



# Accountability in Research

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## Introduction: Accountability in Neuroethics

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## INTRODUCTION: ACCOUNTABILITY IN NEUROETHICS

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An often-asked question of people interested in neuroethics is how neuroethics differs from genetics. A common answer addresses not only the differences between the two areas of scholarly inquiry, but similarities as well. The latter, areas of overlap, are concerned with issues such as personal privacy, confidentiality, impact on third parties, and prediction. The former emphasize areas that are uniquely at the nexus of *neuro* and *ethics*: the features of ethics inquiry that are intimately related to the special status of the brain as the seat, if not keeper, of personal identity. No foreseeable genetics test will predict, for example, whether a state of minimal consciousness following a brain injury will be transient or persistive. No parallel exists to the ethical challenges that accompany the use of beta blockers that can suppress memories, at once providing the opportunity for relief to patients suffering from post traumatic stress disorders while putting others, such as military personnel, at grave risk by compromising their ability to make reasonable or moral decisions about impending actions based on learned past experiences. There are innumerable challenges of this nature—an exemplary handful of some of the most compelling are tackled in this special issue of the *Journal of Accountability in Research* on neuroethics.

In the first article, Adrian Carter and Wayne Hall discuss the issue of consent in research studies in which drugs of addiction are administered to addicted persons. They review two of the main foci of debate about addiction research—capacity to consent, and the impact on vulnerability to increased drug use. Carter and Hall

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challenge the presupposition that addicted individuals are unable to give free and voluntary informed consent to participation in this kind of research. They consider the participation of treated vs. non-treated participants as well as consent during withdrawal and intoxication and conclude with recommendations for minimizing the impact of addiction on consent and for enhancing autonomy throughout the research process. Their recommendations concern pivotal decisions about what to disclose and when, a theme that continues throughout this journal issue.

This issue of disclosure in neuroscience research is further discussed by Lisa Parker and Michelle Kienholz. These authors focus on disclosure at various stages of research, from features of study design to dissemination of research results. They make the point that, although a decade of deliberations on these issues has not resulted in consensus, researchers should have a plan for managing and disclosing research findings, and that relevant aspects of this plan must be discussed with prospective subjects during the informed consent process. Citing a recent consensus article on incidental findings, the authors endorse the recommendation that plans for disclosure be based upon the classification of incidental findings according to their potential to afford strong, possible, or unlikely net health benefit, and incisively discuss the inherent difficulties of such a recommendation for findings in the brain. They point out that, however this calculation is resolved, the values that ground disclosure practices are those at the foundation of human subjects protections and the ethical justification of research.

These two salient issues, protection of subjects and research ethics, are further elucidated in Stacey Tovino's article in "Incidental findings: A common law approach," and K. Robin Pierce's analysis of the ethical and legal implications of research that uses deception in recruitment in "What a tangled web we weave."

Tovino's article takes a fresh look at incidental findings by examining what case law can tell researchers about liability and responsibility. Through the description of seven cases that involved a range of research activities, Tovino shows that, despite some important court nods to the obligations of researchers, legal liability for disclosure of incidental findings remains unsettled. She concludes that the increasing number of lawsuits regarding

participation in biomedical research is likely to lead to the introduction of novel claims of liability.

Pierce's article examines the use of deception in recruitment to neuroscience research. Using the example of early stage psychosis, she considers both the upstream and downstream implications of this practice. Focusing on two aspects of this research—the stigmatizing nature of the underlying condition and the collection and use of genetic samples—her analysis carefully balances the vulnerabilities of research participants and the preservation of scientific integrity.

In what may seem to be a long leap from one discipline to another, Dave Secko, Kieran O'Dougherty, and Michael Burgess, elucidate parallels and continuities between genetics and neuroethics in their article "Perspectives on engaging the public in the ethics of emerging biotechnologies: From salmon to biobanks to neuroethics." With extensive experience in the area of public engagement and deliberative democracy, in fields as diverse as salmon genomics and insurance risk regarding biobanks, the authors have both data and wisdom to impart on the much younger discipline of neuroethics. Through their work on genomic technologies in Canada, the U.S.A., and Australia under the project "Building a GE3LS Architecture," the authors have brought a wealth of insight to critical issues in biotechnological innovation. Here, they emphasize the need for clearly articulated goals for engaging the public and an inclusive process that fosters respect and common ground. They also highlight how strong interests and a wary public will have an impact on discussions of politically charged issues such as intelligence and aggression.

Timothy Caulfield and Ubaka Ogbogu wrap up the series on accountability in research and neuroethics with their article "Biomedical research and the commercialization agenda: A review of main considerations for neuroscience." Inasmuch as commercialization has been examined in depth for genetics, comparably little analysis exists for neuroscience. The authors highlight the impact of commercialization on the research environment—specifically, issues related to patenting, marketing, and representations of biomedical research. They challenge the claim that patents have an adverse impact on the research environment, noting that this concern is not supported by existing evidence. Caulfield and Ogbogu conclude that neuroethics should build on the work done in other domains such as genetics, and develop objective empirical

methods to assess the impact of commercialization on research output, knowledge flow, and technology diffusion.

This special issue on neuroethics addresses a range of ethical and legal challenges facing advances in translational neuroscience research. The challenges are relevant to individual research participants and to society in general. Even while the themes of this special issue are selected from among many possibilities they demonstrate, without a doubt, that there is no area where accountability, neuroscience, and ethics do not intersect.

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