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Promoting diversity and inclusion in neuroscience and neuroethics

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Neuroscience is moving at breakneck speed towards understanding how the nervous system and the human brain function in order to develop novel treatments for neurological, neurodevelopmental and psychiatric disorders. Pursuing responsible neuroscience research requires a range of potential ethical, legal, and social implications (ELSI) to be addressed. Neuroethics seeks to address these ethical considerations. Like other biological sciences, neuroscience and neuroethics struggle with diversity yet there are compelling reasons to foster diversity in these disciplines.

I argue that these fields need to commit to the inclusion of diverse individuals for at least two reasons. First, as a matter of social justice, individuals who have been systemically oppressed and marginalised could (and should) benefit from contextually relevant research which includes their priorities and views. Second, for the advancement of science, it is increasingly clear that diverse groups yield the most innovative and impactful scientific solutions. The underrepresentation of some groups among researchers and patient cohorts forces us to reflect on who will likely benefit from the neuroscience and to consider whether there are potential gaps - including possibly overlooked bias - in the research agendas, questions, methodologies, and resultant neurotechnologies. For example, increasingly the neuroethics agenda seems to focus on neurotechnological advancements, commercialisation of devices and brain data privacy. Dominating questions relate to the use of expensive novel technologies, such as deep brain stimulation, responsive neurostimulation, neuro-wearables, as well as brain-computer interfaces. While investigating ethical implications of these topics is certainly important, the results may not be immediately relevant to people from marginalised communities - particularly those from low-income and middle-income countries (LMICs) in Africa and other continents – given that they are almost exclusively available to select individuals in high income countries (HICs). Ironically, the majority of people with disabilityadjusted life years (DALYs) related to neurological, psychiatric, and substance-use disorders live in LMICs[2],[3].

Furthermore, in LMICs, there are other priorities for neuroscience research, like identifying cost-effective innovative therapies for the highly prevalent neuroinfectious diseases of the central nervous system – such as meningitis and encephalitis^[1]. Additionally, stroke – which is the second largest cause of death in the world and has more than 80% of its burden accounted for by people in LMICs – is also a neurological illness of priority. In Sub-Saharan Africa (SSA) for instance, stroke incidence rates are increasing, with more younger people being affected as compared to people from European descent and occurrences leading to worse outcomes[3]. With the exception of the African Neurobiobank for Precision Stroke Medicine: ELSI Project (part of the Human Heredity and Health [H3Africa] consortia)[3], and the Africa Ethics Working Group (part of the Global Initiative in Neuropsychiatric Ethics [NeuroGene]) - ethical implications of neuroscience research on the African continent have hardly been investigated. Including researchers and research participants from Africa and other LMICs in the conceptualisation and design of international neuroscience and neuroethics research would be one way of fostering opportunities to critically re-consider ethical questions and priorities.

My own research has focused on exploring the stigma associated with attributing a disease to genetics among South African Xhosa people with schizophrenia and rheumatic heart disease^[4]. My current research focuses on exploring the views of South African parents of children with neurodevelopmental conditions on questions concerning feedback of individual genetic research results. We have found that African people are deeply interested in participating in research and that they have some expectations of deriving some form of benefit from scientific research. Yet Africans continue to be systematically left out of many scientific advancements and benefits. I believe we are at a critical point in time where we urgently need to collectively push for transformative systemic change. As an African woman in academia. I firmly believe in the need to advocate for both the inclusion of African people in neuroscientific research and for considerations of potential neuroethical issues pertinent to African populations in the international neuroethics discourse.

For broader stakeholders I propose the following three actions. First, large funding agencies such as the NIH and Wellcome Trust should expand the scope of projects they fund and specifically target large-scale international funding for neuroscience and neuroethics under the leadership of researchers from LMICs in collaboration with those from HICs, much like H3Africa[5]. Related to this, funders should ensure that efforts to build capacity of early career investigators and trainees in underrepresented populations in LMICs are underway, in

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order to establish a healthy pipeline of diverse scientists in these disciplines. To their merit, the aforementioned funders have already begun initiatives to fund neuroscience and mental health research and have stated an intention to involve researchers from LMICs, however there is no consideration for neuroethics in these calls. Second, it is important that scholars from LMICs in neuroscience and neuroethics be invited and elected to serve in leading international societies such as the Society for Neuroscience and the International Neuroethics Society. For conferences and meetings, they should occupy roles such as symposium and session chairs and be involved in panel sessions. Additionally, they should be represented in leadership positions in institutions, and occupy positions such as research and program directors, as well as chairs of councils, advisory boards, and editorial boards, in order to ensure that diverse views are represented in seminal discussions which are geared towards moving the field forward. Third, it would be wise to have regular open and critical dialogues (in the form of meetings, public talks, and publications) about equity and social justice among neuroscientists, neuroethicists, philosophers, social scientists, and the public.

In conclusion I believe that if we envisage that neuroscience and neuroethics will truly be of benefit for people of different racial, cultural, ethnic, gender, religious, abilities, and national origins – and, if we are serious about promoting social justice – then the researchers, research participants and research agenda need to be (urgently) expanded to be more inclusive. My hope is that, as a global scientific community, we can stand in solidarity to ensure that these disciplines commit to fostering equity, diversity, and true inclusion of all people to ensure that everyone is represented and able to reap the benefits of international neuroscience.

Declaration of Competing Interest

Author declares no conflict of interest.

Contributors

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