



# Decoding the Brain, Respecting the Person: A Neuroethical Inquiry into Consent and Cognitive Liberty in South Africa

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**Abstract** As neurotechnologies emerge in South Africa’s clinical, research, and consumer health landscapes, existing informed consent models, predominantly shaped by Western individualist ethics, prove insufficient. Neural data, uniquely intimate and increasingly commodified, poses profound ethical and legal risks, including mental privacy violations, behavioural profiling, and cultural alienation. This article interrogates these risks through a neuroethical lens grounded in African relational philosophy, particularly Ubuntu, which emphasises communal personhood, collective decision-making, and spiritual interconnectedness. We analyse the limitations of South African and international legal frameworks, arguing that they neither adequately recognise neural data as a distinct category nor accommodate culturally appropriate consent processes. In response, we propose a pluralistic, relational consent framework

that incorporates tiered, dynamic, and interactive mechanisms, sensitive to linguistic, educational, and spiritual diversity. By centring cognitive liberty and advocating for *sui generis* neurorights protections, this paper contributes a decolonial, culturally situated perspective to global neuroethics and informs more inclusive governance models for neural technologies in legally and socially pluralistic societies.

**Keywords** Neuroethics · Informed consent · Ubuntu philosophy · Cognitive liberty · Neural data governance · Culturally responsive bioethics

## Introduction

The integration of neurotechnologies into South African healthcare is slowly but surely emerging, with

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applications in both clinical and research settings. Neurostimulation devices are being explored for therapeutic relief in conditions such as epilepsy, chronic pain, Parkinson's disease and depression; while neuroprostheses aim to restore motor or sensory functions in individuals with neurological impairments [1]. On the continental research front, African institutions are advancing neuroscience research through efforts that encompass neuroimaging, neurophysiology, and neurorehabilitation, contributing to a deeper understanding of brain function and neurological disorders [2]. Africa faces a significant burden of neurological disorders, including epilepsy, stroke, and neurodevelopmental disorders [3], and advancements in neurotechnologies could enhance diagnostic accuracy and therapeutic interventions for these conditions [4]. However, while the adoption of neurotechnologies such as brain computer interfaces (BCIs) and neural implants in South Africa remains limited, primarily due to funding constraints, infrastructure challenges, and a lack of specialised expertise [5], digital mental health tools are gradually gaining traction due to increased smartphone use and mental health awareness. It is in this context that ethical concerns about informed consent, especially as it relates to data protection and mental privacy, and the need for culturally relevant solutions arise.

As neurotechnologies begin to take root in South Africa's healthcare and research landscapes, ensuring that informed consent processes are ethically sound and culturally attuned becomes a critical imperative. The unique socio-cultural fabric of the country, marked by linguistic diversity, collective decision-making traditions, and persistent stigma around mental health, demands that consent mechanisms go beyond legal formality to foster genuine understanding, trust, and voluntariness [6]. Consent materials should be accessible across languages, free of technical jargon, and adapted to reflect varying levels of health and digital literacy. In rural and low-income communities, where digital tools are increasingly used for mental health interventions, individuals may face pressure to consent without fully comprehending the implications of neural data collection or AI-driven analysis. Moreover, cultural norms in many South African communities emphasise relational autonomy, where health decisions are often made in consultation with family or community elders [7]. Consent models must therefore be

flexible enough to respect these relational dynamics while still upholding individual privacy and autonomy [8]. Western-informed consent frameworks, with their emphasis on individualism and contractual clarity, often fail to resonate in such contexts, highlighting the urgent need for locally grounded, culturally responsive approaches that uphold both ethical and legal standards in neurotechnology deployment [9].

The ethical tensions surrounding informed consent for neurotechnological interventions in South African contexts are best understood through an interdisciplinary theoretical lens that draws from African relational ethics, global neuro-rights scholarship, and evolving theories of autonomy and consent. These perspectives provide the normative foundation for interrogating why dominant individualist models of informed consent fail to adequately address the moral and socio-cultural dimensions of neural data collection and use in the South African context.

This paper thus aims to critically examine the limitations of current informed consent models when applied to neurotechnologies in culturally pluralistic settings such as South Africa. In doing so, it advances a neuroethical argument for the development of more inclusive, contextually grounded, and relational approaches to consent. The objectives are threefold: first, to analyse how African relational ethics, particularly the Ubuntu informed philosophy of personhood, challenge conventional assumptions of individual autonomy in consent practices; second, to explore the relevance of emerging international neuro-rights frameworks in safeguarding mental privacy and cognitive liberty in under-regulated contexts; and third, to evaluate the potential of relational autonomy and values-based decision-making models to enhance the ethical legitimacy and practical effectiveness of consent processes in the neurotechnological domain. Each of the following sections discusses in detail one of the three conceptual frameworks that together offer a richer and more just foundation for informed consent in the South African context and other similarly situated settings. To ground this theoretical inquiry, it is first necessary to understand what makes neural data ethically distinct and why its collection and use pose complex challenges for conventional informed consent frameworks.

## Why Neural Data Complicates Informed Consent

Informed consent is a fundamental ethical principle in bioethics, whereby the principles of autonomy, voluntariness, and comprehension are essential for meaningful consent, particularly with neurotechnologies that involve the collection and processing of neural data during neurotechnological research or the use of digital mental health tools.

Some challenge the idea that neural data is increasingly classified as medical data based on its sensitive nature, which may lead to the unjustified expansion of medical oversight into normal aspects of daily life [10]. However, neural data is arguably distinct from other types of personal data because it provides direct insights into brain activity, cognitive processes, emotions, and intentions, making it uniquely tied to an individual's identity and mental states [11]. This raises significant ethical, legal, and technical challenges, particularly regarding informed consent in neurotechnologies [12]. A key concern is its direct link to mental privacy and cognitive liberty, as neural data can reveal highly personal thoughts and emotions, making it more invasive than other forms of personal data [12]. Additionally, it poses risks of behavioural and psychological profiling, as it allows for the analysis of subconscious preferences, emotional responses, and cognitive patterns [13]. Without proper safeguards, companies or governments could exploit neural data for targeted advertising, neuro-marketing, surveillance, or behavioural manipulation [14]. Given these risks, informed consent must ensure that individuals fully understand how their neural data will be processed, stored, and protected. International discussions on neuro-rights highlight the importance of autonomy and free will, recognising that brain data could be used to influence free choice [15].

Another concern is the difficulty of anonymising or deidentifying neural data. Unlike other personal information, brain activity patterns are highly unique, meaning that even deidentified neural data could potentially be re-identified using advanced AI techniques [16]. This raises concerns about long-term data privacy, particularly in cases where companies retain neural data indefinitely. Informed consent should therefore include clear policies on data storage, retention, and the right to withdraw consent at any time. A further challenge is the long-term and unknown risks of neural data use. AI and neurotechnologies are still

evolving, meaning that data collected today could be repurposed for unforeseen applications in the future. If companies retain neural data indefinitely, individuals may lose control over how their cognitive information is used. To address this, informed consent processes must clearly specify how long neural data will be stored, whether it will be used for future research or commercial purposes and allow individuals to revoke consent at any time.

Neural data requires a higher standard of informed consent due to its deeply personal nature, potential for behavioural profiling, cybersecurity vulnerabilities, and long-term risks. Add to this the socio-cultural issues discussed below, and it is clear that consent frameworks must be transparent, ethical, user-centric, and socio-cultural sensitive to ensure that individuals fully understand how their brain data is collected, analysed, stored, and used.

## African Relational Ethics: Ubuntu and Communal Personhood

At the core of African moral philosophy lies the concept of Ubuntu, often encapsulated in the phrase "I am because we are". Metz's articulation of Ubuntu, one of the most influential and substantive accounts, seeks to present it not merely as a cultural ethos but as a robust, normative ethical framework capable of guiding moral reasoning and public policy in African contexts and beyond [17]. In this context he argues that human dignity, or intrinsic moral value, arises from individuals' capacity to engage in communal relationships characterised by mutual identification and solidarity [18]. More specifically, this perspective emphasises that moral worth is deeply rooted in one's ability to foster harmonious relationships with others. According to Metz, Ubuntu offers a relational approach to ethics, contrasting with the individualistic tendencies of Western moral theories. However, this approach has been critiqued by Van Niekerk for either failing to integrate Ubuntu's virtue-ethical elements or succumbing to fallacies common in African philosophical projects. The "fallacies common in African philosophical projects", as referenced in critiques like those by Van Niekerk, typically include the essentialist fallacy, treating complex and diverse African traditions as monolithic, and the romanticist fallacy, idealising traditional African values without

adequate critical scrutiny [19]. These fallacies risk oversimplifying or uncritically affirming African worldviews, undermining the philosophical rigour of African moral theories. Instead, he argues for a perfectionist, virtue-based account of Ubuntu which defines moral value in terms of perfecting an essential human capacity such as the disposition toward communal relationships. This essential feature is emergent from rationality and language-use, aligning with both African communitarianism and broader human nature and maintains Ubuntu's appeal as a moral ideal grounded in human flourishing through relationships. In the broader domain of ethics, Molefe challenges the dominant interpretation of African ethics as fundamentally communal or relational. Instead, he argues that African moral thought is best understood as morally individualistic, grounded in the concept of agent-centred personhood [20]. According to his perspective, African ethics is, at its core, morally individualistic, prioritising the cultivation of moral character and personhood in the individual. While social relationships and community norms matter, the individual's moral excellence is the ultimate goal, and the community serves only an instrumental role in helping individuals achieve that goal.

Understanding how informed consent ought to function in the context of neurotechnologies in South Africa requires an appreciation of the philosophical debates within African moral thought. If we take Metz's interpretation of Ubuntu as a relational moral framework, mentioned above, informed consent must be conceived not solely as an individual decision, but as a socially embedded process that cultivates trust and relational accountability. However, in distinction to this, Van Niekerk's account, which regards Ubuntu not merely as a set of communal norms but as a moral ideal aimed at cultivating human excellence, would hold that consent processes should not merely respect communal norms, but should be ethically developmental, fostering moral self-understanding and personal growth. Finally, Molefe's further corrective which holds that African ethics, while communally situated, is ultimately morally individualistic and agent centred would situate the responsibility for achieving moral excellence, and by extension, for making informed, voluntary decisions, with the individual, while the community would play only an instrumental role. Together, these perspectives illuminate the need for a layered, context-sensitive model of

consent in neurotechnological research and practice, one that supports communal consultation, encourages moral reflection, and centres the individual's informed, uncoerced participation.

African relational ethics is also not merely about present interpersonal ties but also includes inter-generational moral authority and ancestral relationships. Within many African traditions, personhood, or moral standing, is affirmed through honouring the wisdom of elders and the ongoing presence of ancestors and considers the head and brain not only as sites of cognition, but rather of spiritual connection [21]. In parts of rural South Africa, particularly among isi-Zulu and Sesotho-speaking communities, the head is regarded as the dwelling place of ancestral wisdom and spiritual authority [22]. In the Yoruba cosmology – the first-mentioned a West African ethnic group inhabiting parts of Nigeria, Benin and Togo—the *Ori*, translated as the “inner head”, is believed to be the metaphysical seat of a person's destiny, spiritual identity, and divine guidance [23]. In this context users of neurotechnologies that may “read the brain” may be reluctant to use these technologies without first consulting spiritual leaders. For them, placing electrodes on the head without proper ritual acknowledgment may not merely entail a scientific procedure, but an intrusion into the sacred domain of the self. These examples illustrate how neural imaging tools may be perceived not just as diagnostic devices, but as instruments capable of disturbing spiritual balance and ancestral alignment. In these contexts, the head is not understood in purely biomedical terms as the locus of cognition, but as the interface between the physical and the spiritual realm. Neurotechnological interventions, such as brain scans or implants, can therefore be perceived as spiritually invasive, particularly if they are conducted without proper recognition of these relationships. Informed consent, in this light, may require more than scientific or medical explanation, it may also involve symbolic gestures or ritual affirmations that align with beliefs about ancestral dignity and spiritual balance. This tension between biomedical interpretations of the brain and culturally embedded spiritual meanings is clearly illustrated in the case study from The L $\alpha$  $\beta$  (Box 1) [24], where researchers navigated participant concerns about neurodata, ancestral respect, and the sanctity of the head through a relational, culturally sensitive approach to informed consent.

**Box 1** Case study on culturally attuned consent and participant-led neuroethics at *The Laβ*.

Culturally attuned consent and participant-led neuroethics at The Laβ

At *The Laβ*, a participant-led neuroscience research initiative, culturally grounded approaches to consent are foundational to all EEG-based studies. Using portable, mobile neuroimaging equipment, the team engages participants in diverse scenarios, from singing in tongues and meditative drumming to reflecting on social justice through freestyle rapping or digital sketching. These activities yield neurodata that is not only cognitively rich but also spiritually and emotionally significant

Several participants, particularly those engaging in spiritual rituals, expressed concerns about receiving neurodata reports that might conflict with their belief systems. In some cases, participants preferred not to interpret their brain data at all, viewing it as a sacred expression of their inner state. This underscored the importance of respecting the spiritual ontology of the brain in consent practices. Researchers responded by co-designing flexible consent models that allow participants to choose not only *whether* to receive feedback, but *how* and *when* they engage with their data, if at all

The Laβ team facilitates trust-building through multiple “touch points”: pre-scan conversations, in-the-moment expression, and post-scan interpretive sessions. Participants are empowered to shape their scanning experience, often with input from family or spiritual advisors. This model aligns closely with Ubuntu ethics, prioritising relational agency, continuous dialogue, and collective decision-making. Neurodata protection is also a key concern, given the multi-modal nature of recordings (e.g. EEG data, audio, video, qualitative notes) and robust protocols have been adopted to safeguard identity, ensure transparency in algorithmic use, and uphold participant rights to withdraw

By integrating relational ethics and cultural sensitivity into every phase of consent, The Laβ exemplifies how community-based neuroscience can honour both the cognitive and the spiritual dimensions of personhood in African contexts

In addition, ritual and ceremony are central to moral meaning-making in worldviews informed by Ubuntu. Ethical decisions are often enacted through rites and embodied practice such as weddings, healing ceremonies, or naming rituals, rather than solely through verbal agreements or rational debate [25]. If neurotechnological practices promote neurobiological explanatory models that override or marginalise traditional epistemologies, they risk not only ethical harm but also contributing to cultural erasure. Consent practices should therefore allow room for embodied, symbolic, and community-based forms of ethical affirmation. A crucial component often overlooked is the notion that personhood must be earned through moral excellence and communal

recognition. In Ubuntu, personhood is a moral status that individuals achieve through demonstrating virtues such as generosity, humility, and care for others [26]. This challenges assumptions in Western bioethics that personhood, and by extension the capacity to consent, is automatically granted to all autonomous adults. In some communities, elders or spiritual leaders may judge whether someone is “ready” to decide with moral significance [27]. While this raises concerns about paternalism, it also encourages a more developmental view of consent, rooted in ethical maturity rather than legal age or cognitive ability.

Moreover, Ubuntu ethics places strong emphasis on relational obligations and insights associated with care ethics. Individuals are not only entitled to autonomy but are morally obligated to uphold the wellbeing of others. While Metz found similarities between Western ethics of care and African relational ethics, he argues that Afro-communitarian ethics as grounded in Ubuntu extends beyond care to also include shared identity, communal belonging, and the moral value of harmony [28]. Unlike the Western care ethic, which focuses on emotional responsiveness and individual empathy, Ubuntu ethics frames personhood and moral standing as emerging through participation in a moral community defined by solidarity and mutual identification [29]. This broader relational framework offers distinct advantages for developing culturally grounded consent models that align with African worldviews. This may reshape the purposes of informed consent in research: not simply to protect the individual, but to honour their relational duties, whether to family, ancestors, or future generations. In community-based neuro-research, some individuals may for example see participation as a moral act of service to others.

Moreover, ethical dilemmas emerge when integrating traditional healers into neurocognitive diagnostics. In South Africa and elsewhere in Africa, collaborative models between traditional healers and psychiatric professionals have shown promise in providing culturally congruent care yet these collaborative attempts also reveal deep-rooted mistrust and epistemic divides. In the Sodo district of Ethiopia a team of researchers used the theory of change and an integrated healthcare approach to develop a mental healthcare plan [30]. In Uganda, a study was done to investigate the possibility of traditional healers collaborating with formal child

and adolescent mental health systems to bring about lasting change [31], but concluded that mistrust and competition among the parties prevented them from doing so. Although these examples do not yet combine neurotechnologies, they are examples of how indigenous knowledge systems on health and well-being are being integrated into healthcare services and offerings. These tensions necessitate consent models that navigate plural knowledge systems without imposing biomedical dominance.

Issues of language and conceptual misalignment further complicate consent: clinical terms like schizophrenia may be inadequately translated or misunderstood within indigenous cosmologies [32]. The lack of direct translations for biomedical and neurotechnology-related terminology in indigenous languages presents a significant barrier to informed consent. For instance, the Zulu term for schizophrenia, *ukuphambana*, roughly translates to “madness,” “contradiction,” or “conflict,” lacking the clinical specificity found in diagnostic manuals such as the DSM-5. Kamaara et al. argue that psychiatric genomics research in Africa must move beyond superficial or literal translation of Western psychiatric and genomic concepts [33]. Instead, it should engage substantively with African conceptual schemas, values, and worldviews to ensure ethically valid informed consent. Language is not merely designative (pointing to fixed realities), but constitutive, it shapes how people understand the world. Attempts to translate complex psychiatric and genomic terms into African languages often miss this interpretive depth, risking miscommunication and invalid consent. Even when informed consent materials are translated, ethical concerns remain about participants’ full comprehension of the risks and benefits involved. Broader issues such as low health and research literacy further complicate efforts to ensure socio-culturally appropriate consent. African researchers have also identified several factors that contribute to misaligned informed consent: diagnostic misconception (where participants mistakenly believe that research will directly benefit their diagnosis), information overload (particularly when individuals are asked to consent to multiple studies simultaneously), and situational vulnerability (where consent is requested too soon after a diagnosis or traumatic life event)[34]. These dynamics can create significant ethical challenges.

These factors demand a reconceptualisation of consent as an ongoing, dialogical process, not a one-time transaction.

## Neurorights: Mental Privacy, Cognitive Liberty, and Identity

As neurotechnologies evolve, international scholarship, led by figures such as Marcello Ienca [15] and Rafael Yuste [35], has begun advocating for the recognition of a new class of human rights: Neuro-rights. These include mental privacy, cognitive liberty, personal identity, equal access to cognitive enhancement, and freedom from algorithmic manipulation. Neuro-rights proponents argue that neural data require *sui generis* legal protections, given their potential to directly access, decode, or alter thoughts and emotions [36]. Ienca and Andorno propose mental privacy as a distinct legal right, recognising that brain data, unlike other biometrics, may reveal not just what we are, but what we think and feel [37]. Yuste et al. have further advocated for the integration of neurorights into international human rights frameworks [38]. This scholarship underscores the urgency of developing consent models that not only inform but empower, protecting individuals from exploitation, behavioural manipulation, or discrimination based on brain-based inferences. In contexts like South Africa, where legal systems and enforcement mechanisms may be uneven, the absence of strong neurorights frameworks heightens the risk of unregulated neural data exploitation, particularly among socio-economically and digitally vulnerable populations.

International regulatory frameworks such as the General Data Protection Regulation (GDPR) [39] and UNESCO’s 2021 Recommendation on the Ethics of Neurotechnology represent important steps toward protecting personal data and mental privacy, yet they reveal notable gaps in responding to the ethical demands of neural data. Under the GDPR, neural data may fall under “special categories of data” such as biometric or health information, but it is not explicitly recognised as a distinct category. This leads to uncertainty in its legal status, especially when such data is processed to infer mental health conditions, personality traits, or behavioural patterns. While Article 9 requires heightened consent standards, the GDPR does not adequately protect against the risks of behavioural profiling, algorithmic manipulation, or the irreversible embedding of neural data into AI systems. The GDPR’s anonymisation requirements are particularly strained when applied to high-dimensional, personal neural signals that are inherently difficult to de-identify. The EU Artificial Intelligence Act [40] attempts to

prohibit AI systems that exploit cognitive or physical vulnerabilities, but the scope of protection remains theoretical, especially concerning direct-to-consumer neurotechnologies. These regulatory shortcomings are not merely theoretical, they carry tangible risks, as demonstrated by real-world cases of brainjacking, AI bias, and consent failure, such as described in Box 2 below.

### **Box 2** Case studies on brainjacking, AI bias, and consent failures

Case studies on brainjacking, AI bias, and consent failures

#### **Case Study 1: Brainjacking and Medical Risk**

In one documented case, commercial EEG headsets were found to be vulnerable to remote hacking—commonly referred to as ‘brainjacking’. This form of intrusion allowed bad actors to manipulate brainwave data streams, introducing false signals that misrepresented a user’s emotional state or cognitive functioning. In a medical setting, this could translate into inappropriate clinical responses, such as the misdiagnosis of neurological disorders or the administration of unwarranted treatment [41, 42]. The neuroethical concern is clear: without robust cybersecurity standards and legal protections, individuals’ mental integrity can be compromised, resulting in physical, psychological, and reputational harm

#### **Case Study 2: AI Bias and Predictive Policing**

A predictive policing tool using neural data analysis was deployed to identify individuals at high risk for criminal behaviour.

However, due to biased training data and flawed assumptions, the model disproportionately flagged individuals from historically marginalised communities based on spurious correlations [43, 44]. These included biometric signals associated with stress or trauma, which the algorithm misinterpreted as indicators of criminal intent. This demonstrates the danger of relying on reductionist AI models that fail to contextualise neurodata, conflating correlation with causation and reinforcing structural inequalities

#### **Case Study 3: Black Box Diagnostics in Oncology**

In an oncology trial, an AI tool trained on EEG data was used to identify potential brain cancer biomarkers. Patients were informed that AI would assist diagnosis but were not told that the algorithm was non-transparent and unvalidated. The model later misclassified benign cognitive patterns as malignant, leading to unnecessary invasive procedures [45]. This illustrates the ethical risk of using ‘black box’ AI systems in clinical settings without explainability or adequate human oversight—especially when the input data, such as brain signals, is complex and context-sensitive

#### **Case Study 4: Digital Mental Health Platforms and Consent Illusions**

An AI-driven mental health chatbot was promoted as a confidential tool for users struggling with depression and anxiety. However, buried in the terms and conditions was a clause permitting the sale of anonymised user data to third-party analytics firms.

This data included inferred mental health diagnoses derived from user interactions [46, 47]. When a data breach exposed this information, users experienced public stigma, job loss, and emotional trauma [48]. This case raises critical concerns about the transparency of consent processes, especially in low-literacy contexts, and underscores the need for neuro-specific data protection regulations

The law does not yet impose neuro-specific consent protocols, nor does it address how emotional or cognitive inference could be manipulated for commercial gain. However, the European Parliament did suggest that legislative proposals may be necessary to protect neurodata and other sensitive health information, reflecting the EU’s proactive approach to emerging technologies that could affect mental privacy [49]. In the United States, the Health Insurance Portability and Accountability Act (HIPAA) [50] governs health data within clinical settings but offers no protection for neural data collected outside medical contexts such as consumer mental health applications or wearable BCIs. The Federal Trade Commission (FTC) [51] focuses on consumer protection but lacks the regulatory depth to prevent neuroethical violations, relying largely on reactive enforcement. Recognising these gaps, UNESCO’s 2021 Recommendation on the Ethics of Neurotechnology calls for international recognition of mental privacy, cognitive liberty, and identity protection [52]. The document urges member states to treat neural data as a distinct category, demand explicit and revocable consent, and safeguard against unauthorised or secondary use. However, these remain normative aspirations, with no binding legal status or enforcement mechanisms.

While international regulations establish important ethical and legal principles for informed consent, they also fail to address the socio-cultural barriers that exist in South Africa [53]. As mentioned above, one of the most significant challenges is language and literacy barriers. Western-informed consent models assume high literacy levels and the ability to comprehend complex legal and medical terminology. Many individuals, particularly in low-income and rural communities, have limited exposure to digital platforms, making it difficult for them to navigate complex privacy policies or AI-driven consent forms [54]. Furthermore, South Africa has 11 official languages, and many individuals may not be proficient in English or Afrikaans, the primary languages in which consent documents are typically written. This creates a barrier to meaningful consent, as individuals may sign agreements without fully understanding the implications of data collection, sharing, and AI-driven processing. To address this, informed consent should be provided in multiple languages and written in plain, accessible language. Additionally, the use of oral, visual, or interactive consent mechanisms could

improve comprehension for individuals with limited formal education or digital literacy [55].

Another critical gap in international consent frameworks lies in their narrow emphasis on individual autonomy, which often fails to account for the relational and communal foundations of personhood in many African contexts discussed above. Rooted in the philosophy of Ubuntu, decision-making in South Africa, particularly in rural and traditional communities, is frequently a collective process, involving dialogue with family members, elders, and spiritual leaders [56]. In this view, moral agency is not solely vested in the isolated individual, but emerges through shared identity, mutual recognition, and communal responsibility. Western-informed models that demand strictly individualised consent may inadvertently undermine the legitimacy of health decisions in these settings, marginalising those who draw moral strength from relational ties. A truly context-sensitive consent model must therefore honour both relational autonomy and the right to confidentiality, supporting inclusive processes that reflect Ubuntu's ethical emphasis on dignity, harmony, and interdependence. The contrast between Western individualistic consent models and African relational approaches grounded in Ubuntu is captured in Fig. 1 below, which illustrates how consent can shift from a private, legal transaction to a communal, trust-based process rooted in collective identity and shared moral responsibility.

These international developments signal a growing global awareness of the unique ethical challenges posed by neural data. However, the lack of binding mechanisms and the limited recognition of culturally specific consent models raise critical concerns for countries like South Africa. South African lawmakers and regulators must grapple not only with the legal classification of neural data, but also with the ethical imperative to develop consent models that are both robust and culturally congruent. Importantly, there is also a need to analyse whether South Africa's existing laws such as the Protection of Personal Information Act (POPIA), the National Health Act (NHA), and the Mental Health Care Act (MHCA) adequately account for the socio-cultural complexities discussed earlier in this paper, including communal decision-making, linguistic diversity, and traditional beliefs surrounding the head and brain. In what follows, we examine how these domestic legal frameworks interface with global norms and where they fall short in

addressing the distinctive neuroethical concerns raised by informed consent in culturally pluralistic contexts.

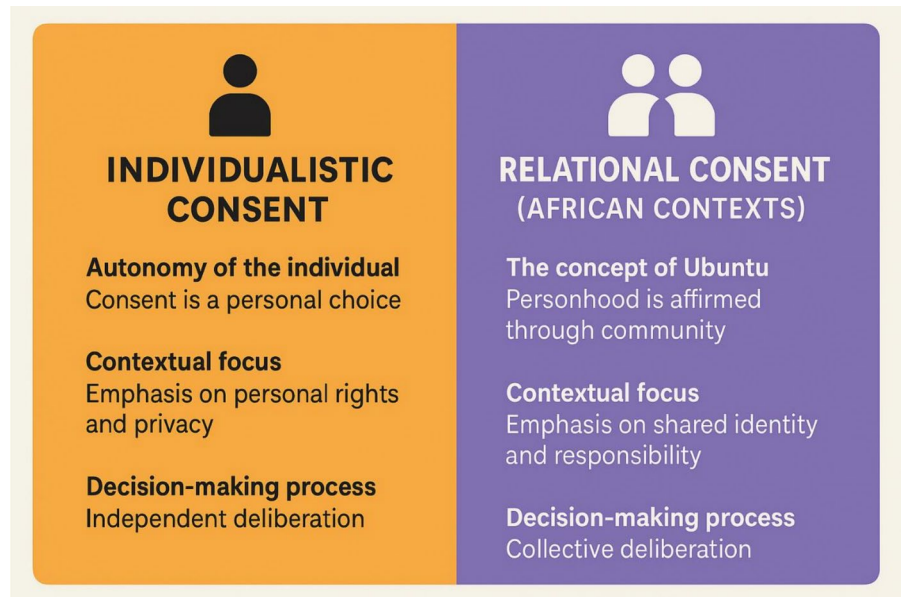
In light of international neuroethical developments and the promise of context-sensitive informed consent models, South Africa's domestic legal framework must be analysed for both its alignment with global standards and its responsiveness to local socio-cultural complexities. While legislation such as the POPIA, the NHA, and the MHCA enshrine core principles of consent, autonomy, and privacy, they largely reflect Western biomedical ethics and do not yet fully accommodate Ubuntu-informed relational personhood, linguistic diversity, or indigenous healing systems. The following sections evaluate the extent to which these laws integrate or fall short of addressing the neuroethical imperatives identified in international frameworks and in South Africa's own pluralistic context.

South Africa's Constitution, particularly sections related to the right to dignity (Sect. 10), equality (Sect. 9), freedom and security of the person (Sect. 12), and privacy (Sect. 14) provides an overarching framework within which the POPIA, NHA and the MHCA operates [57]. These constitutional provisions reinforce that any intervention—especially those affecting a person's mental health and bodily integrity—must respect the individual's autonomy. Informed consent is, in effect, a procedural safeguard ensuring that state and medical interventions do not unnecessarily infringe on these rights.

#### Protection of Personal Information Act 4 of 2013

POPIA is South Africa's comprehensive data protection law, and it places a strong emphasis on obtaining valid consent as one of the legal bases for processing personal information [58]. POPIA defines consent as "any voluntary, specific and informed expression of will in terms of which permission is given for the processing of personal information" (Sect. "Introduction"). This means that the data subject must actively affirm, in a manner that is documented or recorded, that they agree to the processing of their personal data. The salient requirements regarding consent are that the consent should be specific, freely provided, informed (adequate information about the nature, purpose and extent of the processing of the information must be provided); and it should be unambiguous (Sect. 11). For sensitive personal information,

**Fig. 1** Differences between individualistic and relational consent



which in POPIA includes data revealing racial or ethnic origin, political opinions, religious beliefs, health information, including sensitive personal information, the Act requires that consent be even more explicit (Sects. 26 and 27). Although POPIA is structured around several key principles and conditions rather than singling out “consent” in isolation as one of the grounds for the lawful processing of personal information (Chapter 3 of the Act), various sections underscore its importance.

Neural data reveals intimate aspects of a person’s cognitive, emotional, and psychological life, making it highly sensitive and comparable to biometric or health data under South Africa’s POPIA. The application of POPIA to neural data as a new category of sensitive data in South Africa presents several challenges, the first of which relates to its definition and categorisation. Not yet explicitly included under POPIA, some ambiguity may arise as to how it should be classified and regulated. A second complication concerns the complexities regarding consent, as the nature of neural data and the role of neuroscience may be difficult to clearly explain to data subjects, especially where AI systems are involved [59]. This also relates to the transparency requirement of POPIA, as laypersons may generally not understand how their data will be utilised via the application of complex AI algorithms.

Evolving neurotechnologies that collect increasingly granular neural data challenge the adequacy of

South Africa’s POPIA, which predates these developments and does not explicitly recognise neural data as a distinct category. While POPIA aligns in part with international standards like the GDPR and UNESCO’s call for mental privacy, it falls short in addressing the unique ethical stakes of neurodata, particularly in culturally pluralistic societies. An Ubuntu-informed perspective highlights that consent is not merely an individual transaction but a relational and contextual process, embedded in communal trust, spiritual meaning, and collective identity. In this light, data governance must confront not only legal gaps but socio-cultural challenges such as low health and digital literacy, linguistic diversity, and communal forms of decision-making. Without clear legal recognition and culturally attuned safeguards, the risk of exploitative consent practices and cognitive privacy violations increases, especially for digitally vulnerable populations [60]. As neural data is inherently difficult to anonymise and prone to misuse, robust protections must reflect not only legal duties but an ethical commitment to human dignity, cognitive integrity, and relational justice [61].

National Health Act 61 of 2003

The National Health Act (NHA) upholds fundamental principles of autonomy and informed consent, positioning them as cornerstones of health service

provision in South Africa [62]. While Sects. "Proposals to Enhancing Consent Processes through Relational Autonomy and Values-Based Decision-Making" and "Conclusion" mandate that no medical intervention may proceed without the health user's voluntary and informed agreement, these provisions reflect a predominantly individualistic framework that mirrors international norms. However, when viewed through the lens of Ubuntu-informed relational ethics, this approach may not fully resonate with the lived realities of many South Africans, particularly in rural or traditional communities where, as discussed above, decision-making is more likely to be communal, relational, and spiritually grounded. International neuroethical standards, such as those advocated by UNESCO, increasingly recognise the significance of context, equity, and cultural pluralism in neurotechnology governance. Yet, the NHA does not explicitly accommodate consent practices shaped by collective identity, intergenerational wisdom, or spiritual consultation, which are often central to how mental health and neural interventions are understood. Nor does it provide guidance for how healthcare professionals should engage with patients whose understanding of neural data may be influenced by cultural beliefs or spiritual meaning-making. For the NHA to remain ethically responsive in a neurotechnological era, it must evolve to integrate culturally attuned consent processes that not only protect individual privacy and autonomy but also foster trust, solidarity, and communal well-being, values central to both Ubuntu and the broader neuroethical discourse.

#### The Mental Health Care Act 17 of 2002

The MHCA affirms the right to informed consent as foundational to ethical mental health care in South Africa, echoing international standards that prioritise autonomy, dignity, and privacy [63]. However, as neurotechnologies like brain-computer interfaces and neuroimaging increasingly enter mental health contexts, the MHCA's existing provisions fall short of addressing the complex neuroethical risks these tools pose, particularly regarding the interpretation, storage, and possible secondary use of neural data. While Sects. 8 and 9 of the MHCA rightly uphold the principle of voluntary and informed agreement to treatment, they reflect an individualised notion of consent that may not align with Ubuntu-informed relational

ethics or the communal nature of decision-making in many African communities. In these settings, mental illness is often viewed not only as a personal condition but as a disruption of spiritual or communal harmony, with decisions around care frequently involving elders, family members, or traditional healers. This tension between the MHCA's legal model of individual consent and the collective ethos embedded in Ubuntu reveals a critical interface where international neuroethical standards, such as mental privacy and cognitive liberty, must be localised through culturally grounded practices. Moreover, while the MHCA regulates both voluntary and involuntary admission procedures and includes safeguards around the disclosure of health information, it does not yet reflect the specific ethical challenges associated with neural data, such as its difficulty to anonymise or its potential for misuse in AI-driven mental health diagnostics. To ensure dignity and justice in a neurotechnological era, the MHCA must be reimagined to accommodate context-sensitive, relational models of consent and integrate ethical safeguards that reflect both global neuroethical principles and South Africa's socio-cultural realities.

#### The Traditional Health Practitioners Act 22 of 2007

The Traditional Health Practitioners Act (THPA) provides a formal framework for the registration and recognition of traditional health practitioners in South Africa but remains largely silent on how such practices intersect with patient rights, data protection, or informed consent, particularly in relation to emerging neurotechnologies [64]. As international neuroethical standards increasingly emphasise mental privacy, cognitive liberty, and culturally sensitive consent practices, the THPA's silence on these dimensions presents both a regulatory gap and an opportunity for alignment. Traditional healers play an indispensable role in the provision of mental health and neurological care in many South African communities, offering holistic treatments that integrate emotional, spiritual, and communal well-being. Their practice reflects Ubuntu-informed relational ethics, where healing is not solely an individual journey, but a communal process rooted in ancestral connection, collective identity, and spiritual balance. This relational model challenges the assumptions embedded in Western-informed consent frameworks, which often prioritise

individual autonomy and confidentiality above community engagement.

Traditional health practitioners play a significant role in mental health care in South Africa, particularly in communities where cultural and spiritual practices are deeply rooted. Their contributions include holistic care that not only addresses a person's mental health condition but also the spiritual and social aspects of such person's well-being. Traditional healers are more accessible than Western-trained mental health professionals, especially in rural areas where formal mental health services may be limited. They also provide culturally relevant care, which may be more acceptable to individuals whose beliefs may not resonate with Western medical practices. Linked to their accessibility, is the benefit that they may be able to identify mental health issues early and refer individuals to specialised care when necessary. Their role in communities cannot be separated from the community trust that they hold, making them effective in raising awareness and reducing stigma around mental health [65].

From practice it is also clear that the traditional healers often consider confidentiality to be sacred and an integral component of the healing process [66]. For example, in settings where clients share deeply personal traumas or fears, healers may ensure that the details are kept private, reinforcing the therapeutic relationship and fostering openness. Since decision-making regarding treatment in rural or indigenous communities routinely involves family elders or village leaders (e.g. where a person is experiencing symptoms attributed to ancestral concerns) a healer might consult the family or community for spiritual guidance [67]. This collective approach may inadvertently expose private health matters. In cases of ritual-based healing, traditional healers may perform ceremonies involving the family or broader community [66]. While these rituals aim to restore balance or address mental health issues, they might inadvertently reveal sensitive information during communal prayers or discussions. In some some traditions, mental health challenges are viewed as a disruption of harmony within the family or community. A healer may need to disclose certain elements of the individual's situation to bring the community together for support, such as organising a reconciliation ceremony.

Balancing the individual's privacy with collective healing may become a delicate task. To protect confidentiality while adhering to traditional practices, some healers may communicate using symbolic or metaphoric language [68]. For example, rather than explicitly naming a mental health condition, they might refer to it as "a misalignment of spirit" or "disharmony with ancestors," preserving dignity while addressing the issue.

This raises complex tensions with conventional data protection principles under POPIA and the MHCA, which emphasise individual privacy and informed consent. However, rather than viewing these frameworks as conflicting, they can be seen as complementary if appropriately reinterpreted. For example, neuroethical principles advocating for culturally adaptive and context-sensitive consent models resonate strongly with the relational and symbolic communication practices of traditional healers, who, as mentioned above, often use metaphoric language to protect a patient's dignity.

Updating the THPA to reflect the ethical obligations of traditional healers in the age of neurotechnologies, such as clarifying rights to mental privacy, spiritual data sovereignty, and culturally situated consent, would not only align the Act with international standards but also reinforce the legitimacy of Ubuntu-informed approaches to mental health. In doing so, South Africa could pioneer a pluralistic neuroethical framework that bridges biomedical, legal, and indigenous systems of care.

In the context of informed consent and the broader discussion above, South Africa's current health laws—such as the National Health Act (NHA) and the Mental Health Care Act (MHCA)—establish important foundations for patient autonomy and privacy. However, they fall short of addressing the ethical complexities introduced by neurotechnologies and neural data. Key regulatory gaps include the lack of legal recognition of neural data as a distinct category, insufficient guidance for culturally appropriate and relational consent models, and inadequate safeguards against risks like re-identification and secondary use. To uphold both constitutional and individualistic values of dignity, relational accountability, and mental privacy, legal reforms are needed to create a more context-sensitive and neuroethically robust consent framework for brain data governance in South Africa.

## Critical Reflections on Informed Consent in the Neurotechnology Context

Despite its centrality in bioethics and human rights law, the concept of informed consent remains fraught with tension when applied to neurotechnology and mental health research, particularly in contexts like South Africa. At the international level, legal frameworks such as the GDPR and UNESCO's Recommendation on the Ethics of Neurotechnology gesture toward enhanced protections for neural data, including calls for heightened consent standards, recognition of mental privacy, and safeguards against algorithmic exploitation. Yet these instruments fall short in offering enforceable mechanisms or acknowledging the lived realities of participants in non-Western settings. Neural data, unlike conventional biometric or health data, blurs the boundary between physical information and cognitive identity, raising unique questions about the voluntariness, reversibility, and ethical sufficiency of consent when the brain itself becomes the site of observation or manipulation.

In South Africa, legislation such as the POPIA, the NHA, and the MHCA incorporate informed consent as a legal safeguard, but none explicitly recognise neural data as a distinct and particularly sensitive category of information. Nor do these instruments adequately account for the country's socio-cultural and linguistic diversity. Informed consent forms are often drafted in highly legalistic or biomedical language, assuming high levels of literacy and individualistic decision-making [69], assumptions that do not hold across many communities in South Africa. Where the head is regarded as a sacred site of ancestral connection, and health-related decisions are commonly made with guidance from elders, traditional healers, or faith leaders, Western models of isolated, rational consent may misrepresent the ethical expectations and spiritual concerns of research participants [70]. Ethically, this raises significant concerns about autonomy and justice. A purely procedural model of informed consent, focused on disclosure, understanding, and signature, may satisfy legal requirements while failing to build genuine trust, cultural resonance, or moral legitimacy. Consent processes that do not account for contextual vulnerability, such as economic pressures, digital illiteracy, or stigma related to mental health,

risk becoming coercive or meaningless in practice. Equally problematic is the potential for downstream harm through misinterpretation or misuse of neurodata, whether through flawed AI models, discriminatory profiling, or re-identification of supposedly anonymised brain activity (see Box 2). The socio-cultural dimensions are no less urgent. As shown in participant-led research models like The L $\alpha$  $\beta$  (see Box 1), consent must be dynamic, dialogical, and relational. This means creating "touchpoints" that allow for ongoing reflection, culturally appropriate metaphors, and the possibility of withdrawal or reinterpretation over time. Incorporating Ubuntu ethics into these models, through solidarity, mutual recognition, and collective accountability, offers a path to more inclusive, context-sensitive consent frameworks. These must also reckon with spiritual understandings of personhood and the role of the community in affirming individual agency.

Traditional bioethics frameworks are grounded in principlism, particularly the principle of respect for individual autonomy [71]. However, relational autonomy offers a more nuanced account, especially relevant in contexts where autonomy is expressed through relationships, cultural norms, and communal support. Scholars such as Gauthier-Mamaril argues that autonomy is socially constituted and context-dependent, challenging Western liberal notions of isolated decision-making [72]. In parallel, values-based decision-making, as developed by Fulford, emphasises that all health-related decisions are shaped by personal and cultural values [73]. This approach recognises that consent decisions are not purely rational calculations but are deeply embedded in moral worldviews and social identities. In the case of neural data, values such as spiritual harmony, communal solidarity, and ancestral respect may influence whether individuals feel comfortable participating in neurotechnological research or treatment.

### Proposals to Enhancing Consent Processes through Relational Autonomy and Values-Based Decision-Making

To address the multi-layered ethical, legal, and socio-cultural complexities of informed consent in neurotechnology, it is imperative to move beyond conventional, individualistic consent models. Instead, we

propose a composite framework grounded in relational autonomy and values-based decision-making, drawing on Ubuntu philosophy and practical experiences from participant-led neuroscience research in South Africa. These approaches collectively aim to render consent processes more contextually meaningful, ethically robust, and practically effective, particularly for communities historically underrepresented or underserved in medical and technological governance.

#### Reframing Consent as a Relational and Socially Embedded Process

Relational autonomy challenges the liberal individualism that dominates traditional bioethics by recognising that autonomy is not exercised in a vacuum but shaped through relationships, community ties, and shared cultural meaning systems. Within African ethics, especially as articulated through Ubuntu, moral agency emerges not solely from individual rationality but from a person's embeddedness in networks of care, respect, and mutual recognition. This understanding reframes informed consent as an ongoing, relational process, not a discrete event or formality. For example, neurotechnology interventions such as EEG studies or Deep Brain Stimulation (DBS) may involve communal reflection, consultation with elders, and spiritual leaders, or require ritual acknowledgment to be considered ethically appropriate. Thus, incorporating family, or community-informed consent, alongside mechanisms to safeguard individual autonomy, offers a culturally congruent and ethically grounded alternative to dominant models of informed consent.

#### Implementing Dynamic, Tiered, and Interactive Consent Mechanisms

Neurotechnologies collect high-resolution, high-dimensional data that may be reused, repurposed, or fed into machine learning algorithms for various secondary applications. Static, one-time consent is insufficient for technologies that evolve over time and whose risks may become apparent only later. We therefore recommend tiered consent protocols that differentiate between levels of sensitivity and intended use of neural data (e.g.,

clinical diagnosis, algorithmic training, commercial applications). Moreover, consent processes should incorporate ongoing check-in points, as demonstrated in the participant-led research at The  $\text{L}\alpha\beta$  (see Box 1), where participants can review, amend, or withdraw consent as their values or understanding evolves. Visual tools, metaphors, and culturally adapted analogies, such as describing “beta and gamma waves as cousins”, can help make complex neuroscientific concepts more intelligible, fostering genuine comprehension rather than mere procedural compliance. Table 1 below synthesises how various strands of Ubuntu-informed ethics, ranging from Metz's relational approach to Molefe's agent-centred model (discussed above) can be translated into consent practices that are culturally resonant, ethically robust, and responsive to the realities of neurotechnology research in South Africa.

#### Strengthening the Legal Recognition and Ethical Treatment of Neural Data

South Africa's POPIA currently offers important safeguards for sensitive personal information, but it lacks explicit recognition of neural data as a distinct category. Given the highly intimate nature of brain data, and its potential to reveal not only identity but mental states, affective patterns, or vulnerabilities, this legal gap exposes individuals to unregulated risks. We propose amending POPIA to explicitly classify neural data as special personal information, thereby affording it heightened legal protection. Furthermore, researchers and companies collecting or processing brain data should be subject to neuroethical guidelines, mandating transparency, explainability, and human oversight for AI systems that interpret or act upon neural data. A participatory regulatory approach that includes traditional healers, community health workers, and neuro-ethicists in drafting these rules can ensure both ethical alignment and cultural legitimacy.

#### Embedding Values-Based Decision-Making in Consent Protocols

The consent process must also acknowledge that decisions are not made in a vacuum, but are guided by deeply held personal, moral, and cultural values.

**Table 1** Layered informed consent models

Ubuntu ethics dimension	Ethical emphasis	Consent practice implication
Relational Consent (Metz)	Solidarity, mutual respect, community trust	Consent as an ongoing social process, not isolated decision
Perfectionist Consent (Van Niekerk)	Moral development, flourishing through dialogue	Use consent moments to deepen ethical understanding
Agent-Centred Consent (Molefe)	Autonomy, self-realisation, uncoerced choice	Ensure personal willingness and moral agency in decisions
Spiritual and Cultural Beliefs	Respect for ancestral wisdom, spiritual identity	Adapt language and processes to cultural meaning systems
Collaborative Practice Models	Integration of sangomas and psychiatric care	Develop pluralistic, collaborative ethical protocols
Contextual Risks and Vulnerabilities	Mitigating stigma, information overload, timing of consent	Avoid trauma-linked consent timing, reduce coercion
Benefit-Sharing and Justice	Equity, transparency, community benefit	Include community in governance and benefit-sharing agreements

Values-based practice, as developed by Fulford, emphasises the need to uncover and respect these diverse value frameworks. This is particularly salient in neural data collection, where spiritual beliefs or ancestral respect may lead participants to decline data return or withdraw from studies. Consent documents should therefore include value-clarifying components, allowing participants to express their comfort levels, expectations, and boundaries. Researchers and clinicians must be trained to facilitate such conversations respectfully, using tools from medical humanities, cultural safety training, and moral deliberation [74].

#### Safeguarding Vulnerable Populations and Preventing Coerced Consent

Given South Africa's persistent inequalities and widespread poverty, structural pressures can distort the voluntariness of consent. Individuals may feel compelled to participate in neurotechnology research due to financial incentives, access to care, therapeutic misconceptions, or social pressure from peers or communities. To counteract this, ethics committees must mandate contextual vulnerability assessments that consider the timing, setting, and mode of consent. For example, it is inappropriate to obtain consent immediately following a psychiatric

diagnosis or traumatic experience. Intermediaries such as community health workers or mental health advocates should be empowered to facilitate consent, ensuring that participants have the time, information, and support necessary to make informed choices. Additionally, public education initiatives can improve neuro-literacy, enabling participants to better understand how their brain data will be used and what rights they retain.

#### Developing Community-Centred Benefit-Sharing and Governance Mechanisms

Any ethically legitimate consent model must be anchored in fairness and justice. Communities contributing neural data, especially for research that could generate commercial products or insights, should have a voice in how benefits are distributed. The Rooibos Benefit-Sharing Agreement offers a precedent (see Box 3 below): research ethics committees should require similar community benefit-sharing protocols in neurotech research [75]. In addition to monetary or service-based returns, this could include data access, co-authorship, neurofeedback reports, or mental health support for participants. Decision-making bodies governing such processes must reflect the relational ethos of Ubuntu, foregrounding collective well-being, transparency, and dignity.

**Box 3** The Rooibos benefit-sharing agreement**The Rooibos Benefit-Sharing Agreement – A Model for Ethical Consent and Community Equity**

In 2019, after years of negotiations, the South African San and Khoi communities signed the Rooibos Benefit-Sharing Agreement—a groundbreaking legal arrangement ensuring that Indigenous knowledge holders receive a portion of profits derived from the commercialisation of rooibos tea, which was cultivated using their traditional knowledge. The agreement mandates that 1.5% of the farm gate price be paid annually into a trust administered by community representatives. This case exemplifies an ethical model of relational, community-based consent rooted in fairness, recognition, and reciprocity. Just as the San and Khoi contributed knowledge that enabled scientific and commercial advances, communities participating in neurotechnology research—especially those contributing neural data—should be granted a say in how research benefits are shared. Echoing the relational principles of Ubuntu, consent in these contexts must go beyond individual agreement and include ongoing dialogue, transparent governance, and equitable returns. Similar protocols in neuroethics could include access to mental health services, co-authorship opportunities, community consultations, and data sovereignty mechanisms that uphold both dignity and justice.

Ultimately, obtaining valid informed consent in the neurotechnology domain cannot be reduced to compliance with static legal forms. It requires a careful balancing of legal robustness, ethical responsiveness, and cultural humility. Reforming South Africa's consent practices and legislation will involve explicitly recognising neural data as sensitive, ensuring multilingual and participatory consent mechanisms, and building ethical guidelines that integrate Ubuntu-informed relational ethics. Only then can we move toward consent models that are not only legally defensible but also ethically grounded and socially just.

**Conclusion**

As neurotechnologies increasingly intersect with healthcare, data practices, and spiritual worldviews in South Africa, the inadequacies of universalist consent models become ever more pronounced. This article has argued for a relational, context-sensitive approach to informed consent that centres Ubuntu ethics, cognitive liberty, and mental privacy. By recognising neural data as ethically distinct and culturally embedded, and by advocating for the legal acknowledgment of neurorights, we call for consent practices that are

not only legally valid but also culturally meaningful and morally just. A truly inclusive neuroethical framework must integrate African philosophies, accommodate linguistic and spiritual pluralism, and protect individuals against emerging threats of neurodata exploitation. South Africa's legal and policy responses must evolve accordingly, ensuring that the deployment of neurotechnologies enhances, rather than undermines, human dignity, autonomy, and communal wellbeing.

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**Declarations**

**Ethics Approval** This work did not involve any human research participants and consequently ethical approval and/or consent is not a required.

**Competing interests** The authors have no competing interests to declare that are relevant to the content of this article.

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