

Rethinking ethics and compliance in interdisciplinary and big data-driven neuroscience projects

Title page

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From Ethics to Compliance and Back: Rethinking ethics in interdisciplinary and big data-driven neuroscience projects

Standfirst

The focus of much of contemporary research ethics is on compliance with established protocols. However, large data-driven neuroscience research raises ethical concerns that are novel, emerging, and have no agreed-upon solution. We therefore argue for the re-introduction of philosophical ethical reflection into the core scientific activities of neuroscience research.

Introduction

Research ethics as applied ethics has a focus on the protection of research subjects, the minimization of risks and the compliance with rules and regulations. In this comment we argue for an enlargement of research ethics to address issues of philosophical ethics more broadly. This broader scope is particularly warranted in interdisciplinary neuroscience research driven by big data. Such work raises novel ethics-related questions which established research ethics processes struggle to address. We argue that it is important to integrate those ethical issues into the scientific research itself. Doing so will simultaneously enrich the scientific research and lead to a better understanding of ethical concerns.

From Philosophical Ethics to Research Ethics Compliance

Philosophical ethics as a discipline focuses on the reflection of good and bad, right and wrong and has a long and venerable history. Many theories have developed positions that help us to understand and justify moral positions and judgments. Typically, ethical reflection is triggered by difficult cases and dilemmas for which there is no consensus on what counts as the right thing to do. However, there are cases where right and wrong are rather easy to distinguish such as the Nazi atrocities in research triggering the development of the Nuremberg Code¹. The subsequent creation of the field of research ethics through the Helsinki Declaration and the Belmont Report aims directly at reducing risks and preventing the abuse of human subjects. Research ethics, in contrast to philosophical ethics, is characterised by a clear understanding of ethical issues, established processes and mechanisms to address them and a focus on compliance within these processes.

The use of the term 'ethics' in scientific research tends to refer to research ethics. In biomedicine, ethics is typically perceived as a well-understood problem that can be resolved in a straightforward manner. Researchers normally believe that they know which ethical issues their work will raise. There are well-established ethics review procedures that help researchers to identify and resolve such issues. Ethics approvals usually clearly state which ethics processes researchers must comply with in order to be allowed to undertake the research.

This understanding of ethics as research ethics, while somewhat contested², is deeply entrenched in the biomedical sciences and increasingly accepted across other scientific and technical disciplines³.

However, as research ethics has become dominant in the sciences, its limitations are becoming more visible, leading to our call for increased attention to philosophical ethics.

Why Philosophical Ethics Cannot be Ignored

The standard approach of research ethics and compliance runs into problems where ethical questions are not well understood or where no unambiguous remedies are known. This is often the case where research aims to address grand challenges ⁴ or deal with ‘wicked problems’ ⁵ which have no simple solution. Highly interdisciplinary large-scale and data-intensive neuroscientific research offer good examples of the problem. Such research typically brings together neuroscientists, psychologists, psychiatrists, biologists, and scientists from other disciplines and creates large amounts of data which calls for appropriate analysis methods.

Research of this sort tends to be heavily engaged in traditional biomedical research ethics focusing on data protection, data security and legal issues. However, in addition, it also raises questions of philosophical ethics which are open and do not offer clear solutions. Scientific progress will create new ethical questions and it may also render existing ones in a different light.

One example is the anonymity of brain images. It has long been considered sufficient to remove personal information and facial features from brain scans to anonymise the scans and thus allow them to be freely shared. However, recent research shows that it is possible to identify even a defaced brain scan which then turns it legally into personal data raising ethical concerns ⁶. There may be solution to this, but at present it is an area where scientists cannot rely on existing guidance.

Privacy and data protection are generally accepted and legally protected values. However, big data research can raise broader questions of data ethics and data governance ⁷. Proposed solutions, for example the European Data Spaces⁸, are still at an early stage and do not offer clear guidance. Similarly, novel analysis methods, such as federated data analysis, are still in their infancy.

An important philosophical ethics question in research is how to deal with possible trade-offs between ethical principles. One important example is openness. Openness is increasingly seen as a cornerstone of good science, as it promises transparency and reproducibility, as well as fairness with regards to research findings as expressed by the FAIR initiative ⁹. Such openness, however, often conflicts with other ethical principles, such as data protection and can raise questions of unintended use of findings, including dual use issues ¹⁰. Dealing with these trade-offs or dilemmas, typical for philosophical ethics, may require the integration of ethical questions into the scientific research itself.

Deep-seated ethical dilemmas are not confined to data and data governance. Another example is the use of artificial intelligence (AI) which rapidly pervades many scientific disciplines. The ethics of AI ¹¹ highlights various concerns, some of which are relevant to research. An important one is the danger of perpetuating bias hidden in AI models. More broadly, the influence that AI-based tools can have on the interpretation of data and thus on findings and implications of research are active subjects of debate.

Beyond AI, ethical questions are often linked to epistemology. Which phenomena can be observed, which data is relevant and valid, and which conclusions are justified? In mental health research this touches the perennial question of the relationship between brain, mind, and body ¹². Being diagnosed with a mental disorder can result in the attribution of “sticky” labels to individuals with potential negative social consequences like stigmatisation.

This leads to large-scale ethical questions that high-profile research investments can encounter. These include the fundamental question of justification of research expenditure which creates opportunity

costs. Resources spent on research cannot be used for other purposes, including the alleviation of underlying causes of ill mental health.

These examples are intended to support our main argument that ethical problems and dilemmas are not external to the research, but form part of its motivation, its practice, and its outcomes. We therefore argue that it would be beneficial to embrace them and explicitly integrate philosophical ethical inquiry into the scientific research itself.

What's next? How to include Philosophical Ethics into Research

Obviously, the format of a comment only allows to provide some brief pointers for next steps. In the first instance, the situation calls for a culture change. Neuroscientists and others working in complex interdisciplinary scientific research need to recognise that complying with research ethics does not replace the need for broader ethical reflection. Thankfully, many young people in science show an awareness of and interest in ethical questions. This should be fostered through education and training, but also through recognition in scientific career paths, e.g. by modifying evaluation criteria for promotion or tenure decisions.

Another key avenue is to broaden the debate by integrating additional stakeholders through participatory research, also known as public and patient involvement (PPI). The involvement of patients¹³ or more generally, experts by experience¹⁴ is crucial and increasingly important, although still rare. Engagement with further stakeholders, like citizens in general, service users or policymakers can inform ethical reflection.

This type of engagement requires a willingness to transcend disciplinary boundaries and translate scientific knowledge in accessible ways. This often requires scientists to leave their comfort zone, which can be challenging. Incentives can include financial support for the time spent on such work by all who contribute to it. Project structures can foster engagement, such as setting up boards comprising relevant stakeholders, defining deliverables on the topic, or the integration of reporting requirements.

The cultural shift we are suggesting will encourage greater reflexivity in neuroscientific research which will foster engagement with broader philosophical ethical questions. To succeed, this change will have to be supported by the scientific system overall and be implemented by research policy, funding and research organisations. It will need to draw on existing institutions, notably existing research ethics structures which will not become redundant but will likely extend their remit. The shift can draw on existing work in the philosophy of science as well as the discourse on responsible innovation¹⁵. Crucially, however, it requires wide-spread agreement based on the main argument of this article that the limitations of current research ethics need to be overcome.

Conclusion

In this article we argue that the current focus on research ethics might be too narrow for scientific research, using the example of interdisciplinary and big data-driven neuroscience projects. Research ethics as it stands is a well-established part of the research landscape fulfilling important tasks in risk management and the protection of research subjects. However, we argue the separation of philosophical ethics from research should be abandoned.

Research, both in terms of increase of knowledge and eventual practical outcomes is by its nature an ethically charged activity. There is no morally neutral research. We are proposing to re-integrate aspects of philosophical ethics into the scientific research itself. This can range from the macro

questions of justification of funding regimes to micro questions of conceptual definitions and ethical implications of methodology choices.

Unlike many scientific research questions, philosophical ethical questions often do not have clear-cut answers that can be based on empirical evidence and established procedure. Ethics can therefore be an uncomfortable companion of science. However, our experience with contemporary big-data research in neuroscience suggests that the re-integration of ethical with scientific questions can benefit both domains. Science holds the promise to improve the human condition. Realising this ethical premise calls not just for excellent science, but for explicit attention to the often-hidden ethical assumptions and implications that come with all scientific research.

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