Bioethics is a somewhat odd discipline, spawned from medical practice and science, theology, law and philosophy, now increasingly embracing the methods of the social sciences. It does not fit easily into academic descriptors and is barely tolerated as a branch of applied ethics in exercises designed to measure the worth of disciplinary research.\(^1\) If we ask what it is that bioethicists do, the question can be answered in a variety of ways. These answers are held together by the common thread that bioethics takes the life sciences (broadly construed) as its subject matter and aims to reach normative conclusions about what ought to happen in particular instances. Bioethics is oriented towards influencing decisions and their corresponding actions, such as that doctors should respect their patients; medical aid in dying should/should not be legislated; non-human animals should not be exploited, researchers ought/ought not to create CRISPR babies, and so forth. Such conclusions may be based on philosophical argument alone, or informed by detailed empirical research. Either way, we expect bioethics scholarship to lay out the normative issues at stake, and ideally, reach justifiable conclusions about them.

Given the normative bent of bioethics, it is essential to consider what responsibilities follow from this. Specifically, to what extent should bioethicists be committed to act on their normative conclusions? Francois Baylis and Alice Dreger frame the issue thus: “Working in fields where recognizing injustices is expected as part of the knowledge required for being a professional, is it enough to aim at being a competent knowledge-producer or is there an attendant duty to act (when possible) on this responsibility?\(^1\)

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\(^1\) For example, the UK’s Research Excellence Framework (REF) or Australia’s Excellence in Research for Australia (ERA).
knowledge, in a committed and sustained fashion?"\textsuperscript{2} This is the question motivating this special issue of \textit{Bioethics}. Most of the papers were first presented at a symposium hosted by PEALS (the Policy, Ethics and Life Sciences Research Centre) at Newcastle University, UK, in 2017. The symposium, “Bioethicists as Advocates and Activists: Professional Boundaries and Commitments”, brought together a range of scholars and activists, to consider whether bioethicists should engage in activism, and if so, what follows from this obligation. The questions are pertinent, especially in the current academic landscape in which academics are increasingly required to show how their research has impact beyond being read by other academics.

The widely expressed view from the symposium was that bioethics activity occurs on a spectrum, from scholarly to activist, with no sharp dividing lines between different forms of activity on that spectrum. Where any individual academic sits on that spectrum will reflect a number of factors, ranging from inclination and opportunity to personal experiences and capacity. The topics we study as bioethicists may be driven by personal interest, but also by the priorities of funding bodies, outcomes of grant applications or collaborations that arise in serendipitous ways. The opportunities we have to contribute to policy and practice, for example through membership of institutional or national committees, vary. Some of us thrive on engagement beyond the academy, while others prefer to develop ideas and arguments for others to take up.

The issue opens with Hilde Lindemann’s paper highlighting different approaches to bioethics, and how these can influence ways in which one could or should undertake

activism as a bioethicist. She is critical of an over-reliance on idealised moral theories, suggesting that conditions in the real world are anything but ideal. Instead, she endorses a naturalised moral epistemology, based upon critical examination of how people actually behave, and collective judgements of whether this behaviour is good enough. Lindemann argues that while bioethicists using idealised moral theory can regard themselves as a ‘solitary judge’, naturalised bioethicists should work collaboratively with others to negotiate moral issues in a way that is good enough for everyone involved. This has implications for how activism should be conducted, and she gives examples of activism that have arisen from this type of group deliberation: for instance, joining forces with others to write academic articles and blog posts arguing against the use of a particular drug with some pregnant women, thereby raising awareness of this issue within the bioethics and medical communities. Tellingly, Lindemann refers to ‘our’ activism and uses an inclusive ‘we’, emphasising the collective nature of this endeavour. She concludes by suggesting that ‘contemplative’ bioethicists (who choose not to engage in activism) and activist bioethicists both have roles to play in engaging with advances in medical knowledge, and that it is important that they do not operate in isolation but instead listen to, and learn from, each other.

Heather Draper turns to the task of investigating different types of bioethics activism. She begins her paper by noting that in order to determine whether academic bioethicists should also be activists, we need a clearer understanding about which of the broad range of external activities academic bioethicists engage in count as

3 Lindemann, H. (2019). Bioethicists to the barricades! Bioethics this issue
4 Draper, H. (2019). Activism, bioethics and academic research. Bioethics this issue
bioethics activism, and why. The result is a taxonomy that distinguishes academic bioethics activism from activities that may fall short of activism such as giving expert evidence, sitting on national or local policy groups, research impact efforts, being an ethics consultant, and some forms of advocacy or whistle-blowing. Draper also notes that bioethicists, and other academics, may use their professional knowledge and skills to support their activism in areas completely unrelated to their professional research, including activism in their work place (e.g. as part of a trades union or efforts to increase diversity and equality in the academic or student body). Unlike activism related to professional areas of expertise, these activities fall short of bioethics activism, and would not, therefore, fulfil the professional obligation to be an activist – if this exists. Existing and vested interests activism may prompt people to take jobs or change the direction of their research to better align their academic work and activism. Then there is activism that, whilst it originates in one’s professional work, becomes incompatible with the obligations of paid employment.

If we accept that bioethics is frequently if not always activist in nature, how should this be done responsibly? Jackie Leach Scully addresses this in her paper, in which like others she argues for what she calls a ‘continuum of commitment’ that reflects the longstanding tension between the conceptualisation of academic inquiry as the search for pure understanding, versus its service to the goal of changing the world. Scully identifies five core responsibilities of bioethicists that arise at different levels of engagement in advocacy and activism, and goes on to discuss how the precise nature and salience of these responsibilities change as a bioethicist moves along the

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5 Leach Scully, J. (2019). The responsibilities of the engaged bioethicist: scholar, advocate, activist. *Bioethics this issue*
trajectory of commitment. However, she also argues that because (bio)ethics always seeks to make normative statements, in practice there can never be a hard line between scholarly bioethics and being an advocate/activist in the same way that there may be in other, less normative academic fields.

Interestingly, and perhaps significantly, five papers in this collection draw on the authors’ own experiences in moving between more traditional academic roles and activism. Wendy Rogers uses the example of her involvement in campaigning against forced organ harvesting from prisoners of conscience in China to argue that the apparent dichotomy between objective scholarship and overt activism is just that – apparent rather than substantive.6 Claims about loss of objectivity, bias and blunted academic rigour can arise irrespective of any commitment to activism, as can loss of credibility and reputational damage. Rogers acknowledges that activism could potentially undermine the quality of one’s academic work, but this is by no means inevitable and can be successfully addressed in the research of activists. However, other challenges are more enduring, such as concerns about efficacy in achieving activist goals, and tensions in both demarcating and juggling academic work with activism. Her detailed example of becoming involved in campaigning on behalf of prisoners of conscience in China who are murdered for their organs illustrates the value of academic skills in performing relevant research and writing compelling arguments. Since writing this Bioethics paper, Rogers’ co-authored research into compliance with ethical standards in the reporting of donor sources and ethics review

in peer-reviewed publications involving organ transplantation in China\textsuperscript{7} gained international headlines and is leading to retractions in journals including \textit{Transplantation}, the flagship journal of The Transplantation Society.\textsuperscript{8}

Rogers’ activism arose from her professional interest in the ethics of organ donation.

Deborah Zion argues that bioethics research can be a form of activism in itself as well as making an important contribution to the efforts of activists, and that bioethics academics have a particular obligation to the vulnerable.\textsuperscript{9} Drawing on her own research with refugees, Zion describes how her research, which has a strong empirical element, enables her to fulfil this obligation by ensuring that the voices of refugees are heard. This, she suggests, serves several purposes: it keeps the human rights abuses perpetrated against refugees in the public (and political) eye, it ensures that refugees are drawn back into the human circle rather than being dehumanised, and it enables researchers like herself to bear witness to their plight.

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Jenny Kitzinger and Celia Kitzinger, while already established academics in their respective fields, were motivated by personal experiences to take up activism on behalf of patients with severe acquired brain injuries. Their paper documents their journey triggered by a family tragedy through academic research and public engagement, to advocacy and activism. After their own experiences in the care of their severely brain-injured sister Polly, the Kitzingers undertook research into the experiences of others who had a family member in a vegetative or minimally conscious state, following an acquired brain injury. Based on their findings from this body of work, the Kitzingers embarked on a range of activities to secure changes in the treatment of patients with these conditions in the law, in policy and in practice. In the decade since Polly’s accident, alongside lobbying for reform the Kitzingers have become passionate advocates for individual families struggling with unfamiliar and sometimes hostile medical and legal systems. The Kitzingers are frank about the challenge of balancing activism with academic work, the need for self-care and sustainable practices, and evolving ethical issues arising from publishing from their advocacy work.

Ayesha Ahmad’s account of her work creating an intervention that both promoted Afghan women’s stories of, and aided recovery after, gender based violence demonstrates how activism weaves together the personal and the academic. As with


11 Ahmad, A. (2019). Taking on the Taliban: Ethical issues at the frontline of academia. Bioethics this issue
other academics working on global health issues, particularly in the humanitarian space, Ahmad demonstrates an acute awareness that research in the area almost invariably demonstrates an urgent need to address oppression and inequality, and this in turn feeds a sense of personal obligation to not only document, but also to press for change. Ahmad’s understanding of the powerful and empowering nature of women’s stories stems from her personal experience of her grandmother’s stories. Her own account of her journey as a researcher in this area reveals how academic activism is sometimes necessary within academia as well as in the world beyond. Although described by others as an academic and activist for women in Afghanistan, she explains that she needed to become an activist within her own academic discipline, challenging the silencing effect of feminist anti-imperialist critiques and an ‘academic apathy from those who wish to stay safe and distant from ideologies that define women’s lives’, which resulted in a similar resistance to receiving the women’s stories as they faced in Afghanistan.

Tom Shakespeare also draws on personal experience to discuss the interaction between activist and academic lives. However, unlike the others, his trajectory as he describes it is from a largely activist to a more academic stance, while retaining some elements of an activist identity. Writing specifically about disability bioethics, he recounts his experience of the tension that Scully discusses in her paper: what happens when scholarship begins to challenge some of the certainties, sometimes oversimplifications, of activism. Arguably, these issues arise earlier and more acutely

12 Shakespeare, T. (2019). When the political becomes personal: Reflecting on disability bioethics. Bioethics this issue
within disciplinary areas that have grown out of emancipatory movements, such as disability bioethics or feminist bioethics, which Lindemann also mentions.

In describing the pain of discovering that some activist colleagues were unable to tolerate the level of nuance demanded by his academic work, Shakespeare brings home the very real personal as well as professional costs that activists as well as academics may have to pay. Greg Moorlock raises similar issues when, in contrast to some of the other contributors to this issue, he considers activism from the specific perspective of a junior academic and asks whether it might be best left to those more established in their careers.\textsuperscript{13} Those in senior positions have less to lose by taking an activist stance, compared with younger colleagues who may be awaiting tenure or promotion. He suggests that although bioethicists may have an obligation to stand behind their arguments and use their professional position to try to effect positive change, the likelihood of this being successful, along with the associated costs of doing so, may depend upon factors related to one’s career stage and standing as an academic. Although not unique to junior academics, he highlights the typical difficulties they face in terms of precarious employment, competing demands on time, and not being taken seriously. Bringing about change requires getting people to listen, and Moorlock argues that this is more likely if you have established the reputation and credibility that comes with being a respected senior academic. Moreover, he suggests that engaging in activism at an early career stage may actually hinder the development of credibility, thereby preventing effective activism later in one’s career.

Although activism often arises from an immediate need to respond to injustice, \textsuperscript{13} Moorlock, G. (2019). Do junior academic bioethicists have an obligation to be activists? \textit{Bioethics this issue}
Moorlock’s arguments suggest that the responsibility for pursuing such activism falls on those who are better positioned to achieve the desired end, and that this will often be senior academics.

Predictably, both the symposium presentations and the papers in this special issue raise more questions than answers, and indicate areas that need further investigation. For example, while there is a strong consensus that there exists a continuum of commitment, the taxonomies offered here do not examine in detail the way that engagement might change over a career or a lifetime. A further point is that the contributors to this special issue and to the recently published *Bioethics in Action*,¹⁴ which also looks at bioethics’ real-world impact, show an undeniable gender bias. Is this apparently skewed interest in activism a reflection of women bioethicists’ lived experience as members of a marginalised group, of the political concerns of feminist bioethics, or something else? Perhaps most importantly, if we accept that some form of activism is a legitimate element in a bioethical life (even if not every bioethicist can or wants to engage in it), what should we be doing about managing the risks?

Whilst social media has made it easier to communicate with larger and wider audiences, it has simultaneously increased the potential personal, professional and institutional costs of pursuing change, whether this is motivated by the pressure to demonstrate impact or by a sense of professional or personal obligation. Can bioethics as a field take up the responsibilities of engagement, including the management of institutional expectations, professional protection, and training for students and junior colleagues?

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