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Responsible Translation of Psychiatric Genetics and Other Neuroscience Developments: In Need of Empirical Bioethics Research

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In recent years, billions of dollars have been allocated to large-scale neuroscience projects with the goal of advancing our understanding of neural function, developing neurotechnologies and, ultimately, improving neuropsychiatric care and prevention. These projects include the United States' Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, the European Union's Human Brain Project (HBP), the U.S. National Institute of Mental Health's Research Domain Criteria (RDoC) Initiative, and the Psychiatric Genomics Consortium (PGC), among others. Although these initiatives will undoubtedly yield clinical benefits, if we aim to responsibly research and translate the knowledge and technologies they produce, it is essential to empirically examine the potential harms—including opportunity costs—and the ethical or “neuroethics” challenges generated.

These initiatives are already yielding benefits. For example, over the past 8 years, the PGC has identified more than 100 genomic loci that are reliably associated with schizophrenia (Schizophrenia Working Group of the PGC 2014). The PGC achieved this by pooling resources and large samples from studies around the world and using an unbiased array-based genetic testing approach. This recent progress is in stark contrast to the years of struggle psychiatric genetics researchers faced trying to replicate findings obtained through candidate gene approach studies with small samples and little collaboration across research laboratories (Farrell et al., 2015; Need and Goldstein 2014). The success of initiatives like the PGC is evidence of how large-scale neuroscience projects can accelerate our understanding of psychiatric illnesses, which are known to be multifactorial and highly complex from a biological standpoint. Findings such as the identification of genomic loci associated with schizophrenia can lead to better risk prediction, resource allocation, prevention, drug targets, diagnosis, and treatment selection.

The potential clinical benefits of these initiatives for individuals at risk or suffering from mental illness are immense. Particularly since—unlike other fields of medicine—current understanding and use of an individual's biological information in psychiatric care is minimal. Despite potential clinical benefits, these initiatives generate profound ethical challenges that need to be addressed. Their subject of study is the brain, and as many have argued: “when you start tinkering with the brain...it's really tinkering with who you are.” (PCSBI, 11). Developing knowledge and technologies that may lead to more effective ways of modifying emotions, memories, thoughts, and behavioral outputs, generates ethical concerns, in great part, because these features are closely associated with an individual's identity and capacity to act freely.

Once we acknowledge the importance of examining the ethical challenges raised by initiatives aimed at understanding and improving our capacity to modulate the brain and behavior, we need to consider how to identify, examine, and address the neuroethics challenges generated. In their article, Kong and colleagues (2017) try to set “an ethics agenda for psychiatric genetics as it relates to” the clinical and public health contexts. (Kong et al. 2017, 2) They identify important ethical questions related to these initiatives, for example: how should scarce mental health research resources be allocated between psychiatric genetics and psychosocial research; what impact will developments in psychiatric genetics have on the way patients, clinicians, and society understand and respond to mental health disorders; and whether psychiatric genetics should be translated using a public health genetics approach. Although Kong and colleagues do argue for more ethics research to examine the potential impact of translating psychiatric genetics research on individuals with mental illness, their ethical agenda for psychiatric genetics is based on theoretical analyses of what they believe are some of the key issues that need to be addressed. (Kong et al., 2017, 12)

Conceptual and theoretical work related to the ethics of emerging biomedical knowledge and technologies plays a key role in helping identify potential ethical problems and clarify concepts. However, as bioethicists, if we want to effectively question the investment in or maximize the net benefits of certain neuroscience research, we need to go beyond theoretical analyses. Neuroethics literature is full of theoretical analyses about potential ethical challenges, but very little empirical work about whether these concerns are actually a problem for stakeholders, if so, how are they manifested, and what novel policies can help manage these ethical challenges.

For instance, since deep brain stimulation (DBS) trials for treating motor disorders such as Parkinson’s disease and other neuropsychiatric disorders began almost 25 years ago, there have been hundreds of theoretical papers about numerous possible ethical challenges (e.g., dehumanization, loss of autonomy, changes to personal identity, authenticity of affective states, how to obtain meaningful informed consent, therapeutic misconception, human enhancement). However, in 25 years of work on DBS there is a surprisingly small amount of empirical literature about the perspectives and experiences of stakeholders (e.g., patient-participants, caregivers, clinical trial or treatment decliners, clinicians, researchers) regarding these neuroethics issues and whether and how these issues are manifested. Similarly, in the psychiatric genomics arena, except for the helpful research of some investigators on mental health clinicians’ attitudes and use of genetic testing (Finn et al. 2005; DeLisi et al. 2006; Hoop et al. 2008; Lawrence and Appelbaum 2011; Klitzman et al. 2014) there is also an exceptionally small body of empirical neuroethics research. This empirical work is necessary to set a well-informed neuroethics agenda, understand how neuroethics challenges manifest, and generate management plans that can help maximize the benefits and minimize potential clinical and social harms.

As psychiatric genetics and other neuroscience research moves forward, there are at least four actions that bioethicists can take to develop well-informed ethical agendas and management plans for ethical issues generated by emerging neuroscience knowledge and technologies. The first is to collaborate closely with neuroscience researchers. The second is

to empirically examine stakeholders' perspectives and the actual manifestation of neuroethics issues. The third is to closely examine whether current policy adequately addresses the neuroethics issues. Lastly, involve stakeholders in the process of generating recommendations to optimize the utility of neuroscience research and technologies.

CLOSE COLLABORATION WITH RESEARCHERS

It is important for bioethicists to work closely with psychiatric genetics researchers for various reasons. To generate well-informed bioethics analysis, it is necessary to understand the capacity and limitations of the technology, the goals of those developing the technology or applying it in novel contexts, and the challenges faced when developing and translating the technology. These issues impact ethical analysis and the implications of the technology for patients and society. Collaborating with psychiatric genetics researchers provides an opportunity to get closer to the action and develop a deeper understanding of these issues, many of which are not written about in scientific literature. Furthermore, psychiatric geneticists will face numerous unexpected scientific and ethical challenges that will be more quickly identified and addressed, or hopefully prevented, by working together with bioethicists.

EMPIRICALLY EXAMINE NEUROETHICS ISSUES

Theoretical bioethics analysis can help identify potential ethical challenges. However, to set a well-informed ethical agenda and effectively promote responsible research and translation we need to empirically examine whether these ethical issues are actually a problem, and, if so, how are these manifested. Furthermore, there may be critical, but unexpected ethical issues that are uncovered only when individuals are exposed to these technologies. Therefore, it is necessary to collect data to understand the experiences and perspectives of stakeholders regarding ethical issues. These data help accurately define the ethical challenges generated by emerging technologies. This is the first step to be able to evaluate if current policy adequately addresses these problems and, if that is not the case, then, what needs to be done to address these challenges.

EVALUATE HOW CURRENT POLICY ADDRESSES NEUROETHICS ISSUES

Empirical and theoretical bioethics analysis is key to identify and define ethical challenges. But, to effectively address these challenges, it is essential to understand the policy context in which these technologies are developed and translated. Critical evaluation of policy (e.g., laws, regulations, research and clinical practice norms and guidelines) relevant to the development and translation of these technologies is essential to understand what kind of protections are available to promote ethical research and translation, and where current policy fails to provide adequate protection. If there are certain areas in which current policy provides appropriate protection, it is important to educate stakeholders about these protections. When current policy fails to provide adequate protection, then, it is necessary to develop a management plan to help address these ethical challenges.

INVOLVE STAKEHOLDERS WHEN GENERATING MANAGEMENT PLANS

Finally, when generating a plan to manage the ethical challenges that are not properly addressed by current policy, it is important to not just rely on bioethicists' perspectives, but to integrate the perspective of multiple stakeholders. This can be achieved by not only collecting data from stakeholders but also making them part of the process of generating the management plans. Integrating multiple stakeholders in this process helps provide a more accurate representation of the interests affected by these technologies and the risks, benefits, and feasibility of recommendations.

At the end of the day, as bioethicists, our goal should not be to simply raise questions, but set well-informed ethical agendas and search for answers to effectively address ethical challenges. These four actions can help us achieve that.

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