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## The limits of responsible innovation: Exploring care, vulnerability and precision medicine

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#### ABSTRACT

Drawing on insights from feminist and Science and Technology Studies writing on care and vulnerability, this paper will critically explore conceptualisations of responsibility, care and vulnerability in relation to contemporary approaches to Responsible Innovation (RI). Drawing on examples of some of the social and ethical challenges of precision medicine, we highlight the on-going, distributed and complex nature of innovation and responsibilities in relation to markets, patient and carer experience and data practices associated with these new technologies to highlight some of the limits of RI. We end by reflecting on the implications of our analysis for the social and ethical challenges of precision medicine and RI more generally.

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#### 1. Introduction

Public and policy concerns about the risks of emergent technologies have lead to the development of a range of policy tools to guide the innovation process. One such approach which has gained popularity in recent years is Responsible Innovation (RI). A variety of frameworks and initiatives have emerged under this broad banner. For example, public research funding organisations such as the UK's Engineering and Physical Sciences Research Council have developed a range of RI agendas aimed at the research community. Typically these are focused on encouraging, supporting or in some cases requiring researchers to be reflexive about their research practices, to consider the implications and applications of their actions, and to involve and engage with publics and their concerns through the research process (see for example [W1]. Social scientists have been actively involved in developing and embedding these initiatives in Higher Education and research funding institutions across Europe and the USA. Their work has focused on helping researchers and innovators to assess and respond to a plethora of evidence concerning the extent to which emergent innovation meet societies' needs, and fostering appropriate modes of engagement for stakeholders to help to anticipate and mitigate the risks which might arise from the development of the

transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow a proper embedding of scientific and technological advances in our society) [2].

RI has had particular currency in research and policy communities concerned with environmental and bio-technologies such as synthetic biology, nanotechnology and geoengineering, especially those associated with large EU and/or national research funding programmes. A range of detailed models or frameworks for RI have been proposed in order to achieve the dual goals of more ethical and engaged research and innovation. For example, Fisher [4] has developed a 'decision model' for the purpose of encouraging researchers' reflection on the process of innovation based on the principle of 'midstream modulation'. The model can be embedded into the research process in the form of an interview protocol which functioned as a feedback mechanism, thus 'creating a more self-critical environment for knowledge production, and perturbing the system in research-tolerable ways' [4].

Building on this, Owen et al. have suggested a framework for RI based on three dimensions: anticipation of potential impacts; reflection on underlying purposes; inclusive opening up of reflection to broad, collective deliberation [3]. This, they suggest, needs to

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technology [1–3]. In one of the most influential contributions on the subject, Von Schomberg describes Responsible Research and Innovation as a.

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be an 'iterative, continuous and flexible process of adaptive learning' (755) [3]. For Owen et al. [3], rather than researchers following rules it is necessary to emphasise values of care and responsiveness. They stress the importance of collective future-oriented care, characterised by anticipation (rather than prediction) of potential problems and the intertwining of the futures of all relevant stakeholders broadly defined. In this framework, more responsive processes of innovation not only prevent risks and promote safe and effective technologies, they also bring brings jobs, prosperity and social benefits.

The broad consensus around the benefits of these approaches to research and funding processes notwithstanding, a range of critical concerns have been raised about the limits and problems of the notions of responsibility and innovation which underpin these kinds of approaches to RI.

In one recent article, de Saille and Medvecky [5] have argued, that RI offers a limited view of how we might exercise our responsibilities for the future via innovation. They note that RI tends to equate innovation with positive economic growth, but that this does not tackle the problematic consequences of economic growth for society or the environment:

once RI is unpacked to reveal the moral underpinnings of its original formulation — in which 'responsible' has a caretaker mission to ensure that new technologies are both environmentally safe and sustainable (the requirements for which are not necessarily commensurate) — the relationship between RI and economic growth can become very unhappy indeed (5-6) [5].

In their exploration of what might constitute 'responsible stagnation', de Saille and Medvecky [5] consider how RI might involve less, not more, technological innovations, and focus on the kinds of social innovations that could be more 'responsible' by virtue of their judicious slowing down of the innovation and profit cycles, e.g. the case of Patagonia, which sells outdoor equipment using re-cycled materials using a business model with a modest price and profit margin.

Van Oudheusden [6] has also argued that responsible innovation agendas do not tend to engage with how innovations are produced or marketed and what kinds of social and political consequences this brings, because they focus on the ethical rather than the economic. The operationalisation of RI frameworks in activities such as Technology Assessment, do not tend to address the processes through which power is distributed and contested: 'Rather, these frameworks largely ignore questions about the politics in and of deliberation, the authoritative allocation of values, and the institutional uptake of deliberative engagements' (67) [6]. Di Guilio et al. [7] have also drawn attention to the need to engage with marginalised perspectives in RI and to move from frameworks and methodologies based around 'idealised rational forms of deliberation' to include more marginalised perspectives which recognise vulnerability.

Drawing on a rich vein of feminist scholarship, other Science and Technology Studies scholars have further troubled the idea of RI as matter of collective care for the future as proposed by Owen et al. [3]. Groves points out, the emphasis in much RI on consulting and engaging with a wide array of stakeholders stops short of critical engagement with the ways in which society is organised around 'living the future' via imaginaries which drive particular practices of investment and growth. Instead Groves suggests we need 'a new ethos for living with technology' (13) [8] and a more thorough consideration of how subjects and material arrangements interact [9].

These critical interventions suggest that contemporary RI agendas might be based on rather limited conceptualisation of responsibility, innovation and care for the future. Although these approaches champion researchers', innovators' and funders'

responsibilities to consider the consequences of their work for society, there is little scope for these and other involved actors to engage with or intervene in the wider systems of distribution or exchange of any products or technologies which might arise from their efforts. Although there is clearly an openness to mitigating risks or slowing the innovation process, the emphasis in much of RI remains on investment in technological (as opposed to social) innovation and on innovation rather than ethical forms of inaction. And efforts at deliberation or public engagement conceived around 'stakeholders' and consensus limit the kinds of voices and considerations of responsibility and innovation.

In order to further our understanding of the limits of contemporary approaches to RI, we can also turn to feminist and STS writings on innovation, care and vulnerability.

Following Puig de la Bellacasa [10], in a recent special issue on care and technology, Martin et al. [11] argued that to fully engage with what care might mean in relation to science and technology we need to focus on who is asked to or able to care, for what kinds of things and futures and to open up consideration of the kinds of social actors, things and contexts we engage with as part of these processes. So rather than thinking primarily in terms of stakeholders and technological innovations, we need to consider those who might be absent or marginalised from engagement processes or markets through which technologies might develop, and care about these markets and other kinds of things and processes they involve or interact with too. Feminist STS writing also stresses the importance of a careful consideration of the 'dark side' of care:

Care is a selective mode of attention: it circumscribes and cherishes some things, lives, or phenomena as its objects. In the process, it excludes others. Practices of care are always shot through with asymmetrical power relations: who has the power to care? Who has the power to define what counts as care and how it should be administered? Care can render a receiver powerless or otherwise limit their power. It can set up conditions of indebtedness or obligation. It can also sediment these asymmetries by putting recipients in situations where they cannot reciprocate. Care organizes, classifies, and disciplines bodies (625) [11].

This warns us to take care around ideas such as 'care for the future' and its articulation in RI agendas, drawing attention to the dangers and damage of particular ways of caring and those it diminishes. As STS researchers who have become enrolled in responsible innovation agendas have also argued, care can all too readily become a matter of 'observation' at a distance - a performance of concern - rather than critical intervention which reshapes technological innovation [12]. Martin et al. conclude: 'The lesson here is that an ethic of response-ability, and thus an ethic of care, cannot be institutionalized or standardized' (641) [11] as the process of standardisation or institutionalisation inevitably involves acts of caring less or carelessness, problematising RI which seeks to embed 'care for the future' in institutional processes.

These arguments are also developed in a rich and diverse literature on vulnerabilities, which has grown from feminist work on the ethics of care [13] and STS analyses of innovation [7] [14]. The starting point for many feminist analyses of vulnerability is that the human body and subject is inherently vulnerable, and in need of care [15–17]. Vulnerability, or the human capacity to suffer, therefore brings with it certain kinds of moral and political obligations to intervene, innovate, care. This reminds us to consider how innovations, be they technological or social, address vulnerabilities, meet material, bodily and psychological needs; how they prevent exploitation; and how they protect us from hazards. However, thinking with vulnerability also focuses attention on the

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