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Insiders and outsiders: lessons for neuroethics from the history of bioethics

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Abstract

Recent disputes over the NIH Neuroethics Roadmap have revealed underlying tensions between neuroethics and the broader neuroscience community. These controversies should spur neuroethicists to more clearly articulate an oft-cited ideal of “integrating” neuroethics in neuroscience. In this it is useful to consider the integration of bioethics in medical practice as both historical precedent and context for integration in neuroethics. Bioethics began as interdisciplinary scholars joined biomedical institutions to serve on newly-created IRBs and hospital ethics committees. These early bioethicists identified as outsiders and their presence was initially resisted by some in the medical establishment, but over time they became integrated into the very institutions that many had originally come to critique. This work has transformed medical practice, but also required compromises and intellectual costs. Also, the successful integration of bioethics relied in part on structural features of postwar medicine with no clear analogue in contemporary neuroscience; for neuroethics, imaginative new approaches will also be needed. While neuroethics to date has focused somewhat narrowly on questions in neurotechnology, I argue that successful integration in neuroethics will likely require a broader vision, encompassing the clinical neurosciences as well as questions at the interface of neuroscience and society.

Keywords

bioethics; neuroethics; neurotechnology; non-human primates

Over its short history, the young field of “neuroethics” has enjoyed remarkable public support within neuroscience. For instance, since 2006 the Annual Meeting of the Society for Neuroscience has hosted a featured lecture on neuroethics, articles on neuroethics topics have been published in leading neuroscientific journals, and neuroethics has been emphasized from the inception of the U.S. BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative. However, recent events have revealed tensions between neuroethics and the broader neuroscience community. In several respects, these tensions recapitulate controversies from the history of bioethics—some that have essentially been resolved, and others that continue to pose challenges for bioethics as an enterprise. Neuroethicists and neuroscientists may then find it useful to re-examine the history of

bioethics as precedent and context for their own challenges in incorporating ethical inquiry more fundamentally in the practice of neuroscience.

Some of these tensions have surfaced in the work of two groups assembled by NIH in 2018 to plan for the second half of the BRAIN Initiative. The “BRAIN Initiative Working Group 2.0” was to review the overall neuroscientific plan and explore new scientific opportunities,^{*} while a “Neuroethics Subgroup” (working in parallel with the Working Group 2.0, with three overlapping members) was charged with developing a Neuroethics Roadmap[†] for further research in the Initiative. Both groups issued reports for public comment in May 2019 in anticipation of the June 14, 2019 meeting of the NIH’s Advisory Committee to the Director (ACD), where the future direction of the BRAIN Initiative would be charted. While many of the public comments to the Neuroethics Roadmap were supportive, over 300 neuroscientists principally engaged in research with non-human animals submitted a highly critical comment that called for an entire chapter addressing animal research to be deleted. These neuroscientists regarded this chapter’s call for further moral inquiry into non-human animal (especially primate) research as excessive and unnecessary given existing extensive regulation, and accused the Neuroethics Subgroup of overreach.

At the ACD meeting Anne Churchland,[‡] a neuroscientist member of the Working Group 2.0 and also of the ACD itself, also criticized the Neuroethics Roadmap.[§] First, Churchland expressed skepticism about a proposed target (following the Human Genome Project and European Human Brain Project) of spending 5% of NIH BRAIN funds on neuroethics. Second, echoing the public comment on research with non-human animals, Churchland opposed what she perceived as a call for additional regulation of such research. Finally, Churchland objected to a proposed “transformative project” to enlist neuroethicists, humanists and philosophers alongside neuroscientists in a broad effort to investigate the neural basis of consciousness.

Churchland’s criticisms were significant not only for their substance but also given her position as a member of the Working Group 2.0, indicating that the two groups’ work had not in fact been complementary. Given these objections and the lack of coordination between the Working Group 2.0 and Neuroethics Subgroup, the ACD then had to deliberate on how to proceed. National Institute of Mental Health Director Joshua Gordon warned that given internal timelines for designing new programs, waiting to approve these reports until the ACD’s next meeting in December would hamper planning for the next phase of the

^{*}Draft for public comment at <https://braininitiative.nih.gov/strategic-planning/acd-working-group/brain-research-through-advancing-innovative-neurotechnologies>. Initial presented June 14 version at <https://acd.od.nih.gov/documents/reports/06142019BRAINReport.pdf>. Final approved October 21 version at <https://acd.od.nih.gov/documents/presentations/10212019brain2.0.pdf>.

[†]Draft for public comment at <https://braininitiative.nih.gov/strategic-planning/acd-working-group/neuroethics-roadmap>. Initial presented June 14 version at <https://acd.od.nih.gov/documents/reports/06142019BNSReport.pdf>. Final approved October 21 version at <https://acd.od.nih.gov/documents/presentations/10212019bnsroadmap.pdf>.

[‡]When presenting this work to non-neuroscientific audiences, I have at times had to distinguish Anne Churchland, neuroscientist, from Patricia Churchland, philosopher—Anne Churchland is the daughter of Patricia and Paul Churchland. Perhaps more relevant to the discussion is that much of her graduate and postdoctoral research was in non-human primates, and that her lab’s current research in rodents is deeply informed by findings and models from non-human primate research. As I explore in the last section, Anne Churchland has also been influential in addressing broader cultural and structural issues in neuroscience, most notably around issues of gender equity.

[§]<https://videocast.nih.gov/summary.asp?live=33272&bhcp=1>. Summary of Neuroethics Roadmap at 2:14; Churchland’s criticisms at 2:37.

BRAIN Initiative. Some ACD members considered approving only the Working Group 2.0's neuroscience-focused report, while having the Neuroethics Roadmap revised. Ultimately, however, a decision was made to withhold approval on both reports (which were eventually approved after long efforts at revision on October 21). Thus, the neuroscience community's objections to the Neuroethics Roadmap were ultimately significant enough to delay implementation not only of this document, but also of the strategic plan for the second half of the entire NIH BRAIN Initiative.

Viewed optimistically, this outcome testifies to the importance placed on neuroethics within the NIH. Still, many neuroethicists were disheartened by the criticisms of Churchland and the 300+ signatories of the public comment on research with animals. These seemed to envision neuroethics narrowly as a matter of burdensome, duplicative regulation threatening to hinder scientific research, and also challenged neuroethicists' claims to disciplinary expertise. This picture stands in contrast to a more collaborative ideal of "integration" proposed by neuroethicists and neuroethics bodies. For example, a facilitatory rather than regulatory role for neuroethics was advocated in the President's Commission on Bioethics's *Gray Matters* report:

Executed well, ethics integration is an iterative and reflective process that enhances both scientific and ethical rigor. Without ethics integration, neuroscience and neuroscientists might overlook fundamental ethical and social dimensions of the complex phenomena they seek to understand. And if ethicists are not conversant in the *science* of neuroscience, they will be unable to make a meaningful contribution to the *ethics* of neuroscience (2014, 12).

Ethics is more than regulatory compliance or risk mitigation, and integration involves a deep collaboration between ethics and science such that the contributions from all disciplines are strengthened (2014, 12-13).

From the NIH BRAIN Initiative Guiding Principles (for transparency, I am a co-author):

neuroethics is vital to neuroscience research. The consideration of ethical, legal, and societal implications of neuroscience research facilitates progress in neuroscience and that neuroscientific advancements support human well-being. Integrating neuroethics into the NIH BRAIN Initiative serves the interests of all involved stakeholders. Success requires collaborative input from many disciplines – neuroscience, medicine, bioethics, philosophy, law, and others (Greely et al. 2018).

Churchland's objections and the public comment on animal research have shown that this integrative conception is not yet broadly shared among neuroscientists. Furthermore, I think the problem goes beyond superficial matters of perception or public relations. Instead, I regard these objections as a wake-up call for neuroethicists to engage more deeply with the problem of what "integration" really should entail in the practice of neuroscience. While neuroethics bodies may assert that integration enhances rigor, strengthens science and serves scientific interests, ultimately neuroscientists will arrive at their own judgments about whether integration really does advance rather than block progress in neuroscience.

In fact, ethics integration can be a difficult, contentious, and sometimes painful task. Neuroethicists will need to do more to articulate how integration will work in practice, what it demands of ethicists and practitioners, and what benefits integration can and cannot be expected to deliver. For this reason, we should turn to the precedent established by the organizational successes of bioethics within medical institutions, which have transformed medical practice and discourse. As we will see, from its beginning bioethics has also faced the question of regulation versus facilitation, and was ultimately welcomed into medical institutions (raising new concerns of co-optation). At the same time, we should also be aware of important structural differences between the circumstances of medicine at the birth of bioethics, and the circumstances of neuroscience at the birth of neuroethics. As some of the features that have facilitated the success of bioethics have no clear parallel in neuroethics, pursuing the integration of neuroethics within neuroscience will depend in part on devising new approaches. In particular, such integration will require adopting a broader vision of neuroethics than has generally been advocated.

From medical ethics to “bioethics”

Albert Jonsen’s *The Birth of Bioethics* (1998) describes a profound transformation in medical practice, which began in the United States and has since spread globally (Culliton and Waterfall 1978; Wilson 2014). Before World War II, discourse about ethics in medicine was almost exclusively the province of physicians, and it would have been considered impertinent for a philosopher or theologian (except in communicating doctrine to co-religionists) to tell physicians how to perform their duties. But in the postwar era, medical knowledge advanced in ways that aroused both public acclaim and fear. Interventions that initially seemed miraculous—such as dialysis, transplantation, mechanical ventilation, assisted reproduction, and genetic engineering—were quickly recognized to pose complex questions about the value and sanctity of life, and about tradeoffs between individual well-being and the common welfare. Many came to perceive that medical ethics, understood as a discourse limited to physicians, was not equipped to address these challenges. While physicians’ claims to physiological expertise were enhanced by their growing technical abilities, such expertise did not grant authority to decide on society’s behalf how scarce life-saving resources should be allocated, or what lives were worth living, or when some people’s interests could be sacrificed for the health of others (Rothman 1991).

Soon scholars from other disciplines such as philosophy and theology joined in discussing these problems. Some physicians welcomed these outsiders, but more traditional voices decried what they perceived either as an abandonment of their professional responsibility to make difficult decisions on patients’ behalf, or as external interference in their work. In 1968 Walter Mondale proposed a commission including doctors, researchers and laypersons to explore ethical implications of biomedical advances. In Congressional hearings, several invited physicians and investigators called for increased funding for their own projects while dismissing proposals for interdisciplinary scrutiny. The surgeon Owen Wangenstein asserted, “If you are thinking of theologians, lawyers, philosophers, and others to give some direction here... I cannot see how they could help. I would leave these decisions to the responsible people doing the work” (U.S. Senate 1968, 100). Jesse Edwards, president of the American Heart Association, expressed concerns about stymying research: “The one thing

we would want to avoid would be getting into a technical situation which would make it easy for restrictive legislation” (U.S. Senate 1968, 317).

A series of public controversies undermined such assurances. In clinical research, abuses at Tuskegee, Willowbrook and other institutions indicated that investigators acting without oversight could not be relied upon to resolve conflicts between research objectives and patients’ interests. In clinical care, highly-publicized and tragic cases (e.g., Quinlan, Cruzan, several infants in intensive care) revealed life-and-death decisions that had previously been matters of professional discretion. Mondale’s efforts eventually resulted in a series of federal commissions on ethical issues in biology and medicine. These commissions, and the NIH’s response to Henry Beecher’s documentation of dangerous research without consent (discussed below) led to Institutional Review Boards (IRBs) to oversee research. Similarly in *Quinlan*, the court called for hospital ethics committees to be established for clinical dilemmas. Both responses (partly deferring to physicians’ professional independence) did not result in centralized oversight, but instead a federated model in which institutions established their own IRBs and hospital ethics committees.

IRBs and ethics committees created roles for theologians, philosophers and other outsiders within hospitals and biomedical research institutions. But at first these early outsiders did not actually have a method to offer for addressing the questions they faced. Theologians used a moral language concerning the sanctity of life and the inviolability of persons that was suited to the grave problems posed, but also recognized that arguments from religious premises could not ground broad consensus in a diverse society. Philosophers brought argumentative rigor and conceptual distinctions, but also found that the predominantly linguistic and formal concerns of mid-century Anglophone metaethics spoke little to the substantive moral concerns posed by medical advances.

As described by Jonsen, these early bioethicists essentially adopted the method of committee deliberation as their form of inquiry. Rather than starting from first principles (as many originally were trained to do), they sought to articulate and balance different perspectives about cases, focusing principally on the moral concerns of the clinicians, patients and researchers who were directly involved. As virtues, this method gave their work an immediate practical character, and demonstrated appropriate intellectual humility in the face of normative disagreement. However, this approach also elided questions about the nature of bioethicists’ own disciplinary expertise and claims to authority, and placed limits on the scope of normative questions that bioethics would entertain.

Internal and external critique

Bioethicists began as outsiders, but soon became insiders. As a key example, physicians began to engage them in the practice of bedside consultation (Ruddick 1981; White, Shelton, and Rivais 2018; Baker 2018). Just as an internist treating a patient with a complex kidney problem would seek advice from a nephrologist colleague, attending physicians also began to elicit bioethicists’ input on ethically complex cases. Some early bioethicists were surprised to be privy to confidential details about patients and invited to leave notes in patients’ medical records—access that was itself governed by a broader network of

professional norms and courtesies into which these outsiders were newly incorporated. Being seen by clinicians as practical problem-solvers contributing to patient care gave bioethicists greater legitimacy and facilitated their involvement in institutional policy. Partly through their advocacy on behalf of patients and families in decision-making, the principle of patient autonomy eventually attained preeminence in physicians' own understanding of their obligations.

Bioethicists were either slow or resistant to recognize that these developments also involved the accrual of professional power. Social scientists such as Renee Fox (1990) and Charles Bosk (1999), perhaps more attuned to informal modes of authority, noted that bioethicists' access to cases depended on their collegial relationships with clinicians while their salaries often depended on their perceived utility to administrators. As Daniel Callahan (1996), a founding figure in bioethics, later reflected,

We courted legitimacy, sought money from the big foundations, tried to make it in the higher reaches of academia, and endlessly worked to persuade physicians and biomedical researchers that we should be seen as allies and not as opponents.... We became insiders by default, without ever resolving in any full way the question of whether those who pursue bioethics should be insiders or outsiders.

This assimilation of bioethics into the medical establishment was unfortunately linked to intellectual blind spots, such as the underdevelopment of bioethical inquiry into questions of justice and access to care. Given its organizational home within medical institutions and its practical focus on problems among clinicians and patients in that setting, the moral claims of those excluded from those institutions were often missed. This belated recognition of bioethicists' professional power also prompted debates over its proper exercise—hence, “the ethics of bioethics” (Eckenwiler and Cohn 2007)—and ongoing, unresolved disputes over whether bioethicists themselves should adopt a code of ethics (Freedman 1989; Baker 2005; Tarzian, Wocial, and ASBH Clinical Ethics Consultation Affairs Committee 2015; Schwab 2016).

Without necessarily intending to, bioethicists became colleagues with clinicians and clinical investigators in a shared enterprise. While this embedded them within the same institutions that they had been called to critique, they ultimately have been successful in contributing perspectives to medicine and clinical research that previously had been excluded. It may be helpful here to contrast two broad modes of critique: *internal* and *external*. Internal critique is discourse among people who are committed to a shared institution or practice. Such critique seeks to improve how common ends are achieved; it requires trust among participants and presumes good will. External critique does not involve such shared commitments. External critique therefore can be much more radical, including criticism of the ends or ultimate value of the object of inquiry, without deference to claims of competence or expertise by those engaged in the practice in question.

One landmark early episode in bioethics illustrates both the power and limitations of internal critique. Unlike most of the early bioethicists, Henry Beecher was very much an insider: he was Dorr Research Professor and established the Department of Anesthesia at Massachusetts General Hospital. Informed by his own research quantifying the placebo effect (Beecher

1955), he was an early proponent of controlled clinical trials and more generally for rigor in science. Among his many contributions to bioethics, he was one of the first to recognize the potential conflict in roles between clinician and investigator. Much of his work was motivated by concern for the public legitimacy of science, which could be threatened either by unreliable methods or by unethical treatment of human subjects.

In “Ethics and Clinical Research”, Beecher (1966) documented 22 cases of unethical research that endangered human subjects without their knowledge or consent, yet were conducted at leading institutions and published in elite journals. Beecher published this exposé at significant professional risk, but in his paper also made revealing choices. Beecher declined to identify the investigators or the studies in question, with the justification that he was concerned with research practice in general. Also, Beecher’s article was not addressed to the public so much as to other medical researchers, and he framed the rationale for his own paper in terms of a shared commitment to biomedical research:

I should like to affirm that American medicine is sound, and most progress in it soundly attained. There is, however, a reason for concern in certain areas, and I believe the type of activities to be mentioned will do great harm to medicine unless soon corrected. It will certainly be charged that any mention of these matters does a disservice to medicine, but not one so great, I believe, as a continuation of the practices to be cited (1966, 1354)

Beecher then described cases in which effective treatments were knowingly withheld from patients with life-threatening illnesses, in which drug toxicity was repeatedly tested in children, and in which physiological mechanisms were investigated via medically unnecessary procedures, among others. Yet he went on to assert, whether naively or disingenuously, that “thoughtlessness and carelessness, not a willful disregard of the patient’s rights, account for most of the cases encountered.” Beecher still assumed that human subjects protection would depend mainly upon the professional integrity of investigators, and did not yet envision empowering patient-subjects or external oversight (Rothman 1991; Miller 2012).

While incomplete in these ways, Beecher’s paper had immediate impact. Congressional pressure on the NIH, which had funded or conducted many of the studies he critiqued, led to changed policies as described above, establishing IRB review. Beecher himself came to use his position within medicine to promote the inclusion of other disciplines in bioethical discourse. When he later established an Ad Hoc Committee at Harvard Medical School to examine the problem of brain death, he took care to include not only physicians and scientists but also a legal scholar, a theologian and a medical historian (Definition of Irreversible Coma 1968; Belkin 2014). At Mondale’s hearings in 1968, Beecher drew on this experience to contradict Wangenstein and Edwards, arguing for the necessity of a multidisciplinary and intellectually diverse group to address unresolved problems posed by advances in research (U.S. Senate 1968, 103-104). When Callahan and Willard Gaylin established the Hastings Center, Beecher served as a founding member of its Board.

Returning to present-day neuroethics, I interpret the ideal of *integrating* neuroethics and neuroscience as a vision of neuroethics as focused on internal, rather than external critique.

In Gray Matters, the NIH BRAIN Neuroethics Guiding Principles, and the Neuroethics Roadmap itself, neuroethics is promoted as essential to a shared aim of advancing neuroscience—as opposed, e.g., to an external aim such as protecting transcendent values from infringement by neuroscience, which might sometimes involve prioritizing those values over neuroscientific progress. Gray Matters calls for integration of ethics “early and throughout the research endeavor,” and proposed the inclusion of ethicists in research teams—both of which have been reinforced in the later documents. As more external critics of both neuroscience *and* neuroethics have noted (De Vries 2007; Slaby and Choudhury 2018), such statements position neuroethicists as colleagues engaged in a shared practice with neuroscientists (and potentially also as having a shared interest in the continued prestige of neuroscience), much as bioethicists became colleagues and insiders in medical institutions.

In many respects the prospects for an “insider” neuroethics are strong. As Beecher encouraged the incorporation of interdisciplinary ethical perspectives in medicine, neuroethics has many champions within neuroscience. Also, a factor that facilitated the integration of bioethics in medical institutions was that the ultimate aims of those institutions were ethically compelling—e.g., restoring health, alleviating suffering, and finding new therapies. Philosophers and theologians did not perceive inherent compromises in helping to find moral means of advancing these aims. Similarly, the aim of advancing our understanding of the nervous system can be readily adopted by interdisciplinary neuroethicists. This aim is not only necessary to developing therapies for grave neurological and psychiatric disorders, but also belongs to a broader project of human self-understanding that is itself intrinsically compelling. However, as in the case of bioethics, incorporation of neuroethics within neuroscience will also involve compromises and challenges.

Some domains of neuroscience are structurally less amenable to ethics integration; one such example may be the commercialization of neurotechnology. Many companies are very interested in extending recent consumer advances in mobile computing and artificial intelligence to the human brain, with potentially transformative effects. Such applications also deserve sustained ethical inquiry, but recent controversies over “AI ethics” have illustrated that integrating ethics “early and throughout” commercialization will pose deep challenges (Vincent 2019; Naughton 2019). First, while advancing our understanding of the nervous system is a broadly ethically compelling aim, a corporation’s aim in commercializing some technology will often be less broadly compelling. And while being perceived as ethical may be important for a company’s public relations and employee morale, it is unlikely that fundamental engagement with ethical questions will reliably advance commercial interests. Attempts to integrate neuroethics in commercial neurotechnology may thus introduce potentially irreconcilable disputes amid accusations of co-optation and superficiality.

Another example of a challenging domain for integration is neuroscience research conducted in non-human animals, especially primates. There are two broader trends at work that seem in fundamental conflict. First is the growing complexity and sophistication of neuroscience, both in its techniques and its concepts. As neuroscientific questions progress from discrete parts of the nervous system towards its higher-level features, many human systems of interest will have no homologue in nonmammalian or rodent models, increasing the

scientific need for and value of non-human primate models. Meanwhile, in our society the domain of moral concern is increasingly extended to animals. Ironically, this trend is driven in part by scientific findings on neural correspondences between humans and non-human primates. That is to say: the importance of the brain as a locus of fundamental significance to our natures, and the recognition of shared neural architectures across species, are basic premises for both proponents and opponents of research on non-human primates.

Within neuroscience, it is nearly axiomatically accepted that non-human primates do not hold rights and moral claims equivalent to humans, and that the project of understanding the human nervous system is important enough to justify research on non-human animals (subject to due constraints of animal welfare). These views are increasingly questioned outside of neuroscience. It is difficult to envision how neuroethics can accommodate such opposed views about the relative importance of neuroscientific research and animals' rights, if neuroethicists are to work alongside neuroscientists who conduct research on non-human primates. So, I suspect that a neuroethics that is integrated with neuroscience is unlikely to represent the full range of views about non-human animal research that is found in the broader society, and may then fail to prepare neuroscientists for engaging with a more deeply conflicted public.

Differing structural barriers to integration

The broad alternative to a neuroethics of internal critique is one of external critique—one in which ethicists stand at a distance from the activities of neuroscientists. While such a discipline would have greater latitude to take adversarial rather than facilitatory stances towards neuroscientists' methods or even their claims of expertise, it would likely also have less practical influence on how neuroscientists think about their work. And while many neuroscientists would see value in having neuroethicists as colleagues in a shared enterprise of advancing ethical neuroscience, far fewer would prioritize supporting external scrutiny from neuroethicists who were removed from and uninterested in contributing to neuroscientific aims.

Bioethics has been quite successfully integrated with medicine, with profound effects on clinical practice and on clinicians' conception of their responsibilities. While this is a promising precedent, we should also attend to structural differences between medical practice in the postwar era and neuroscience today. Returning to Churchland's criticism of the Neuroethics Roadmap, I understand her as expressing skepticism of how integration will work in practice, with the added concern that neuroethics without integration could inhibit rather than facilitate progress in neuroscience. Given the proposed target of 5% of NIH BRAIN spending, she calculated that this would amount to \$25 million per year and questioned what to expect from this investment:

\$25 million, depending on how you count, is about 250 full-time employees. I wasn't sure what all 250 neuroethicists would be doing for the BRAIN Initiative. Part of the reason I was concerned about this leads to my second point. Which is, I just wanted to make sure that this additional funding didn't lead to a duplication of regulation and oversight that exists already.

Perhaps one way of phrasing this worry might be: if these neuroethicists do not have a clear role in a shared enterprise of advancing neuroscience, then might they (as bioethicists accrued power in medical institutions) assign themselves the authority to oversee and even impede the research being performed?

One development that facilitated incorporation of the early bioethicists into medicine was their participation in bedside consultation. Consultation was already part of clinical practice, and bioethicists applied their different skills to assist in making difficult decisions and resolving disputes. Working alongside clinicians that treated them as colleagues informed their own professional identities in the medical establishment. Is there an analogue to “the bedside” for neuroethicists that would inform their identities and perception as colleagues alongside experimental neuroscientists?

One potential role noted in *Gray Matters* is research ethics consultation, in which scientists call on ethicists for advice on ethical issues that arise in their studies. But there are important differences. First, while clinicians had an established practice of bedside consultation with one another into which bioethicists could be incorporated and recognized as colleagues, experimental scientists do not “call consults” on their scientific colleagues in the same manner. (They seek technical assistance and form collaborations, but these activities are governed by different norms—such as norms of reciprocity, mentorship and authorship/assignment of credit.) Relatedly, perhaps because it is based on the model of clinical ethics consultation, to date research ethics consultation has been principally concerned with clinical and translational human subjects research (Cho et al. 2008; McCormick et al. 2013; Porter et al., 2018). The value of such practices to neuroscientists (like Churchland) who work with cellular or animal models has not been established.

A deeper concern is raised by Jonsen’s critique, based on his account of the history of bioethics. Jonsen (2008) credits a focus on clinical dilemmas as “the practical origin of bioethics,” which

saved the life of bioethics, which (although it had no name in those years) was threatened by huge questions that drew it up into a hot air balloon of speculation. The ethical concerns had no purchase on concrete problems until the researchers and transplanters set to work on patients. Clinical ethics and research ethics (in the restricted sense of protection of human subjects) became the matter of bioethics and gave rise to its methods.

Bioethics took its grounded, practical character from bioethicists’ involvement in the moral claims of patients and clinical research subjects in the medical setting. Without a direct link to such concrete individual human interests, the work could dissolve into abstractions removed from the daily concerns of those engaged in care and research.

One framing of the structural challenge for integration in neuroethics is as follows: Beecher’s work in bioethics was partly motivated by concern for the public legitimacy of clinical research, which was then just beginning as a systematic discipline. But such concerns are less urgent for neuroscience today, when scientists enjoy relatively high public trust (Funk et al. 2019) and the populace is not dubious but instead perhaps overly credulous

of neurobiological claims (Weisberg, Taylor, and Hopkins 2015). Clinicians and clinical researchers came to welcome bioethicists as colleagues who could help to resolve practical problems in their work—appealing to their professional identities. What analogous factors would motivate bench neuroscientists to seek collaborations with neuroethicists? Neuroethics might appeal to them at a universal level as ethical individuals who are concerned about the implications of their work, and we might devise institutional incentives (or punishments) to induce cooperation. But are there factors that could appeal to them specifically through their practical identities as neuroscientists and their professional aims of advancing our understanding of the nervous system?

The consciousness “transformative project” may have been intended to articulate a research program central to progress in neuroscience that would involve neuroethicists as scientific colleagues. As articulated in the Neuroethics Roadmap,

Ethicists and scholars from a variety of disciplines, including the humanities, would explore assumptions of what consciousness is, how it might be measured and operationalized in the lab – and how such measures could be applied in real-world settings – and more broadly, how these neuroscientific insights might inform societal views and policy in areas such as health care, law, and other realms.

This vision is exciting, but may trade on an ambiguity about roles for neuroethicists in an empirical investigation of consciousness. In philosophy (one of the disciplines invited to contribute), these questions are usually treated as belonging to two distinct domains. What consciousness is and how it can be measured are customarily seen as questions in the philosophy of mind, while applications to social or policy issues would belong to moral theory. Most scholars in one domain do not specialize in the other. Churchland noted that the philosophy of mind is not typically the domain of neuroethicists, and expressed skepticism about contributions from non-neuroethicist philosophers:

I think that neuroethicists play a critical role in helping neuroscientists define ethical issues within their research program, but if you’re talking about understanding consciousness, what you’re talking about ultimately is discovering a neural mechanism, measuring neural activity, understanding what kind of mechanism neural activity is pointing to. I don’t know that neuroethicists really have the right expertise to do that. The other types of folks that they are hoping to loop in, people in the humanities and philosophers—well, you know, those people have been working on the problem of consciousness for many centuries. I wouldn’t say they’ve made an enormous amount of progress.

While I am more sanguine than Churchland about potential contributions from the philosophy of mind, I would agree with her that expertise in these topics is distinct from expertise in ethics. While successful integration of philosophers in this sort of research project might be a hopeful indicator, it would not in itself represent the integration of neuroethics in neuroscience.

Path-dependence, and a broader vision for neuroethics

Reading the history of bioethics may invite us to wonder how small changes in early structural conditions might have produced a different discipline with a different intellectual outlook. What if the NIH had established direct, centralized oversight of extramural research, rather than the federated model of local IRBs? Then there might not have been the same homes for bioethicists within biomedical institutions to work alongside clinicians and researchers, which in fact gave bioethics its embedded and practical character (with attendant shortcomings as well as strengths).

The present-day structure of neuroethics may have similar, potentially unintended consequences for the intellectual orientation of this field. In the United States, while there are other sources of support for neuroethics research, the preeminent source of funding and support for such work is the NIH BRAIN Initiative. The Initiative has supported defining documents for neuroethics, a Neuroethics Working Group (on which I serve as a member; Ramos et al. 2019) to advise BRAIN neuroscientists and staff, and a variety of new funding opportunities for neuroethics research.

While the NIH BRAIN Initiative has had a vital role, we must also acknowledge that this support also involves constraints, reflecting the strategic position of the BRAIN Initiative itself. NIH BRAIN represents less than 10% of the NIH's total investment in neuroscience (Koroshetz et al 2018), with a highly specific focus. Many Institutes support research on particular disorders and the neurobiological systems that give rise to them—e.g., the National Institute of Mental Health for psychiatric disorders, the National Institute of Neurological Disorders and Stroke for neurology (besides dementia), the National Institute on Aging for dementia, and others. Strategically, the NIH BRAIN Initiative is a time-limited project, across Institutes, that aims to accelerate all of these missions through investments in new neuroscientific tools and understanding the brain at a circuit level, which could be applied to many conditions of interest across the various Institutes.

Just as the NIH BRAIN Initiative supports a subset of neuroscientific projects, the neuroethics component of the BRAIN Initiative is not structured to address all of the ethical questions that arise in neuroscience. For example, R01 funding for neuroethics through the NIH BRAIN initiative is not meant to support any research program in neuroethics, but instead

specifically seeks to support efforts addressing core ethical issues associated with research focused on the human brain and resulting from emerging technologies and advancements supported by the BRAIN Initiative.

Efforts supported under this FOA are intended to be both complementary and integrative with the transformative, breakthrough neuroscience discoveries supported through the BRAIN Initiative. (National Institutes of Health, 2019)

This focus reflects the NIH BRAIN Initiative's overall neuroethics strategy,

which emphasizes proactive, ongoing assessment of the neuroethical implications of the development and application of BRAIN-funded tools and neurotechnologies (Ramos et al. 2019).

That is, the strategy does not encompass all ethical issues in neuroscience, nor even all issues that arise with NIH-funded neuroscience—instead, the focus is on ethical implications of BRAIN-funded tools and neurotechnologies.

Organizationally, it is clear why a neuroethics program of the NIH BRAIN Initiative would focus on ethical issues that arise from BRAIN Initiative research. But we should recall that over 90% of NIH-funded neuroscience research (plus neuroscience funded by other agencies or institutions) is outside this scope. For example, capacity to refuse clinical trials of nutritional support in anorexia nervosa likely would not fall within this mandate of NIH BRAIN neuroethics, while capacity to refuse deep brain stimulation as a treatment for anorexia nervosa likely would. Research on family communication for patients who are brain-dead or in the vegetative state generally would not be considered within scope, while implications of novel neuroimaging techniques for these patients likely would. And most research utilizing non-human primates with established techniques is outside of BRAIN, while research applying novel technologies or examining fundamental aspects of brain circuit organization in non-human primates would likely be within its purview.

While the NIH BRAIN Initiative neuroethics program was never intended to address all the ethical issues arising in neuroscience, as the most prominent source of institutional support for neuroethics it will shape the next cohort of scholars to enter and define the field. This influence recalls ongoing concerns about the ELSI (ethical, legal and social implications) program, which occupies a dedicated 5% of Human Genome Project funding (continuing in the National Human Genome Research Institute) and was cited as a precedent for the equivalent target in the Neuroethics Roadmap. There, some have expressed concerns that funding a relatively narrow set of questions has had distorting effects on the field of bioethics:

funding through genome center programs dwarfs all other programs and has changed the face of bioethics. The immense increase in federal sponsorship is restricted to human genetics alone, spawning a more specialized breed of bioethical analyst.

...although issues in human genetics are broad-ranging, they comprise only a portion of the issues facing modern medicine. Because ELSI is the major source of funding for bioethics studies, there is concern that a brain drain is occurring from nongenetic areas of bioethics to the ethics of human genetics (Hanna, Cook-Deegan, and Nishimi 1993).

Similarly: while new neurotechnologies arising from the BRAIN Initiative pose urgent ethical questions, these are not the only urgent ethical questions in neuroscience. But the availability of institutional support for neuroethics related to BRAIN, in the absence of targeted support related to other domains of neuroscience, can be expected to select for a cohort of neuroethicists that is disproportionately focused on such questions at the exclusion of others.

This narrow focus may hinder efforts to integrate neuroethics in neuroscience. If neuroethicists mainly establish working relationships with researchers performing less than 10% of NIH-funded neuroscience research, they may be viewed as interlopers rather than colleagues when deliberating about topics that affect the other 90%. This is illustrated by the public comment on non-human animal research, which notes that research on non-human primates “is a relatively small part of the BRAIN Initiative, and most of whose practitioners are outside the orbit of BRAIN.” The comment goes on to object that “the document proposes to set frameworks, establish principles, and make rules for a large research community, most of which has no connection to the BRAIN Initiative.”**

Taken together, these objections to the Neuroethics Roadmap indicate that a neuroethics that is integrated with neuroscience will need to extend beyond the BRAIN Initiative.

Organizationally I consider it open whether the NIH BRAIN neuroethics program should expand its own focus, or whether other sources of support for neuroethics (from within NIH or other organizations) must be sought, but the imbalance of support for neuroethics inside and outside of BRAIN-funded neuroscience is likely to have long-term effects that hinder integration. In particular, I suggest two domains for expanding the scope of neuroethics that may facilitate broader and deeper engagement with the neuroscientific community.

First, while the BRAIN Initiative is not principally concerned with specific disorders or neurobiological systems, many important ethical questions arise in the context of specific neurological and psychiatric conditions: e.g., the authenticity of suicidal intent in depression, communication in the locked-in state, prognosis in neonatal stroke, decompressive surgery in malignant hemispheric stroke, or implications of stimulant use in attention deficit-hyperactivity disorder. Most of these questions do not directly implicate the new technologies developed in the BRAIN Initiative, although conceptual and empirical progress in addressing them would likely inform our thinking about such tools. There is a rich tradition of bioethical discourse regarding clinical dilemmas in psychiatry, neurology and neurosurgery, but unfortunately this tradition is not well-reflected in present-day neuroethics (Bernat 2008; Fins 2008; McDonald 2019). A natural next step for integration in neuroethics is to seek ways of closing this gap. As new neuroscientific tools are applied in human research subjects and for clinical and non-clinical human uses, those engaged in clinical care can provide insights on how neurobiological interventions are understood and accepted by non-experts, and can also serve as a bridge between neuroethicists and experimental neuroscientists.

Second, when considering rationales for integration that appeal to neuroscientists’ practical identities as neuroscientists, some essential questions concerning neuroscience and society are active concerns of many neuroscientists but to date have not been framed as “neuroethical.” As a ready example, one of Anne Churchland’s broader contributions to neuroscience has been in addressing gender bias in professional advancement (Churchland 2016; Else 2019). Lack of gender, racial/ethnic and socioeconomic diversity in neuroscience (Society for Neuroscience, 2017) has troubling implications not only for the field, but also for society. Some of the most damaging episodes in the history of neuroscience have resulted

**Public comment to the Neuroethics Roadmap.

from the exclusion of socially marginalized views, as in the targeted use of ablative psychosurgery in women and African-Americans (Freeman 1950, 515; Terrier, Levêque, and Amelot 2017) or the classification of homosexuality as a psychiatric disorder. Neuroscience is often regarded as offering claims about what makes us essentially human or about our valued personal traits, but in a demographically narrow community of scholars such claims may only reinforce socially dominant views about what is normal and about whose abilities or activities are worth preserving.

The issue of diversity in neuroscience is deeply important to Churchland and many other neuroscientists, and engages questions that would benefit from the input of humanists and social scientists—e.g., conceptually, to examine notions of merit or neurological normality, and empirically, to investigate what neuroscientists accept as criteria of scientific quality, or perceptions of neuroscience careers among members of underrepresented groups. Other topics concerning the relationship between neuroscience and society similarly implicate neuroscientists' conception of their professional responsibilities, call out for interdisciplinary inquiry, and yet are not categorized as "neuroethical." One is the "reproducibility crisis" (Button et al. 2013), which may require a thorough examination of incentives and pressures in academic neuroscience. Other broadly relevant topics include the open science movement and the gatekeeping role of traditional science publishing, and the problem of "neurohype" in popular reports of neuroscientific findings.

I would propose that an integrated neuroethics must engage with ethical and social controversies that are direct working concerns of those in neuroscience, including the clinical neurosciences. This includes, but is not limited to concerns about the application of novel neurotechnologies. In many ways, a more inclusive conception of neuroethics would cohere with neuroscience's own self-conception as an interdisciplinary field drawing from such disparate domains as physiology, neurology, psychiatry, cell biology, computer science, psychology, engineering and economics. A more broadly engaged neuroethics would not only be a more useful partner to neuroscientists—particularly to those working with clinical populations and those, like Churchland, with broader interests in the relationship between neuroscience and society. It would also be a richer and more interesting discipline in its own right, with more to say about how public views and social relationships will be altered by continuing neuroscientific advances.

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this content is solely my responsibility and does not necessarily reflect the official views of the National Institutes of Health.

References

- Baker R 2005 A draft model aggregated code of ethics for bioethicists. *American Journal of Bioethics* 5(5):33–41.
- Baker R 2018 Philosophers' invasion of clinical ethics: Historical and personal reflections. *American Journal of Bioethics* 18(6):51–4.
- Beecher HK 1955 The powerful placebo. *Journal of the American Medical Association* 159(17):1602–6. [PubMed: 13271123]
- Beecher HK 1966 Ethics and clinical research. *New England Journal of Medicine* 274(24):1354–60. doi: 10.1056/NEJM196606162742405. [PubMed: 5327352]
- Belkin G 2014 *Death Before Dying: History, Medicine, and Brain Death*. Oxford: Oxford University Press.
- Bernat JL 2008 *Ethical issues in Neurology*. Philadelphia: Lippincott Williams & Wilkins.
- Bosk CL 1999 Professional ethicist available: Logical, secular, friendly. *Daedalus* 128(4):47–68. [PubMed: 11645881]
- Button KS, Ioannidis JPA, Mokrysz C, Nosek BA, Flint J, Robinson ESJ, and Munafò MR. 2013 Power failure: why small sample size undermines the reliability of neuroscience. *Nature Reviews Neuroscience* 14(5):365–76. 10.1038/nrn3475. [PubMed: 23571845]
- Callahan D 1996 Bioethics, our crowd, and ideology. *Hastings Center Report* 26(6):3–4.
- Cho MK, Tobin SL, Greely HT, McCormick J, Boyce A, and Magnus D. 2008 Research ethics consultation: The Stanford experience. *IRB: Ethics & Human Research* 30(6):1–6.
- Churchland A 2016 Anne Churchland. *Neuron*. 92(5):940–2.
- Culliton BJ, and Waterfall WK. 1978 Flowering of American bioethics. *British Medical Journal* 2(6147):1270–1. [PubMed: 709314]
- A Definition of Irreversible Coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. 1968 *Journal of the American Medical Association* 205(6):337–40. doi:10.1001/jama.1968.03140320031009. [PubMed: 5694976]
- De Vries R 2007 Who will guard the guardians of neuroscience? Firing the neuroethical imagination. *EMBO Reports* 8(16):S65–69. [PubMed: 17726448]
- Eckenwiler LA, and Cohn FG, eds. 2007 *The ethics of bioethics: Mapping the moral landscape*. Baltimore: Johns Hopkins University Press.
- Else H 2019 How to banish manels and manferences from scientific meetings. *Nature* 573(7773):184. [PubMed: 31506631]
- Fins JJ 2008 A leg to stand on: Sir William Osler and Wilder Penfield's "neuroethics." *American Journal of Bioethics* 8(1):37–46.
- Fox RC 1990 The evolution of American bioethics: A sociological perspective In *Social science perspectives on medical ethics*, ed. Weisz George, 201–17. Dordrecht: Springer.
- Freedman B 1989 Bringing codes to Newcastle In *Clinical Ethics: Theory and Practice*, ed. Hoffmaster Barry, Fraser Gwen, and Freedman Benjamin, 125–30. Clifton, NJ: Humana Press.
- Freeman W, and Watts JW. 1950 *Psychosurgery in the Treatment of Mental Disorders and Intractable Pain*. Oxford: Blackwell Scientific.
- Funk C, Hefferon M, Kennedy B, and Johnson C. 2019 Trust and mistrust in Americans' views of scientific experts. Pew Research Center, August 2. Available from: <https://www.pewresearch.org/science/2019/08/02/trust-and-mistrust-in-americans-views-of-scientific-experts/>.
- Greely HT, Grady C, Ramos KM, Chiong W, Eberwine J, Farahany NA, et al. 2018 Neuroethics guiding principles for the NIH BRAIN initiative. *The Journal of Neuroscience* 38(50):10586–8. [PubMed: 30541767]
- Hanna KE, Cook-Deegan RM, and Nishimi RY. 1993 Finding a forum for bioethics in U.S. public policy. *Politics and the Life Sciences* 12(2):205–19. [PubMed: 11654723]
- Jonsen AR 1998 *The Birth of Bioethics*. Oxford: Oxford University Press.

- Jonsen AR 2008 Any help from strangers at the bedside? *American Journal of Bioethics* 8(3):19–20.
- Koroshetz W, Cordon J, Adams A, Beckel-Mitchener A, Churchill J, Farber G, Freund M, et al. 2018 The state of the NIH Brain Initiative. *Journal of Neuroscience* 38(29):6427–38. [PubMed: 29921715]
- McCormick JB, Sharp RR, Ottenberg AL, Reider CR, Taylor HA, and Wilfond BS. 2013 The establishment of research ethics consultation services (RECS): an emerging research resource. *Clinical and Translational Science* 6(1):40–4. [PubMed: 23399088]
- McDonald PJ 2019 It is time to expand the scope and reach of neuroethics. *AJOB Neuroscience* 10(3):128–9. [PubMed: 31361202]
- Miller FG 2012 *Situating research ethics: Revisiting Beecher and Jonas In The Ethical Challenges of Clinical Research: Selected Essays*. Oxford: Oxford University Press.
- Naughton J 2019 Are big tech's efforts to show it cares about data ethics another diversion? *The Guardian*, 4 7 [cited 2019 Nov 11]. Available from: <https://www.theguardian.com/commentisfree/2019/apr/07/big-tech-data-ethics-diversion-google-advisory-council>.
- National Institutes of Health. 2019 BRAIN Initiative: Research on the Ethical Implications of Advancements in Neurotechnology and Brain Science (R01 Clinical Trial Optional) (RFA-MH-19-400). [cited 2019 Nov 11] Available from: <https://grants.nih.gov/grants/guide/rfa-files/RFA-mh-19-400.html>.
- Porter KM, Danis M, Taylor HA, Cho MK, Wilfond BS; Clinical Research Ethics Consultation Collaborative Repository Group. 2018 The emergence of clinical research ethics consultation: Insights from a national collaborative. *American Journal of Bioethics* 18(1):39–45. doi: 10.1080/15265161.2017.1401156.
- Presidential Commission for the Study of Bioethical Issues. 2014 *Gray Matters: Integrative Approaches for Neuroscience, Ethics, and Society*. Vol. 1 Washington, DC. Available at: <http://ssrn.com/abstract=2459987>.
- Ramos KM, Grady C, Greely HT, Chiong W, Eberwine J, Farahany NA, Johnson LSM, et al. 2019 The NIH BRAIN Initiative: Integrating neuroethics and neuroscience. *Neuron* 101(3):394–8. doi: 10.1016/j.neuron.2019.01.024. [PubMed: 30731065]
- Rothman DJ 1991 *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. New York: Basic Books.
- Ruddick W 1981 Can doctors and philosophers work together? *Hastings Center Report* 11(2):12–7.
- Schwab A 2016 The ASBH code of ethics and the limits of professional healthcare ethics consultations. *Journal of Medical Ethics* 42(8):504–9. [PubMed: 27169708]
- Slaby J, Choudhury S. 2018 Proposal for a critical neuroscience In *The Palgrave Handbook of Biology and Society*, ed. Meloni Maurizio, Cromby John, Fitzgerald Des, and Lloyd Stephanie, 341–371. London: Palgrave Macmillan.
- Society for Neuroscience. 2017 Report of Neuroscience Departments & Programs Survey Academic Year 2016–2017. [cited 2019 Nov 11] Available from https://www.sfn.org/sitecore/content/Home/SfN/News-and-Calendar/Neuroscience-Quarterly/Spring-2017/~/_link.aspx?_id=91E032D1E1D74141961215F890EE1459&_z=z.
- Tarzian AJ, Wocial LD, and ASBH Clinical Ethics Consultation Affairs Committee. 2015 A code of ethics for health care ethics consultants: Journey to the present and implications for the field. *American Journal of Bioethics* 15(5):38–51.
- Terrier LM, Levêque M, and Amelot A. 2017 Brain surgery: Most lobotomies were done on women. *Nature* 548(7669):523. doi: 10.1038/548523e.
- Senate US Subcommittee on Government Research of the Committee on Government Operations. 1968 Hearings on Senate Joint Resolution 145. Washington, DC: U.S. Government Printing Office.
- Vincent J 2019 The problem with AI ethics. *The Verge*, 4 3 [cited 2019 Nov 11]. Available from: <https://www.theverge.com/2019/4/3/18293410/ai-artificial-intelligence-ethics-boards-charters-problem-big-tech>.
- Weisberg DS, Taylor JCV, and Hopkins EJ. 2015 Deconstructing the seductive allure of neuroscience explanations. *Judgment and Decision Making* 10(5):429–41.
- Wilson D 2014 *The Making of British Bioethics*. Manchester: Manchester University Press.

White BD, Shelton WN, and Riva CJ. 2018 Were the “pioneer” clinical ethics consultants “outsiders”? For them, was “critical distance” that critical? *American Journal of Bioethics* 18(6):34–44.

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