Asian participant who highlighted the limitations of sharing data across borders and the fact that consent forms cannot be modified easily, therefore reducing utility of data.

> *“So now we start thinking about how to, you know, how to share our data, you know, internationally, so actually, the personal information issue strongly affects our work. So, we change our consent form, for example, to be able to share across borders and we need to, you know, that is very important, because after we collect the data, we cannot change the consent form”* (Asia2).

These perceptions show that regions may be dealing with internal tensions around consent models and the need to share data. However in the European context consent is strongly tied to data altruism and is clearly established in article 2 of the data governance act [43]. Also, article 22 of the data governance act establishes the use of European data altruism consent forms, which can allow the collection of consent among member states [43].

Anti-Discrimination and Bias

Participants from Europe expressed concerns in terms of the possibility of algorithms being biased or the output of research based on the usage of biased samples. This is developed from a perception that in machine learning, algorithms tend to be fast in detecting bias because the data being used is already biased in some nature. This is illustrated in the statement below.

> *“Another point I was thinking of, which is more in regard to machine learning is that there is always bias in the data and this bias it can be quite easily discovered by the algorithms”* (Europe1).

Although the participant acknowledged that bias can be either intentional or unconscious and brings about multiple risks, another participant points out that questions about reliability and testability and the bias of system decisions will always surface in algorithmic decision systems. Some Asian participants also expressed perceptions that European and North American regions will most likely have challenges around the prevention of discrimination and bias due to ethnic diversity..

An interesting finding around bias was highlighted in the perceptions of some North American participants who are influenced by a sense of discrimination and bias in terms of the oversight that is applied towards the research community and the oversight applied to companies which stems from a belief that companies have a free-market approach while the research community has a closed market approach.

> *"I think we should have a common ground rule of ethical principles that would apply to both researchers and in the industry. What can a researcher do in terms of data, collection and sharing shouldn't be different from what a company can do with data collection and sharing"* (NorthAmerica5).

Engagement

African participants expressed strong views on the lack of education regarding the need to acquire data. This was related to the stigma associated with brain diseases and the need to provide education that brain data needs to be acquired for the study of such diseases to provide an intervention. This perception portrays the need to engage stakeholders and society, as this may influence how neuroscience is conducted and reveals contextual challenges around data collection.

Some North American participants also stressed the need for ongoing engagement and education of Research Ethics Boards (REBs) to help them with informed decision-making derived from the understanding of real actual risks in ethics approval and to understand data and data-related issues. This perception shows that in the North American context, participants may experience a lack of proportionality in analysing risks, which may influence a certain perception of lack of trust in the ethics review process as pointed out below.

> *"So there's this concept of a GUID, which is what NIH uses, allows you to, to make a linkage between studies where the same individual participates in multiple studies, but very many of the REBs or reviewer boards that I've interacted with, really don't know and they're not familiar with a lot of these concepts"* (NorthAmerica2).

This perception is also held by a European participant who pointed out that there is not sufficient competence to translate the complex legal and ethical frameworks into practice. This then becomes a significant barrier, therefore, requiring extensive education of different stakeholders. Some European participants also highlighted a lack of sufficient mechanisms for engagement, particularly concerning research on early prediction of brain diseases and disease trajectories.

Overall, the perception of engagement highlights the diverse contextual and sociocultural needs surrounding engagement.

Independence and Autonomy

African participants appear to be influenced by a need for independent review boards which do not operate under institutional control, as this may stall research in certain conditions, such as when institutions are involved in industrial disputes or strikes. This was mostly reflected in perceptions by African participants who provided examples of how their brain research projects had been affected because ethics review boards were not independent or autonomous.

> *"The practical case I'm experiencing currently is I submitted ethical approval, I will say I submitted this week, and the next week or the next two weeks the Staff Union went on strike and I almost went crazy, because I'm like, okay, what do I do and they said well, nothing the school is shut down both academic and non-academic, everywhere is shut down"* (Africa3).

Independence and autonomy were also expressed by Australian and Asian participants in the context of data subjects having their own free will and having control over decision making around the use of data. Terms such as "human free will" and "rights" were used in reference to independence and autonomy which shows that issues around data access and control may be viewed as a fundamental human right.

Fairness and Transparency

Some participants expressed views about fairness in terms of fair access, which has to do with the requirements for users being allowed to look at and use their data, therefore raising concerns about fair or equitable access to data, research results, and public health benefits derived from those results. While transparency, was expressed in terms of displaying methods of accountability to data and research subjects.

According to Asian participants to promote fairness and transparency, documenting and updating standards to ensure reproducibility of findings and to explicitly state risks in brain data is foundational.

> *"What kinds of a risk may happen for every people…that's why transparency is very important…This should be the basement of the legal principle and of neuroethics"* (Asia3).
> *"We also have to update our ethical standard and practice to keep up with the improvement of fairness and the increased reproducibility of neuroscience research"* (Asia1).

However, some participants have the perception that research subjects may not have access to their data due to paywalls they encounter when they require some information, while another participant has the perception that benefits of research are not efficiently distributed and communicated.

> *"Yeah, so I think one ethical issue that I've really kind of been thinking about a lot is data, or science, accessibility, and how to make really complicated neuroscience accessible to anyone who wants to consume it"* (NorthAmerica4).
> *"let's say that we figure out exactly how to cure let's say Parkinson disease, right….with that comes some inherent knowledge and how the whole basal ganglia motor control circuit works, right? I think that that's something that's immediately going to be yeah, problematic from an ethical point of view, right? Because who has access to that, you know,it is only going to be the rich western countries that can do that"* (Europe 2).

An interesting dimension to fairness in the form of procedural fairness [5, 44] was expressed by African, North American and European participants in terms of ethical approval for research. For example, an African participant highlighted that they need to pay for ethics approval.

> *"So there is not much awareness of the bureaucracy involved in ethical considerations and ethical approval for research… some facilities demand ethical approval fee"* (Africa3).

While a European participant (Europe1) highlighted how the use of the word "drone" in a research proposal raised the need for further justification of the research proposal, the use of the word "robot" was seen as less sensitive. Also, a North American participant highlighted that they need separate ethics approval for data sharing, which is a practice that raises issues. The participant further pointed out that ethics approvals are control instruments creating a perceived lack of fairness.

> *we need separate ethics approval for data sharing agreement, and that gets worse every year So there's a whole administration involved in that, where the ethics people pick that up and impose things upon the researchers, which I think is not always good because this also a control instrument* (NorthAmerica7).

Data Integrity (Data quality, Open Access, and FAIR)

Latin American and North American participants had intensive discussions around data integrity compared to other participants. Data integrity was mostly expressed in terms of data quality, FAIR (Findable, Accessible, Interoperable, and Reusable) principles, and open access to research data. Latin American and North American participants appeared to be highly concerned about the usability of brain data in repositories, with perceptions around how some brain data meet journal requirements but lack reusability.

> *"one thing I'm concerned about in data sharing is the quality of the data that is being shared"* (LatinAmerica2).

Another key concern around data quality from a Latin American participant was on the correctness of simulated data with perceptions showing that simulated data may be harder to validate.

> *"How do we check or how do we guarantee this data generated from simulators are okay?"* (LatinAmerica1).

Another Latin American also expressed strong opinions that while public funding bodies and journals promote open access, regions with low funding (referring to the Latin American region) do not have access to utilize open access, and this results in a non-democratic effect of open access. Also, government structures, political ideologies, and the need for competitive advantage by neuroscientists were highlighted.

This shows that while developing countries with low funding are open to sharing, several factors affect the application of open access and FAIR principles, therefore making data in these regions available but non-findable due to the lack of proper data governance structures. This was also supported by a North American participant who stated that developing countries are more open to sharing data because it may be the essential factor necessary for them to gain access to data.

However, regarding procedures to address data quality, a North American participant provided the following contextual insight.

> *"we're now taking data from around the world. We basically say, in our Open Data Commons, you have to guarantee that you took this data, you know, ethically, and that you have the right to share it from your colleagues and everything else. And, and so we're putting the liability on the data submitter, that everything is okay"* (NorthAmerica3).

Ownership and Intellectual Property

Discussions around ownership of brain data were mostly expressed by North American participants but also cut across African and Latin American participants. Participants were influenced by the need to protect data collected for research. For example, an African participant pointed out the reliance on the use of copyrights as the mode of protection of their research data, while another participant highlighted Intellectual Property (IP) concerns..

> *"The only thing we know is protect your property get a copyright"* (Africa2).
> *"Everybody would be familiar with consent, protection, security, all of that. But then there is the legal rights of IP, and countries unilaterally sort of declaring that we're going to use everybody else's public data, but we're not going to contribute any of our public data"* (NorthAmerica3).

While some North American participants expressed optimism that the trend of giving people professional credit for their work has evolved significantly, Latin American participants believe that there are significant issues with provenance tracking and acknowledgment. This was also expressed by another participant who argued that the licensing structure for provenance tracking and data use agreements in repositories do not provide the necessary apparatus to facilitate the apprehension of users who abuse or misuse data, therefore indirectly influencing ownership and IP.

> *"We don't have an apparatus to go after people who are illegally using our data. So, we may as well just give it to them, because we're not going to go after them and we know we're not going to go after them, right. And I think that those legal issues are really important because the repositories that acquire this data, and that's always where I come from, are not in a position to do this"* (NorthAmerica3).

There is also some concern about how to meet FAIR access requirements and how to also meet the requirements of funding agencies which relate to the ownership and IP of research as well as the ownership and IP of research output.

> *"The issue arises of how do we share our data openly, while still kind of following the agency that is funding us because they have their own guidelines on data sharing"* (NorthAmerica4).

Responsibility and Accountability

Participants, especially from Asia, North America, Latin America, and Europe, highlight a lack of responsibility and accountability from researchers, especially when data is shared across borders, as some believe that poor quality data shared across borders can raise several ethical and legal issues and the responsibility of neuroscientists does not terminate at the point the data leaves a jurisdiction. Some participants also expressed the need to understand the responsibility of parties involved in data submission in repositories, as liability is not usually clearly defined and the need for repositories to be more accountable. This is illustrated in the statement by a participant below.

> *"I have become a little bit more concerned about repositories and their liability for breaches, right? Thus far, nobody has held the repository liable for data that was improperly acquired, the repository is expected to take it down"* (NorthAmerica3).

A participant also highlighted the need to express responsibility in defining the relationship and interaction that is established between end users of AI and the need to have reflexivity when developing AI that makes use of brain data models for militarisation, as operating under a government framework may be legal but unethical. This is illustrated in the statement below.

> *"So, in neuro robotics, there might be I think, as I mentioned before, you have to be careful with the kind of relationship that will be established between the automated machine, the intelligent machine and the humans or other living creatures, and it could be also animals"* (LatinAmerica3).

Legal Basis

The legal basis behind the collection, processing, and sharing of brain data wss highly discussed and cut across all participants from all regions. Some participants pointed out the lack of laws protecting brain data, and some mentioned explicit laws behind the collection and processing of brain data, while some participants pointed out that while no strict law exists by the government, there is a consensus among researchers and research-performing organizations on how to manage brain data. Some participants expressed the non-clarity of laws, guidelines, and principles as a hindrance behind the collection and processing of brain data.

> *"we want to you know, stick to the regulation and the law, but the regulation and the law is not completely clear. So, what is personal information is very straightforward in some field, like legal fields, but in neuroscience data, it is kind of difficult to define what is personal information, because we are dealing with brain imaging data of a person or a patient"* (Asia2).

African participants also pointed out the strict nature of laws around primate research but highlighted the underdeveloped nature of laws related to human brain research. However, African participants pointed out that the justification of the underdeveloped nature of the laws was related to the limited studies around human brain data (e.g., MRI data) and the stigma associated with brain diseases. Participants did not explicitly state the legal basis behind the use of brain data for the development of algorithms or AI models. However, a European participant explicitly referenced the AI Act and pointed out that the AI Act underpins what can be viewed as Artificial Intelligence in the region. This is illustrated by the statement below.

> *"But of course, there's also novel regulations that are emerging such as the AI act. So what we are doing is we do not fully focus on what traditionally is seen as artificial intelligence, but the definition as it is on the AI act"* (Europe4).

Proportionality

Proportionality was expressed by participants in terms of the need to align ethical and legal principles and the balancing of risks and benefits of research, especially by ethics review boards. This was highly referenced by African participants who pointed to the lack of proportionality in the process of ethics review and ethics approval. This was also related to the inability to verify ethics approval as pointed out by some African participants who called for an ethics verification infrastructure for brain data research. Participants pointed out that the varying protocols and laws create challenges for collecting and sharing brain data because they prevent the balancing of risks and benefits of research, and this has resulted in the placing of an emphasis on risk in a negative sense. This is shown in the statement below.

> *"The other aspects that I think is so, so critical, is, there's so much emphasis on risk in a negative sense, right, and the risk of data sharing and data reuse and data linkage. It's the big*

> *focus for many of these ethics boards is on risk"* (NorthAmerica2).

Beneficence and Non-Maleficence

There was full convergence around beneficence as this was reflected across all regions. Participants expressed the need to prevent harm and promote the common good, which should be underpinned by promoting the welfare of participants. However, African perceptions show that current legal and ethical frameworks such as laws around attempted suicide and mental health, which may be related to a brain condition, and the stigmatisation of brain diseases may prevent this. For example, an African participant provided an example where the law criminalises the act of attempted suicide, which may cause harm to the patient as compared to viewing it as a medical condition and providing adequate medical care as illustrated in the statement below.

> *"That law is being changed now, to see it as an illness, mental illness that requires the individual to be taken to a hospital rather than to a prison. So, you can see, why will you take somebody who attempted suicide to a prison? What do you think will happen there compared to when you take him to a health facility"* (Africa1).

Trust

Trust was rarely reflected in discussions by participants. However, the participant who had perceptions around trust believed that there is a certain lack of trust in the protection of intellectual property and in the reciprocity of data sharing. Also, the participant pointed out that publishers should provide a way to verify their agreement with authors of research data. This lack of trust is also expressed in terms of the data origin, especially if it is from a different region, as there is no way to fully verify the ethics approval or legal equivalency of another region.

> *"we are more suspicious of data that is submitted from other countries than our own, simply because we understand the rules in our own country, and we don't understand them and the others, and we don't have the staff to go and say, oh, yeah, no, this is equivalent and this is okay. But I think that sort of guidance is a problem"* (NorthAmerica3).

Other Principles

Guided by the results of our previous research where we noticed that in the context of brain data governance, neurorights and the retention and destruction of data were barely visible in the landscape of brain data governance, we used probing questions to ask participants about their perceptions around neurorights and the retention and destruction of brain data.

Neurorights

The findings indicated that the vast majority of participants had little to no awareness of neurorights and were unfamiliar with the term. Most participants required an explanation to understand its meaning. While a few participants made attempts to conceptualize neurorights without prior knowledge of its definition or components, the majority offered diverse perceptions and arguments regarding neurorights and what they believed it should encompass. Opinions on the concept varied, with some expressing support for it and others holding reservations.

Retention and Deletion

With regards to retention and destruction, we observed that participants operated under different retention timelines. However, there were different perceptions and proposals on how data retention and destruction should be applied, with participants debating the need to keep data for extensive periods without deletion and more clarity in policies and guidelines from funders, research institutions and data repositories.

Animal Research and Ethics

The discussions also highlight the complex regulatory environment and cultural sensitivity surrounding animal research. In Africa, researchers need to navigate a range of permits, regulations, and ethical approvals, even beyond institutional protocols. The regulations can be strict and may vary from country to country creating challenges for researchers working across borders even within a region.

> *"outside institutional ethical approval, for your animal research, if you're dealing with animals from the natural population and it is not within your province, you are expected to receive and provide permits"* (Africa1).

This also relates to different ethical standards, cultural, and societal views, which were highlighted by some participants. For example, an Asian participant expressed concerns that the perception of certain species, such as primates, varies among countries and can influence the ethical considerations and acceptance of research involving these animals.

> *"And then also some difficulty is the public opinion about certain species, especially the primates, so in the Japan's brain mind project, we use the marmoset monkey as the main target. And the Chinese project, take a macaque monkey as the main target……. some countries do not prefer, like primate brain research, or its use is very limited. So, and then when we publish the result, or exchange such data using our primate brain, so how to take into account different views about primates in different countries. Which is another issue we have to think about"* (Asia1).

It also appears that these varying sociocultural perceptions and standards also affect the publication of research findings in journals and repositories as highlighted by another participant.

> *"I finished a research, sent it to that journal, it didnt even spend 24 h before they responded, that they can't publish my work, because it's animal data, but they now listed that they use C elegans, Drosophila"* (Africa2).

The discussions also indicated that cultural attitudes towards animals may vary significantly between regions. In some regions, there may be less sensitivity and legal protection for animals compared to other regions. These cultural differences can impact how animal research is perceived and regulated. For example, the statements below by participants from different regions highlight such cultural sensitivity.

> *"Animal rights might not be like the highest priority in Latin America"* (LatinAmerica3).
> *"I mean, if you can get five goats or five rats or 10 or 20, the more the merrier because the law does not exist. We are not too sensitive with feelings of animal and animal rights and all that"* (Africa3).
> *"the use of only male animals was quite common, until recently, but these days, inclusion of both male and female animals are required unless there's such need to pick only male or only female subjects"* (Asia1).
> *"one of the reasons I got into Informatics is because I just hated working on animals, right? I just hated it. And if they were going to die, I wanted their data to be used over and over and over again. So, we never had to kill any more animals"* (NorthAmerica3).

Key Contextual Insights and Discussion

The results present the dynamic relationship between ethical and legal principles and the concerns and issues that arise from their application in brain data research. It also provides an underpinning to how neuroscientists, who are key stakeholders in brain data research see these principles as a unified set of principles that raise issues and concerns around intimately connected areas, which include research ethics (e.g. ERBs, open access, research integrity, animal ethics), human rights (e.g. bias, participants welfare, criminalisation of brain diseases), regulations, guidelines and polices (e.g. oversight in repositories, data liability, clarity in regulations) and participatory governance (e.g. stakeholder engagement, education, and participation).We posit that these key principles, issues, or concerns, need to be brought under the radar of discussions to advance the development of a framework for global brain data governance. Therefore, we present the contextual regional insights by the neuroscientists who apply these principles as deduced from the discussions.

Africa

Stigma, Criminalisation of brain diseases and Data Availability Stigma around brain-related issues and mental health can hinder research efforts.

The discussions suggest that brain data may not be readily available due to societal stigma. The challenges in collecting human brain data due to the stigma associated with brain diseases as a result of the lack of sensitisation and engagement is also a concern and majorly focus on need to promote human rights around brain data. With mental health disorders being at the forefront of disabilities, creating a system of social inclusion and awareness is desirable for people with mental health disorders and people with dementia, thereby allowing the collection of brain data. However, research has shown that some of these brain diseases have strong supernatural underpinnings influencing people's perceptions especially in Sub Saharan Africa [45], which results in challenges in data collection and social inclusion. Also, the structure of some laws criminalising cases such as attempted suicide [46] which may be related to brain diseases also adds to the complexity of brain data collection as it creates an atmosphere for the perceived violation of human rights.

Limited Human Brain Research In relation to data collection challenges, the discussions by the participants also show that in some African regions, human brain research using techniques like MRI may be limited. This scarcity of data may contribute to underdeveloped legal regulations and ethical considerations surrounding the use of human brain data for research.

Lack of Regulations and Regulatory Complexity The discussions highlight the complex regulatory environment surrounding animal and human research. From the discussions in African countries, researchers must obtain various permits and approvals to conduct animal research, even when dealing with animals from natural populations and after ethics approval from their respective institutions. The regulations vary from province to province or country to country. Also, the lack of access to established frameworks for the management and sharing of brain data shows that there may be gaps in the existence of adequate brain data governance mechanisms in these regions. Therefore, it is possible that scientists in these regions have access to data but lack the necessary governance infrastructure to share their data under FAIR and open access guidelines due to the lack of a global governance framework. This is supported by a recent report which showed that institutions that can make, create and monitor data governance laws beyond data protection and also promote FAIR are currently lacking in Africa [47].

Research Ethics Committees Insights from the discussions show that in the African context, brain research can face delays in obtaining ethical approvals for brain research. Bureaucracy and strikes or industrial disputes can contribute to lengthy approval processes. Also, some facilities may charge ethical approval fees, adding an additional financial burden for researchers. The key insights suggest that there is a need for independent ethics review boards and a restructure of ethics review process.

Verification of Research Ethics and Data Sharing The lack of standardisation in ethics review procedures may generate challenges in the verification of ethics review from a different region in order to determine reciprocity or even trust in the publishing of data. For example, the lack of a global central infrastructure to verify ethics approval for a particular animal or human brain research is a critical concern both for repositories and for key actors involved in the publishing of data as there is no way to carry out verification. This indirectly creates a lack of procedural fairness which is expressed by some African participants who pointed out the challenges in sharing animal data outside the continent, because publishers and repositories cannot verify their ethical procedures. This creates challenges in sharing animal data due to ethical concerns about animal welfare and may push researchers to explore alternative models or specimens for research.

Sensitivity to Animal Welfare While regulations around animal research vary within the African context, the discussions provided show that sensitivity to animal rights and welfare varies across regions, with stricter regulations in some countries compared to others. Also, this sensitivity together with animal rights and protections might vary and be seen as less stringent when compared to western cultures. This might be due to the lack of visible oversight as compared to western countries. For example, in the American context the Public Health Service Policy on Humane Care and Use of Laboratory Animals (PHS Policy), which is under the provision of the Health

Research Extension Act (HREA, 1985) (Public Law 99–158) [48] and administered by the Office of Laboratory Animal Welfare (OLAW) [49] requires that all institutions using live vertebrate animals in PHS supported research must have an institutional animal care and use committee (IACUC) to oversee the care and use of its animals. However, in the African context such oversight might not be visible in all countries within the region resulting in lack of reciprocity and verification of ethics procedures.

Latin America

Data Protection and Privacy laws The discussion in the Latin American context highlights the absence of specific laws for protecting brain data and the lack of strict privacy laws. This deficiency creates uncertainty regarding data management and raises ethical questions about data usage and sharing. Also, the lack of clear definitions for the proper usage of brain data raises ethical concerns. While the discussions acknowledged that some countries like Mexico, Chile, Argentina, and Brazil are key figures in neuroscience research, participants were not certain that ethical considerations were at par with western standards. However, the Latin American discussions point to the Habeas Data as an important regional framework used for data processing which is considered in Latin America as the constitutional right to privacy and provides the foundation for individuals to access, update, rectify and delete their personal data [50].

Open Access and Data Quality It appears that in Latin America data quality, data integrity, and open access models are perceived to raise ethical issues and concerns. The discussions also touch upon the ethical aspects of open access and data sharing. There are concerns about the open access model becoming a business rather than a means to democratize access to brain data. The financial burden of open access publishing is highlighted, especially for researchers in regions with limited resources and access funding. Participants worry about the distortion of scientific priorities and the impact on research quality when commercial interests take precedence, and it appears that this affects the quality of brain data used in research which is a primary concern.

Animal Research and Rights Discussions highlight concerns regarding animal research and animal rights in Latin America. It is suggested that animal rights and ethics may not be a high priority in the region, and ethical considerations are important in animal research ethics.

Ethical Considerations in Neurorobotics and AI The Latin American perceptions also highlight the importance of considering the ethical implications of robotics and artificial intelligence, particularly when these technologies can be applied in ways that may harm others (including animals) or have unintended consequences. Interestingly, references were made to animals as potential victims of the harms of AI. These key insight, highlight some level of responsible AI that might be overlooked in discussions, as animals may be used in the testing of AI and neurotechnologies. This raises interesting views on how AI laws also apply to animals.

Asia

Unique Ethical Considerations and Privacy in Brain Research Perceptions from the Asian context reveal that brain research is considered distinct from other fields due to its strong association with a person's identity and sense of self. These perceptions highlight subtle but important cultural views about the conceptualisation of brain data. Discussions show that ethical considerations in brain research often revolve around issues of control, bias, privacy, and personal autonomy. Also, addressing issues related to abnormal findings in samples and deciding whether to notify subjects about irregularities in their data is also considered important.

Defining Personal Information in Neuroscience Data Discussions from the Asian context reveal that in neuroscience research, it can be challenging to define what constitutes personal information. Brain imaging data may contain information that could potentially identify individuals, raising concerns about privacy. It is also clear that participants are influenced by the contextual meaning of personal information around brain data. This contextual meaning also affects the sharing of brain data in the form of brain imaging data. For example, a participant argued that the shape of the brain could be a kind of personal information, because different people have different gyral or sulcal patterns which could be used theoretically to fingerprint an individual. This perception on the definition of personal information also highlights the deliberations around the inclusion of face data with human imaging data as participants now face the risk of reidentification due to improvements in scan quality and facial recognition software even with the use of defacing software [21].

Legal and Regulatory Challenges The discussions show that researchers face legal and regulatory challenges, particularly when it comes to sharing data internationally, and suggestions from the Asian context called for streamlining ethical and legal frameworks for brain research, which can benefit both researchers and society by providing clear guidelines and facilitating responsible data sharing. Participants also called for establishing global ethical standards and laws for brain research similar to the approach in the EU, which can provide clarity and ensure that research is conducted ethically and responsibly.

Accountability and Transparency According to the insights, brain research involves a trade-off between benefits and risks and researchers must balance the potential benefits of their work in helping individuals with disabilities against the ethical and legal risks. Maintaining accountability and transparency is considered essential in balancing the benefits and risks of neuroscience research, and researchers must be responsible for data sharing and follow ethical and legal principles to ensure fairness and reproducibility.

Animal Research Insights show that the public opinion regarding the use of certain animal species in brain research varies raising several cultural and societal concerns. Some countries and individuals may have strong preferences against using primates or specific species in research and researchers need to consider these views when conducting and sharing their research.

North America

Privacy and Anonymity Ethical concerns from American discussions also revolve around subjects' privacy and the risk of re-identification, even when using anonymized subject identifiers. This is also a concern expressed by Asian discussions which shows an alignment of concerns regarding current privacy and anonymisation enhancing technologies. This shows that privacy enhancement technologies may no longer be adequate, and the need for standardisation is also essential.

Informed Consent It appears that the different consent models which exist might not be adequate in addressing the potential downstream uses of data as neuroscientists are left with no option but to attempt to clarify to a certain level the potential downstream uses of data with the hope of curtailing misuse and exploitation. It is also interesting that neuroscientists see consent as reducing the utility of data with a perception that participants do not usually know entirely what they are consenting to, and the potential implications on data sharing. Some suggestions also pointed to consent being defined by law. This discussion shows challenges in the North American context which might have been addressed by the EU's approach to consent as stated in the data governance act [43] which uses a data altruism approach.

Ethics Review Boards and Participatory Governance The competence of ethics review boards is discussed, with a need for ongoing education to better understand the complexities of data sharing and ethical issues associated with it. With the call for standardisation among neuroscientists [3, 51], the concerns and principles that influence neuroscientist also converge on institutional bodies such as ERBs responsible for shaping the outcome of brain data governance [52, 53]. The results raise important questions and challenges around ERBs who are responsible for the approval of research. There is already a high focus on the discussions around how the different legal and ethical principles that may prevent collaboration, however the result of the study reveals that ERBs are a major catalyst in the influence of brain data governance. One of the major concerns is a lack of the knowledge and training in ERBs around the ability to put ethical and legal principles into practice and the lack of independent ERBs free from institutional influence or control and allowing public participation.

In the structuring of ethics review boards, the experience to understand data and data-related issues are essential to carry out informed reviews as this lack of experience may create gaps in the evaluation of perceived risks in brain research. For example, the lack of a review board structure that does not include people with lived experience who are stakeholders that can give a fair evaluation of the actual risks involved in brain research may prevent participatory governance, while limiting the realistic justifications in the approval of brain data sharing and research.

Data Accessibility and Open Science Ensuring that scientific research is accessible to a broader audience is seen as both an ethical and legal issue in the North American discussions. This involves addressing paywalls, simplifying scientific language, and making research findings more comprehensible to the public. As the need for participatory governance increases, data subjects need to have access to their data in a simple and understandable format to promote fair access and transparent access to brain data. For example, the benefits of brain data research outputs such as publications are sometimes written in a high-level language and in a complex form that the owners of such data who ought to learn about their conditions end up not benefiting from the results thereby limiting meaningful access to data and reducing a sense of ownership and participation.

Data Liability, Licencing, and Intellectual Property (IP) It appears that legal safeguards and licencing structures in brain repositories may not be adequate to address issues around data misuse, and intellectual property violations. Discussions reveal interesting questions as to how data is currently shared in repositories. Furthermore, it presents various questions as to how data use agreements and licences are enforced in the management of repositories, and how compliance is designed as currently some repositories share and collect data across international borders. Furthermore, the onus of responsibility may be shifted to the data submitter without appropriate legal mechanisms to enforce penalties in situations of misuse or submission of unethically acquired data. In this situation repositories may be left with only the choice of taking down unethically acquired data without proper legal sanctions. Also, IP rights, provenance and ownership are mentioned as critical issues, particularly in a context where data sharing and data protection laws vary from one country to another. Finding a balance between sharing data and protecting intellectual property appears to be challenging.

Complex Data Transfer Agreements The key insights also highlight perceptions around data transfer agreements. Discussions show that collaborations between researchers from different countries can be hindered by complex data transfer agreements, creating data sharing barriers. These barriers to data sharing also include governmental regulations, political dimensions, and researchers' reluctance due to concerns about competition and loss of advantage for publication and grants.

Divergent Views on Ethics A key interesting discussion was the perception of ethics which shows a key contextual underpinning. According to the discussions in North America, ethics is seen as having strong legal connotations, whereas in the European context, ethics often refers to interpersonal conduct and is more dissociated from legal considerations.

Ethical and Legal Oversight in Industry vs Research The key insights also show that neuroscientists in the North American context believe that there is a noticeable difference in the oversight and regulations applied to researchers and companies in neuroscience. Arguments indicate that researchers often adhere to ethical principles and review board approvals, while companies do not have such visible oversight resulting in the lack of common set of ethical principles applicable to both researchers and the industry. The lack of alignment between researchers and industry poses challenges because companies may not engage in governmental regulations and general ethical principles to the extent that researchers do. This misalignment affects data sharing and collaborations between different countries and institutions.

Europe

Reproducibility and Sharing of Simulation Data Discussions in the European context show that there is a challenge in ensuring the correctness and reproducibility of simulation data because it is not solely based on observations. Suggestions show that researchers must strike a balance between reproducing results and ensuring that the simulations are valid.

Legal and Ethical Frameworks Frameworks such as the GDPR and AI act [54] were acknowledged by some European participants which provide guidance. With the development of more laws such as the AI Act in Europe [54] and the deliberations regarding the regulation of neurotechnology and AI as medical devices [55] this may also mean that key actors in other regions may have to reflect on what is traditionally considered as artificial intelligence in their own context as compared to the definition of artificial intelligence in the EU AI to foster collaborations around development of neurotechnological devices and other Neuro-medical devices.

Balancing Anonymity and Privacy with Data Usability While the importance of anonymising data to protect privacy is stressed. However, it appears that balancing privacy enhancing techniques with data usability is a challenge as shown in the European discussions. This contextual concern highlights the fact that researchers are left pondering how best to comply with the different jurisdictional requirements of anonymisation, pseudonymisation, or de-identification without compromising the scientific utility of neuroimages even further [56].

Educational needs and the Communication of Complex Ethical Issues The challenge of effectively communicating complex ethical issues, especially regarding the prediction of disease trajectories and the implications of such predictions, is also highlighted and there is a recognition of the need for education and competence-building among stakeholders and society to implement and navigate legal and ethical frameworks effectively.

Australia

Ethical Issues in Data Sharing and Privacy In the Australian context, discussions emphasize the importance of ethics in handling and sharing data. This includes concerns related to data privacy, and the ethical implications of using neurological or psychiatric clinical data and ensuring concerns related to data security. The potential breach of human rights or personal rights when sharing data illegally is also a concern. Therefore, researchers need to be aware of and comply with legal frameworks, particularly when moving data across international boundaries. In the Australian context, the ethical implications of brain data extend to discussions about human free will and the use of brain data raises questions about personal agency and the potential ethical dilemmas associated with manipulating or interpreting such data.

Animal Ethics and Regulations The discussions in the Australian context highlight the strict animal ethics regulations that govern neuroscience research, particularly involving preclinical animal models. Key insights suggest that some neuroscience research may involve the use of controlled substances, such as drugs. The legal aspects of handling and researching such substances are discussed, emphasizing the need for careful management and compliance with legal arrangements.

Standardisation of Data Retention and Deletion

The ambiguity in the arguments around the retention and deletion of data shows that different neuroscientists operate under different retention and deletion guidelines even in the presence of data management plans. This creates several hurdles which occur at the funding level, sharing level (e.g. publisher or repository requirements) and the institutional level. While neuroscientists in the interviews provided sound arguments about the need to delete and the need to retain data, the arguments appear to be underpinned by the need to meet the requirements of multiple actors which creates conflicts. This also influences ownership of data and raises scenarios where there is a dilemma regarding who owns the research and who owns the research output resulting in intellectual property conflicts.

Conceptualisation of Neurorights

With the advent of neurorights [57, 58] it is also interesting that key actors and experts have no idea about neurorights. This raises interesting questions around how key experts operating under the boundaries of various ethical and legal principles conceptualise neurorights as people with lived experience in the application and generation of brain data who can shape such rights. This might mean that the discussions about neurorights have been limited to other stakeholders who are not neuroscientists or are not people who are actively involved in the collection, processing, and sharing of data. This is also a concern pointed out in previous studies where it was highlighted that scientists, lawmakers, and scholars in the humanities and the social sciences are largely shaping the debate over neurorights [59]. This also aligns with our previous research which shows that neurorights might not be fully discussed in the context of international brain data governance and has low visibility in the international brain data governance landscape [5].

The Need for Animal Data Governance

The insights around animal research and ethics highlight the need for animal data governance which is reflective of the ethical pluralism that exists globally. The discussions above clearly show the underlying challenges around regulations, sociocultural sensitivity, and divergent views around animal research. This calls for an inclusive discourse that adopts procedural ethics which is inclusive. This can involve adopting procedures that provide engagement, acceptable practices, and dialogue e.g. having a central data verification structure for animal ethics and procedures where contentious or disputed data can easily be removed.

Summary

The discussions and results above provide key analytical insights on the principles, contextual issues, and concerns. These key insights call for harmonisation and standardisation of actionable practices and principles to foster collaborations and global governance.

It is essential to acknowledge that within continents, significant differences in perception and cultural nuances among individual countries may necessitate a more nuanced analysis in certain contexts. Therefore, while primarily focusing on continental trends, it is important to recognize the significance of considering country-level nuances in a contextual analysis to gain a more comprehensive understanding of regional dynamics and tailor strategies effectively.

Conclusion

The outcome of this research outlines critical findings which are essential for the continued discussion of a development of data governance framework for brain data while considering global contextual views or ethical pluralism. This is in line with the international neuroscientists used in this study who all agreed that sharing brain data across borders raises several ethical and legal issues and the need to capture divergent ethical, sociocultural views in the development of a global data governance framework. Using interviews provided the opportunity to gain insights from key experts who are neuroscientists involved in various brain projects. the empirical study unravelled various contextual insights around key principles, issues and concerns. Also, key insights around animal research which is usually overlooked were identified. The paper makes important contributions to the current discourse around developing a framework for brain data governance while considering ethical pluralism.

Firstly, it sheds light on the intricate relationship between ethical and legal principles in brain data research, revealing a complex and dynamic interplay that necessitates the development of a robust data governance framework for harmonisation and standardisation. The findings in the analysis underscores the challenges researchers face in distinguishing between ethical and legal principles, highlighting the need for clarity and coherence in guiding research practices. Secondly, the research provides valuable insights into regional variations in ethical and legal concerns surrounding brain data research. By examining perspectives from different continents, the study uncovers nuanced differences in priorities and perceptions, offering a comprehensive understanding of the global landscape of brain data governance. Moreover, the research identifies key principles, issues, and concerns that need to be addressed in advancing the development of a framework for global brain data governance. By presenting contextual insights from neuroscientists across regions, the study contributes to informing discussions and shaping policies aimed at promoting responsible and ethical practices in brain data research.

Furthermore, the research highlights specific challenges and considerations unique to each region, such as stigma around mental health in Africa, data protection laws in Latin America, and the balance between privacy and data usability in Europe. These insights provide valuable guidance for policymakers and stakeholders in tailoring strategies and interventions to address region-specific needs and challenges.

The research not only advances our understanding of the ethical and legal dimensions of brain data research but also lays the groundwork for collaborative efforts towards establishing a comprehensive and inclusive framework for global brain data governance. It is a pointer to the importance of understanding the perceptions, concerns and issues that can arise from neuroscience research especially from the standpoints of those fully involved in the conduct of brain research. The findings also show the current gaps in regulations, policies and guidelines and structures that currently constitute the governance of brain data and brings to the forefront the salient issues that needs to be mitigated and discussed to advanced data sharing while operating under a neuroethical framework.

Author Contributions ***Damian Eke*****:** Conceptualization, Methodology, Supervision, Writing – review & editing. ***Paschal Ochang***: Conceptualization, Data collection and curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. ***Bernd Carsten Stahl***: Conceptualization, Funding acquisition, Resources, Supervision, Writing – review & editing.

Funding This work was supported by the European Union's Horizon 2020 Framework Programme for Research and Innovation under the Specific Grant Agreements No. 945539 (Human Brain Project SGA3). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Data Availability The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Declarations

Ethics Approval The research received Ethics approval from the De Montfort University's Ethics approval committee and considered and mitigated identifiable concerns related to participants' informed consent, privacy, and confidentiality.

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Competing Interests The authors have declared that no competing interests exist.

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