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# Responsible research and innovation: A manifesto for empirical ethics?

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**Abstract**

In 2013 the Nuffield Council on Bioethics launched their report *Novel Neurotechnologies: Intervening in the Brain*. The report, which adopts the European Commission's notion of Responsible Research and Innovation, puts forward a set of priorities to guide ethical research into, and the development of, new therapeutic neurotechnologies. In this paper, we critically engage with these priorities. We argue that the Nuffield Council's priorities, and the Responsible Research and Innovation initiative as a whole, are laudable and should guide research and innovation in all areas of healthcare. However, we argue that operationalising Responsible Research and Innovation requires an in-depth understanding of the research and clinical contexts. Providing such an understanding is an important task for empirical ethics. Drawing on examples from sociology, science and technology studies, and related disciplines, we propose four avenues of social science research which can provide such an understanding. We suggest that these avenues can provide a manifesto for empirical ethics.

**Keywords**

Social control of science and technology, biomedical research, clinical ethics

## Introduction

In 2013 the Nuffield Council on Bioethics released its report *Novel Neurotechnologies: Intervening in the Brain*. The aim of the report is to identify and consider the ethical, legal and social issues that arise from the use of novel neurotechnologies, and in so doing, to make recommendations that could be used to inform research, policy, governance and public engagement in the area. The report develops an ethical framework for research and clinical practice involving novel neurotechnologies, and it appeals to the European Commission's notion of Responsible Research and Innovation (RRI) as a way of implementing the framework. In this paper, we will critically engage with the notion of RRI and the Nuffield Council's rendition of RRI in particular. We do this with the intention of identifying how empirical ethics can contribute to RRI; indeed, we believe that the contribution of empirical ethics is essential to ensuring that the aims of RRI are realised in practice. The RRI initiative, we argue, has opened up a space for empirical ethics and can provide the enterprise with an important purpose. Drawing on a range of empirical ethics studies from medical sociology, science and technology studies, and related disciplines, we propose four avenues of research and illustrate how each avenue of research is essential to ensuring that RRI can actually be achieved.

## The RRI initiative

The notion of RRI has its genesis in a European Commission Science in Society workshop held in Brussels, May 2011. The aim of the workshop, which involved experts from academia and policy, was to formulate a broad understanding of RRI that could be used to inform specific policy recommendations to be implemented throughout the EU. The launch of the initiative reflected a feeling among policy makers and academics that extant policy would be insufficient for managing ethically problematic areas of science and innovation such as synthetic biology and genetically modified organisms.[1]

The key premises of the initiative are that science is the basis for a better future; that the benefits of science

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can be maximised (and the harmful impacts minimised) only if it is carefully directed towards certain societal needs in accordance with societal values, and that as many stakeholders as possible should be involved in anticipating and identifying societal needs and social values. As one of their publications states[2]: 'Responsible Research and Innovation means that societal actors work together during the whole research and innovation process in order to better align both the process and its outcomes, with the values, needs and expectations of European society'.

The initiative, then, seeks to bridge a perceived gap between the scientific community and citizens, and to make science more ethical and useful by doing so. It aligns with the European Commission's goals to foster an inclusive, knowledge-based society with a strong economy, and in the process it draws upon prevalent discourses that herald 'public engagement', 'interdisciplinarity' and 'innovation' as the foundations for robust social and economic development.

Proponents argue that implementing the initiative requires careful assessment of specific innovations and foresight of their likely effects. Such foresight must anticipate the social impact of the specific innovation – how it will impact consumers and communities. This knowledge, it is argued, will inform strategies that can help innovations to become better embedded in society and ensure 'that their positive and negative impacts are better governed and exploited at a much earlier stage'.[3] The reluctant uptake of several recent innovations, such as the airport security body scanners in many parts of Europe, and the energy-usage 'smart-meters' in the Netherlands, are attributed to a lack of such knowledge.

This emphasis on 'social impact' and 'innovation foresight' has opened up a space for empirical ethics within the initiative. It suggests that an empirically derived understanding of the social world (or of 'consumers' and 'communities') is an important component of moral research and innovation practices. As Von Schomberg states, empirical knowledge is necessary for ensuring that technological development aligns with accepted ethical principles (such as those found in the EU charter on fundamental human rights) and that the resulting technologies will not conflict with the values of communities.[3] Here, then, RRI entails describing the cultural and institutional aspects of the innovation processes, and describing and analysing the moral opinions of those who are likely to be affected by innovations. Social scientists who can produce empirically derived knowledge are thus rendered as necessary elements of RRI, although like many elements of the RRI initiative at this point in time, the specific mode of social science involvement is yet to be clearly delineated.

The Nuffield Council on Bioethics' 2013 report *Novel Neurotechnologies: Intervening in the Brain*, however, is an example of a more clearly articulated RRI recommendation.[4] Overall the report is in the same vein as the European Commission's initiative to encourage useful and ethical science and innovation. It begins with the premise that the current prevalence of neurological and psychiatric illnesses that cause a great deal of suffering constitutes a 'great need' for new, innovative therapeutic interventions. Parkinson's, Alzheimer's disease, stroke and obsessive compulsive disorder are given as examples of conditions where new interventions are desperately needed, either because treatments do not currently exist, or if they do, they fail to adequately manage the illness in a significant proportion of people. The report (henceforth NCoB) also points out that the development of new treatments is likely to be plagued by ethical and social challenges, due in large part to the privileged nature of the brain: it is 'uniquely associated with "me", with our subjective self-conception and capacity to develop and exercise this conception through our actions'.[4] Additionally, despite a recent flourishing of research in the neurosciences, many aspects of brain functioning remain unknown. For these reasons, the report states, 'great uncertainty' surrounds the developments of new therapies for neurological and psychiatric illnesses.

The purpose of the NCoB report is to put forward a framework of principles that can help clinicians, scientists and policy makers to navigate this great uncertainty while addressing the need for new interventions. The report has adopted the notion of RRI and has delineated six specific priorities of RRI to make the initiative more concrete. These priorities, it is stated, will be of 'practical use both to those conducting and funding research and to those involved in governing the field by guiding the discharge of their responsibilities'.[4] In the following, we will critically engage with several key RRI priorities of the report. We are supportive of each priority, and we believe the priorities can serve as a framework for RRI in all areas of healthcare, not just neurotechnologies. But as we will argue below, there are specific challenges with each one. Drawing on previous work conducted within social sciences, we will then propose four avenues of empirical research which we believe are essential to ensuring that the Nuffield Council's priorities, and the RRI initiative as a whole, are realised in practice.

## Clearly identified need

The first priority of the NCoB RRI initiative is a therapeutic priority to alleviate suffering. Research and innovation activities should be directed towards the alleviation of suffering of those living with illness, although

the report points out that this does not mean that foundational research, for which the clinical impact cannot always be clearly defined, should be excluded. Innovation, then, is a virtuous activity if it is directed towards the alleviation of suffering, as this ensures that it is fulfilling the needs of society. The report contrasts this 'virtuous innovation' with innovation that produces imitative technologies, distinguished from already existing technologies by superfluous modifications, which largely serve manufacturer's commercial interests rather than those of patients.

There can be little doubt that 'clearly defined need' serves as a good basis for RRI. The need to justify innovation activities in terms of patient need, rather than manufacturers' commercial interests, is demonstrated by the recent profusion of artificial hip models, many of which provide little or no therapeutic benefit over previous models. As Faulkner states, the healthcare policy community has long felt that the design, adoption and diffusion of new artificial hip models has been out of control.[5] Yet delineating 'clearly defined need' in terms of the alleviation of suffering can be problematic. While in most cases human suffering and the need for an intervention are obvious – such as the suffering experienced by people with severe, late-stage Parkinson's – we should be wary of using 'suffering' as a justification in its own right. This can be illustrated with ethically dubious research activities carried out in the past. An example of such activity is Moan and Heath's attempts to produce a 'treatment' for homosexuality at Tulane University in the early 1970s.[6] Moan and Heath inserted electrodes into the 'pleasure centre' region of the brain of their participant, which was then stimulated while the participant performed various heterosexual activities. Moan and Heath's justification for the research was that the patient experienced suicidal ideation, paranoid ideation 'highlighted by a marked fear of the future' and that he felt 'sealed off and alienated from society in general'.[6] The participant was certainly suffering, but few commentators would agree that this justifies Moan and Heath's project. In such cases an individual's suffering is not the consequence of an illness, it arises from an inability to align themselves with prevalent social norms. The distinction here is important.

## Generating robust evidence

This priority states that the innovation of neurotechnologies must involve the generation of robust evidence, and that it should proceed on the basis of best available evidence. Those individuals and agencies involved in innovation, then, must both continually draw upon the available evidence pool as well as actively contributing to it. This will enable the continual appraisal of an innovation's efficacy and safety and ensure that it is directed towards clearly defined therapeutic need. In many areas of clinical research, such evidence is often generated via large, randomised clinical controlled trials, but as the report states, the development of neurotechnologies often proceeds as small-scale studies and investigative treatments, due to their invasive nature and high cost. The report adds that this can be a hindrance to the generation of robust evidence as dispersed, small-scale studies may not produce the consolidated body of data required to produce meaningful evidence.

Another complication with the 'generation of robust evidence', however, is defining what counts as 'evidence' in the first place. There are various ways in which the severity of an illness (and thus the effect of an intervention on that illness) can be measured. This is demonstrated by the range of outcome measures and clinical assessment tools used by clinicians and researchers: some quantify specific biomedical criteria or events (such as frequency or duration of seizure), while others, such as Quality of Life measures, attempt to quantify a patient's experience of illness. It is essential that one of the tools used by clinicians during the innovation process captures clinical improvements that patients and their families find meaningful. If the wrong tool is used, the resulting data will not adequately capture the impact of the technology and its ability to address therapeutic need. Indeed, clinical teams working with innovative neurotechnology-based therapies have noted that the standard, commonly used clinical assessment tools in their area do not necessarily capture meaningful clinical improvements.[7] RRI, then, requires the generation of robust evidence, which depends upon the ability of clinicians and researchers to measure clinical improvements that patients themselves find meaningful.

## Continuous reflexive evaluation

The NCoB report points out that innovation processes seldom follow a linear pathway. As basic science is translated into new therapies, and as novel techniques and therapies undergo incremental improvement, new applications may become apparent. Or alternatively, an innovation may become trapped at an unforeseen hindrance and its anticipated benefits become much less likely to materialise. The report argues, then, that it is vital that those individuals and agencies involved in innovation processes step back from their narrow focus on a particular application and cast a broad, critical eye over the current status of the technology, so that they can continually appraise its ability to address therapeutic need, and so that they can identify other 'spin-off' applications.

The report acknowledges that commercial interests can hinder the capacity of individuals and agencies to

provide such a critical appraisal. But as a body of work in the 'sociology of expectations' literature has made clear, hindrances to critical appraisal and evaluation are deeply embedded in the institutional arrangements that constitute innovation networks.[8] Scientists, clinicians, research institutions, press officers and the media become involved and perpetuate cycles of hype. Such hype is not a by-product of innovation. Rather, it is part of the innovation process itself: narratives of 'breakthrough' and 'discovery', which inevitably downplay the limitations of research findings, are used by those involved in innovation to secure attention, resources and prestige, and thus form the alliances that are necessary for an innovation to proceed. Indeed, such alliance forming is increasingly inscribed in the professional role of scientists and research clinicians. It may, therefore, be difficult for those agents involved in innovation to 'step-back' and critically assess the likely future for their innovation.

## Coordinated interdisciplinary action

Another key priority of RRI, according to the NCoB report, is coordinated interdisciplinary action. The report argues that innovation processes should involve a diversity of actors. The multiple perspectives provided by such diversity enable a more coherent, comprehensive appraisal of an innovation; it enables greater reflexivity, and it ensures that the actual capacities and likely effects (both positive and negative) can be more clearly delineated and assessed in terms of therapeutic need. Here, intra-disciplinary work is equated with fragmentation and myopia.

The report, then, argues that interdisciplinarity is a key component of RRI, but it provides no detail on what disciplines should be involved or how we might go about deciding what particular disciplines are involved; nor does it identify what specific aspects of research and innovation might best be managed by interdisciplinary teams.

Overcoming the challenge we have highlighted here requires an empirically derived understanding of the innovation area. It requires a thorough understanding of the numerous agents involved in research and innovation, the nature of the interactions between these agents, and it requires anticipating the cultural impact of an innovation – the way in which an innovation will shape understandings of health, illness, agency and personhood. It requires, in other words, empirical research that will enable the priorities to become context sensitive.

## Four avenues of empirical ethics research

In the following section, we outline four specific avenues of empirical social science research. We argue that together these avenues of research can generate the knowledge required to ensure that the priorities identified by the NCoB, and the RRI initiative more generally, can be implemented. Each avenue of research will be illustrated with specific examples from sociology, science and technology studies, and related disciplines. As we will see, each involves producing detailed descriptions of specific social contexts. We anticipate that these descriptions could then be used to inform the formulation of normative measures aimed at ensuring research and innovation activities align with the priorities of RRI. However, unlike much of the work that has been conducted under the banner of 'empirical ethics', this does not necessarily involve the explicit examination of pre-identified ethical issues; nor does it necessarily involve examining how clinicians and researchers themselves understand and enact 'ethics'. Nevertheless, we will argue in the subsequent section that this work constitutes empirical ethics, albeit according to a very broad conception of the enterprise.

### *Avenue one: Tracing innovation ecosystems*

As science and technology studies theorists have illustrated, innovations emerge from the interactions involving numerous agents. The success of an innovation depends upon its ability to appeal to, and be co-opted by these agents, who can include clinicians and scientists of various specialisms, engineers, manufacturers and commercial companies, regulatory agencies, and users and patient support groups.[9] Together these agents constitute what could be called an innovation ecosystem. The notion of an 'ecosystem' draws attention to the embedded nature of an innovation: it both shapes, and is shaped by, a network of relations involving assortment of interconnected heterogeneous elements. Within these systems, then, an innovation does not follow a linear trajectory.

A thorough understanding of innovation ecosystems is essential for continuous reflexive evaluation (an NCoB priority) of an innovation. Ideally, by tracing the formulation of such systems and the relations between the elements that constitute them, it becomes possible to predict particular patterns of innovation. Patterns of innovation can be induced by powerful agents within innovation ecosystems – agents such as regulatory agencies or large companies which constitute what Faulkner has called innovation 'structuring forces'.[5] An example of an innovation pattern is the degree of homogeneity between cardiac pacemakers and neurostimulators used in deep brain stimulation techniques.[10] The homogeneity is a result of commercial strategy: in the past manufacturers have been able to save production costs by using many elements of the same manufacturing platform to produce both

technologies. An awareness of such patterns (which may differ greatly between different sectors) will enable the formulation of predictions about whether or not a technology may be leading to an inevitable 'dead-end' and is thus no longer worth pursuing, or whether policy changes are necessary to keep an innovation alive. A current example of 'innovation ecosystem tracing' is the ESRC (Economic and Social Research Council) funded 'REGenableMED' programme in the Science and Technology Studies Unit at the University of York, exploring the development and implementation of regenerative medicine. The programme aims to map the various agents involved in regenerative medicine, with the intention of identifying the social and organisation challenges to generating useful therapies.

### *Avenue two: Mapping the renegotiation of boundaries*

As a great deal of social science work has made clear, the development and dissemination of innovations is a transformative process.[11,12] As innovations undergo incremental modification and adjustment, so do many of the agents working with them: new alliances between agents form; professional boundaries between groups may become permeable; and new social groups emerge which, in the process of delineating themselves, can lead to the establishment of new boundaries and divisions. This transformational aspect of research and innovation is particularly noticeable in the field of regenerative medicine.[13] New alliances have been established involving cell biologists and clinicians, and new interdisciplinary research networks have been established at national and international levels. If we are to facilitate RRI then it is necessary to understand the processes by which such alliances form and the nature of hindrances that can prevent such alliances.

Indeed, such knowledge is particularly important if we are to encourage coordinated interdisciplinary action, stipulated as a priority by the NCoB. It is necessary to have a detailed knowledge of the boundaries which prevent interdisciplinary work (these may be financial, professional, structural), and the tools and technologies which enable and facilitate such work. This requires careful empirical research, particularly ethnographic research in contexts where individuals from different professional backgrounds are working or attempting to work together. Examples of such research can already be found in the social science literature. Coombs and Ersser conducted ethnographic research of interdisciplinary intensive care units, including observations of decision-making interactions and in-depth interviews with members of an interdisciplinary team.[14] They identified a barrier to interdisciplinary care and decision making: the traditional authority of doctors over nurses. Doctors and their biomedical-based understandings of patients tended to be foregrounded during decision making, while nurses, and their detailed knowledge of patients' families and the patient 'as a person' tended to be ignored or devalued. Similarly, Centallas and colleagues carried out ethnographic research with an interdisciplinary team working within a translational cancer research institution.[15] Centallas and colleagues, however, drew attention to enablers of coordinated interdisciplinary action. These were 'participation customs' which were learned and shared by members of the team and which permitted interdisciplinary decision making while enabling each team member to remain firmly entrenched within their own discipline. The team as a whole was able to establish and function as an effective unit without blurring traditional disciplinary boundaries. Research such as this can help inform the production of practical guidelines that encourage and facilitate coordinated, effective interdisciplinary action.

### *Avenue three: Exploring experiences of illness and new biosocial forms*

Understanding the experiences of those with illnesses can help clearly identify the need for new healthcare technologies. It is necessary to examine how individuals make sense of their illness, how this illness is shaped by cultural and social factors, and how it impacts on their day-to-day activities and sense of well-being. Semi-structured interviews would be an appropriate means of exploring these issues with patients, such as Fox and Ward's recommended interview strategy for exploring health identities.[16] Here, in-depth interviews are used to encourage participants to provide context to their world and descriptions of their day-to-day life, and they are then encouraged to reflect on the meaning of these experiences. The knowledge produced by methods such as this can help inform if there is indeed a genuine need for a technological or pharmacological intervention, or whether some other form of intervention may be more suitable to help individual sufferers. This knowledge could also inform the selection of appropriate clinical assessment tools for quantifying the effectiveness of new interventions. It would enable innovators to select clinical assessment tools (such as impairment measures, disability measures and Quality of Life measures) that capture clinical improvements that patient's themselves feel are meaningful.

Importantly, however, methods that provide us with a glimpse of peoples' experiences of illness also enable us to explore biosociality. Biosociality refers the way in which individuals and social groups draw upon biomedical knowledge to make sense of themselves or to advance particular political and social aims.[17]

Healthcare innovations can encourage new forms of biosociality, often encouraging reductive, biomedically based understandings of personhood and illness. This has been illustrated by empirical work looking at the impact of new neurotechnologies and the rise of neuroscience.[18] As Rapp has argued, one impact is that, 'psychodynamic explanations of human variation and suffering' are being eclipsed by 'brain-orientated, hyper-materialist explanations'.[19] Identifying new biosocial forms is a fundamental component of evaluating the potential consequences of a new innovation.

### *Avenue four: Problematizing promissory visions*

As mentioned earlier, individuals directly involved in research and innovation processes are not necessarily in a position to provide a careful evaluation of an innovation: they may be too embedded in the institutional arrangements that are responsible for generating optimistic portrayals of innovations. Social scientists, in contrast, are well suited to providing a more critical perspective; a perspective that is absolutely necessary for continuous reflexive evaluation. For example, a burgeoning body of work within social science has drawn attention to some of the specific institutional pressures that generate over-optimistic portrayals of the impact of innovations.[20] Rödder has noted that increased competition for research funding has meant that scientists and institutions are forced to market themselves to the public and 'key stakeholders'.[21] This has brought about the expansion and professionalisation of science press officers,[22,23] whose role demands that science and research findings are presented in a manner that will attract the attention of journalists. This has resulted in an increase in sensationalist news reporting.[24]

Such work problematizes the promissory visions associated with healthcare innovations, thus opening up a space for a more genuine critical evaluation. Another important role for social scientists is to produce counter-visions of an innovation. Such counter-visions need not necessarily be overcritical of an evaluation, but they can help provide a more realistic interpretation of the future of an innovation and its consequences. In order to do this, they need to draw upon a detailed knowledge of the innovation ecosystem and the way in which the innovation may be implicated in the production of new biosocial forms.

## Discussion: Empirical ethics and RRI

We believe that the RRI initiative, particularly the priorities listed by the NCoB report, should provide an ethical framework for managing research and innovation in all areas of healthcare. Furthermore, we believe that ensuring that the RRI initiative and the NCoB priorities are context sensitive and thus applicable in real life is an important task for empirical ethics. This task would incorporate the four avenues of research that we have identified earlier. Together these avenues of research would produce a pool of knowledge which would help ensure that innovation processes better align with the values and needs of society, and which would enable policy makers and commentators to anticipate the likely impact of an innovation. We suggest, therefore, that RRI, the NCoB priorities, and the four avenues of research can serve as something of a manifesto for empirical ethics.

We envisage that an empirical ethics guided by an RRI manifesto would share the core goals of empirical ethics in its current form, but that the scope would be considerably broader than some descriptions of the enterprise. The enterprise outlined here aligns with Musschenga's description of the ultimate aim of all empirical ethics: to draw upon empirical data to improve the context sensitivity of normative, prescriptive claims.[25] And in many respects, it would align with existing empirical ethics work that, as Musschenga defines it, has sought to describe and analyse specific cultural and institutional contexts in order to evaluate the practicality of guidelines and principles. Examples of such work include Wainwright and colleagues project which, by exploring the specific perspectives of stem cell scientists, highlights the 'socially embedded' nature of the ethical implications of stem cell research.[26] Similarly, Brosnan and colleagues have explored what 'ethics' actually means to researchers working in translational neuroscience, and noted that their ethical viewpoints produce, and in turn were produced by, scientific practice.[27] Such work has sought to describe the moral frameworks of those actors working in clinical contexts, explore how these frameworks are shaped by various cultural and institutional factors, and how ethical work and reasoning is actually conducted in clinical practice and research. We envisage that an empirical ethics directed towards RRI would also seek to explore these aspects. Such research might be necessary, for example, to inform the formulation of specific RRI guidelines, to examine the applicability of specific guidelines and to explore whether such guidelines are influencing research and clinical activities in such a way that aligns with the values and expectations of society.

However, the avenues of research we have listed in this paper broaden the analytical gaze of empirical ethics beyond the examination of pre-identified ethical issues and the explicit examination of how those working in healthcare contexts and innovation understand 'ethics' and engage in 'ethical' work. An empirical ethics that follows an RRI manifesto would be similar in form to what Dunn and colleagues refer to as an

'empirically driven, broad-conception empirical ethics'.[28] They describe this broad conception of empirical ethics as:

> ... making empirical claims that describe or explain the world as it is... The aim [is to] identify the actual ethical issues ... or to make sense of relevant experiences, understandings, judgements or intuitions of individuals who stand in relation to these issues. [This is then used to] recommend some course of action, be it an act, a stance, a guidance for acting or a policy to govern action.

As we have suggested earlier, facilitating ethical research and innovation entails research of social and institutional factors that may not explicitly be identified as 'ethical' by either ethicists or those working within research and innovation contexts. Tracing innovation ecosystems (research avenue one) is a good example. Such research is necessary for directing innovation resources towards clearly identified therapeutic need, but it does not involve the description and evaluation of a specific ethical issue. Indeed, the very notion of 'responsible research and innovation' has, in effect, framed the entire research and innovation process as being morally relevant. Ensuring that research and innovation is responsibly directed towards 'great need' is an important task for empirical ethics, but it necessitates an empirical ethics that is broad in scope.

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