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Fostering Neuroethics Integration with Neuroscience in the BRAIN Initiative: Comments on the NIH Neuroethics Roadmap (2020)

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The BRAIN 2.0 roadmap lauds the neuroscientific advances made in the first decade of the BRAIN Initiative, but also calls attention to the need to carefully consider how these advances will inform and perhaps alter our understanding of “those deepest behaviors that, as humans we hold dear” (Roadmap, Executive Summary). In this short statement, we briefly consider several features of the BRAIN Neuroethics subgroup’s roadmap that lie within our area of expertise, including the recommendations to 1) enhance integration of neuroscience and neuroethics, and 2) provide additional tools and resources for neuroscientists to recognize neuroethics issues and opportunities for neuroethics research.

By way of positioning, we are co-leaders of a neuroethics research group at the University of Washington, developed over the last eight years within an NSF-funded Center for Neurotechnology (focused on engineered neuroplasticity), and we currently are co-PIs on an NIH R01 in neuroethics focused on brain computer interfaces and human agency (1RF1MH117800-01). As a philosopher (SG) and a philosopher/neurologist (EK), our work is grounded in conceptual and normative philosophical analysis, but also includes empirical bioethics – focus groups, interviews, surveys, etc. – to inform our ethical analyses and ensure diverse stakeholder input. Our comments arise from this expertise and experience.

Enhance integration of neuroscience and neuroethics

The roadmap calls for enhancing the integration of neuroscience and neuroethics, as opposed to, for instance, funding “a parallel effort” that recognizes ethical and societal issues as important and worthy of investigation, but more appropriately done, as it were, from the outside. On the one hand, separation allows a kind of independence that might permit a more fully critical stance, given entirely separate forms of funding, and avoidance of the kinds of group pressures to get along and avoid conflict. On the other hand, collaboration and partnership help to ensure that neuroethical thinking is scientifically well-informed, and conversely, that neuroscientific research takes place in the context of ongoing ethical dialogue. Integration of ethics and science “from the earliest stages” calls attention to the need to have ethical considerations voiced throughout the research and development

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process, from initial aims to design considerations to development of prototypes to animal and human testing to outcomes assessment. Such ethics engagement practices should help to ensure timely consideration of pressing ethical issues as well as anticipatory ethical guidance (Sugarman and Bredenoord 2020).

Our own neuroethics research group has been integrated into the Center for Neurotechnology from the earliest days of the Center's existence, and we have experienced the benefits of close collaboration. These benefits include developing *trust* between researchers, through time spent together learning each other's values and practices. We gained a kind of bidirectional understanding of what we each bring to the partnership: the ethics team is *not* about IRB review protocols, but instead provides conceptual and normative frameworks that foreground the importance of human agency and the diversity of perspectives on disability and modes of functioning; the neuroscience and engineering teams offered the ethicists a greater understanding of how different pieces fit together to make a brain computer interface, in terms of power, control/communication interfaces, neurosurgery, electrode design, etc., and a clearer sense of the justifications behind design decisions. Working in collaboration provided the space to bounce ideas off each other informally and regularly. Instead of waiting for papers to be published and then responding to them in additional publications (a process that takes years), our team works alongside the neuroscientists and neural engineers, interacting in shared lab spaces, through graduate student collaborative research projects, within interdisciplinary educational outreach efforts, in monthly leadership meetings, and at organized whole-Center retreats. Regular exchanges facilitate shared projects (e.g., an interdisciplinary study of who is included in neural device research studies and what demographics are recorded in publications) and also create a channel for communication of independent findings to each other prior to publications in ways that could have more immediate effects (e.g., our group studied the perspectives of disabled users of the new technologies, and how they saw their needs; in a later PI interview study, one of the PIs noted that they changed how they talk about research participants and their needs, noting you need to "*...be careful how you talk about these devices because in turn you're talking about the limitations of the person ... whom you're trying to help...I find myself thinking a little-- choosing my words more carefully as I'm describing what we're trying to accomplish and why, so as not to offend those that we're talking about.*")

Of course, setting up an integrated neuroethics team isn't something that easily falls into place, but must be cultivated. We applaud the NIH BRAIN's efforts to fund administrative supplements and ROIs that encourage "embedded ethics" (see, e.g., <https://grants.nih.gov/grants/guide/notice-files/NOT-MH-18-034.html>; <https://grants.nih.gov/grants/guide/rfa-files/RFA-mh-19-400.html>) but also recognize that building a qualified team, ready to take on the challenges of this complicated and fast-moving interdisciplinary space, is a process that takes investment in infrastructure.

Given the report's focus on the value of *integration* of neuroethics with neuroscience, we recommend funding strategies that directly support the institutional infrastructure needed to have multi-level training and mentoring (e.g., faculty-postdoc-grad-undergrad), rather than merely single project-based opportunities for collaboration. Such one-off collaborations make the *development* of expertise across the levels of academia difficult to create and

sustain. Furthermore, longer-term institutional support for integrated neuroethics allows for increasing depth of collaboration, as relationships across areas of expertise are built and nurtured. In our view, trust between neuroscientists and neuroethicists is critical to the success of such collaboration, and it takes time to develop. As the Roadmap reports, effective training grants “might also set up a mentoring cascade in which faculty train/mentor postdocs who then train/mentor graduate students who then train/mentor undergraduate students.” (Ch. 6)

What might this look like? One option would be funding of training grants that include support for faculty in neuroscience and neuroethics at an academic institution to develop ethics/neuroscience exchanges (e.g., including a neuroethics “lab” experience during the first year of lab rotations for neuroscience students, and a neuroscience lab rotation for philosophy graduate students aiming to work in neuroethics). While the value of exchanges has long been recognized – see the Summer Seminars in Neuroscience and Philosophy at Duke (www.ssnap.net)– building them into the research culture of a department or institution is more challenging. Our group has tested this strategy informally, with ethics-motivated neuroscience graduate students joining all or some of our weekly neuroethics research group meetings, to build familiarity with neuroethical issues and capacity to incorporate them into the students’ dissertation projects.

Another option that would provide the institutional infrastructural support would be the Center grant idea, mentioned in the Roadmap, on the model of the NHGRI Center grants (10 years, with research and educational components). This approach would consolidate efforts into building and sustaining expert capacity at fewer institutions. We recognize that development of expertise at a few institutions needs to be balanced with broadening the base of neuroethics expertise. Thus, one could consider incorporating mechanisms into Center grants that provide countervailing pressures to consolidation of expertise, such as providing experiences to individuals at different career levels (e.g., visiting summer programs for undergraduates, dissertation fellowships for graduate students, sabbatical support for visiting faculty, Center hosting of intensive training/workshop summer programs) who can then return to home institutions to develop institution-specific neuroethics engagement. A one-size-fits-all approach is unlikely to be successful across the heterogeneity of educational environments.

In sum, the Roadmap highlights the Gray Matters report recommendations on integrating neuroethics and neuroscience, and its recommendation for how that might work: “Such integration could take several forms, such as education at all levels; institutional infrastructure; research on the ethical, legal, and social implications of BRAIN Initiative research; consultation on research ethics; stakeholder engagement; and inclusion of an ethics perspective within the research team.” We argue that “inclusion of an ethics perspective” can be done relatively superficially, or in a much more integrated and robust way, and we have offered various ways to achieve the latter.

Provide additional tools and resources for neuroscientists to recognize neuroethics issues and opportunities for neuroethics research

Conceptual and philosophical work

To date, much of the funding for neuroethics has been focused on empirically-focused projects (e.g., interviews, surveys, focus groups, etc.; see <https://braininitiative.nih.gov/funding/funded-awards>). While we recognize the critical value of these efforts, we recommend that the NIH recognize the need for funding more conceptual/philosophical work, done in partnership with neuroscience studies. The Roadmap notes the need for more attention to the meaning of terms such as agency, empathy, free will, and consciousness (e.g., “Although not unique to neuroscience, nomenclature is ever important. Efforts should be made to clarify concepts such as consciousness, empathy, and free will, as these are not always used to impart the same meaning in neuroscience research.” (Roadmap, Ch. 2). In our view, this is work that could be productively taken up by philosophers who are not experts in empirical bioethics, but could nonetheless greatly contribute to clarity in the relevant concepts and terms. This may require broadening the notion of a “productive” neuroethics project to those that do not have empirical products in the traditional sense (e.g., empirical data, clinical tools).

Our understanding is that such conceptual or philosophical work is more highly regarded by other brain-related projects (e.g., the EU’s Human Brain Project, and German national grants that support partnered neuroscience/philosophical work), and well-funded in those efforts. The NIH should not be left behind simply because its precedent has been to fund primarily empirical ethics work and so should open existing or develop new funding mechanisms to support such work.

Relational approaches to neurotechnology

Relatedly, we appreciate the Roadmap’s call out for the need to better understand how neurotechnology not only challenges our conceptions of individual identity, agency and autonomy, but also our *relational* identities (“Will we equate ‘who we are’ with brain function at the expense of alternative, more relational conceptions of identity?” (Roadmap, Ch. 1, under The Need for Neuroethics Research). We would recommend greater attention to what might be called middle-level sociality. The Roadmap highlights concerns about individual agency, autonomy, privacy, etc., and it highlights the need for broader recognition of and attention to cultural norms, as well as public engagement, but fairly little attention is paid here to the potential effects of neurotechnology (whether for medical purposes or beyond medicine) on *personal relationships*, particularly those with the user’s family and friends. Data from our team’s focus groups and stakeholder interviews have highlighted how users of DBS technologies felt “dehumanized” by how their family members responded to the reality that they could be “turned up” via their DBS hand-held programmers (Klein et al. 2016). Though our work and that of others has tended to focus on the relationship effects seen through the eyes of the device user, it has become increasingly clear that device users themselves can fail to recognize how neurotechnology affects them, their loved ones, and their relationships with their loved ones. The NIH BRAIN has begun to support research specifically targeted to family and caregivers (for instance, a neuroethics supplement to

1UH3NS100548-01 to study the effects of psychiatric DBS on caregiver-patient pairs), and we expect that more funding in this area will be fruitful.

The Challenge of Post-Trial Obligations to Research Participants

We concur with the attention recommended for addressing how NIH-funded projects will deal with long-term responsibilities to research participants who have implanted neurotechnologies that may offer benefit and will require maintenance and perhaps upgrades. The Roadmap notes that “considerations for safeguards from hacking or misuse, *understanding who takes ultimate responsibility for ongoing support for the technology beyond the lifetime of a research project*, and guidelines guarding against unintended consequences of device use will also ensure sound ethical standards for technologies developed (Ch. 1, our emphasis). Additionally, it later recommends that “When conducting human studies with neuromodulators, including drugs, *outline in detail potential end-of-trial and post-trial responsibilities*” (Ch. 2, our emphasis). Given that research participants take on risks (surgical and otherwise), share a significant amount of their time (studies often go on for years), and have a great deal at stake (opportunities for movement, fulfillment through participation, etc., see Kögel et al. 2020), their interests clearly become morally entangled (Richardson 2012) with those of the researchers, and create additional responsibilities. Rather than leaving post-trial protocols to individual research teams, as is the current state of affairs (Lazaro-Munoz 2018) we recommend a coordinated effort to develop a standard protocol for NIH-funded human subject projects (not just as a required mention in the grant, but as a *budgeted* part of it). Development of this protocol would require input from a variety of stakeholders, including researchers, industry, regulators, funders, and end-users.

Attention to Agency and Autonomy

Our research group has focused on human agency in the context of novel neurotechnologies (Goering et al. 2017; Goering 2014). Such devices offer significant promise in providing or even enhancing agential capacities for many people, but also raise considerable concerns, given that devices target or have effects on areas of human functioning intimately tied to our sense of who we are, and how we author our lives (e.g., Baylis 2013; Schechtman 2009; Glannon 2009). The Roadmap recognizes this delicate situation: “What is more likely in humans are invasive studies including deep-brain stimulation and multi-electrode arrays recording and stimulating the surface of the brain, as well as noninvasive stimulation such as ultrasound and transcranial magnetic stimulation. With any of these technologies, the aim would be to manipulate or control the brain in a way that a patient or participant could not do on their own. This poses a potential challenge to the user’s autonomy and agency.” (Roadmap, Ch. 3). In Table 6, this gets summarized as “Identifying measures to ensure *optimal* autonomy and agency for participants/users.” (our italics). We concur with the emphasis on the autonomy and agency of users, and the threat of manipulations that are unwanted, as well as the possibility of agential confusion (even without manipulation) that might be detrimental to well-being (Goering et al. 2017, Klein et al. 2016.). We worry, though, that the phrasing here – about an “optimal” autonomy and agency” – mischaracterizes the complexity of autonomy and agency, which are likely to be multi-dimensional, have internal as well as relational components, and will likely not be so easily evaluable in terms of “optimal” levels. Perhaps this is a minor point, but it bears scrutiny. We

need to resist over-simplification of these complex phenomena, and recognize that understanding agency, for instance, may not be so significantly different from the “moonshot” of understanding consciousness (Roadmap, Moonshot chapter).

Attention to Bias

We applaud and underscore the attention the Roadmap offers to the problem of bias and the need for inclusiveness. It recommends, for instance, that “Studies should be designed to investigate the impact of many variables on brain function, including but not limited to, sex, race, and cultural experiences. Explicit attention should be given to questions about who will benefit from neuroscience research advances, and how to promote equitability across these and other important domains. Neuroethics deliberation is necessary and requires thoughtful input beyond neuroethics alone – including, for example, experts in sex/gender differences, cultural and societal differences, disease advocacy, and other topics related to human variation.” (Roadmap, Ch. 3). We concur and propose additional emphasis on encouraging all BRAIN-funded projects using humans to report demographic details of their participants, in publications or by other means (e.g., registries). A group at our university has been developing a project focused on the lack of such reporting, and we know that others are working in this area as well. This would be a relatively simple intervention that might help to track the diversity (or lack thereof) of the participant pool.

Of course, ensuring that bias is acknowledged and addressed and that inclusiveness is the norm may more productively be promoted through recruitment of a more diverse research team. Evidence for the epistemic and ethical benefits of diverse research teams is clear (Lee et al. 2015; Campbell et al. 2013); the imperative now is to put our knowledge into effect. In this respect, we recommend funding programs that explicitly aim to diversify the workforce of neuroscience and neuroethics, at a stage much earlier in development than postdoctoral studies (e.g., via the existing F32 mechanism). Summer research programs for undergraduates or graduate student fellowships could be helpful in this regard (the NSF’s research education for undergraduates, or REU program, might be a good model).

Animal care and use

The Roadmap’s section on animal use (Ch. 4) is compelling, though somewhat out of our own area of expertise. As the Roadmap identifies, non-human primates or other animals that are “humanized” to provide better models of disease or function, are similar enough to humans to be useful models, but presumably also share some of the features of humans that make certain kinds of experiments morally problematic if done on humans. We agree that more attention needs to be paid to these issues, and would recommend not only efforts to reduce and replace animal models where possible, but also, importantly, to reassess norms of animal care within scientific research.

Training and RCR

The Roadmap helpfully looks at a variety of mechanisms to implement and fund neuroethics integration with neuroscience research (Roadmap, Ch. 6). “Given the vitality of neuroethics training and awareness to the BRAIN Initiative, NIH and other BRAIN-Initiative partners should consider adding additional neuroethics training opportunities within existing

responsible conduct of research (RCR) training requirements for neuroscientists” (Roadmap, Ch. 6). This aim is laudable, yet we have concerns about the mode of achieving it. Although we recognize the ease of online RCR modules, we have significant reservations about the efficacy of such training to enhance ethical decision-making capacities (Kalichman 2013; Antes et al. 2010). We are concerned that the value of the added (likely online) training will match the investment of the researcher. We would highly recommend more robust, interactive, and in-person trainings as a preferred way to build neuroethical sensitivity and skills in neuroscience researchers.

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