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Title Page

Title: Activism, bioethics and academic research

Running title: Activism, bioethics & academic research

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ACTIVISM, BIOETHICS AND ACADEMIC RESEARCH

ABSTRACT

This paper sketches a taxonomy of the activities in which bioethics academics engage, including activities that may make their own research more impactful, from little or no engagement outside academia to activism or extreme activism. This taxonomy, the first of its kind, may be useful in determining what obligations bioethics academics have in relation to activism and activities that fall-short of activism.

Key words: bioethics, activism, impact ethics, research impact, advocacy,

1. INTRODUCTION

One question that motivated this collection was whether engaging in activism is, or indeed ought to be, an obligation that arises out of bioethics as an academic activity. There is, however, a prior question that will be addressed in this paper; namely what counts as *activism* associated with academic bioethics, as distinct from other activities that fall short of activism, but which may be part of an academic's role. In particular, public engagement and 'impact' are increasingly being associated with academic research, but in different ways and for different reasons. Two examples are the so-call 'impact agenda' in the UK and 'Impact Ethics' as conceived by the team in Dalhousie University, Canada. Each will now be briefly outlined and discussed as a starting point for considering the relationship between bioethics research and activism, and activities that fall short of activism.

Academic research in the UK has been shaped by a national initiative aimed at measuring and assessing research output every eight years. This process is thought to drive excellence in research.¹ The current iteration is called the Research Excellence Framework (REF). Of increasing significance to the REF is 'impact': the effects of research outside academia. This is demonstrated by 'impact case studies' (ICS) outlining specific beneficial effects of published research. Successful ICSs demonstrate a direct link between published research and its impact. In addition, funders of research expect applicants to demonstrate that they will maximise the impact of their results, and a key component of many research applications is a 'pathways to impact' document (or statement) that describes the activities

¹ It is modelled on scientific and clinical research, but applied to all kinds of research including humanities.

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2
3 that researchers will undertake to achieve this. Running alongside REF and funder
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5 preoccupations with impact is the requirement for patient public involvement (PPI),
6
7 particularly – but not exclusively – in clinical research. This encourages researchers to work
8
9 with stakeholders to identify research priorities, define research goals and outcome
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11 measures, design acceptable research methods and so on. All of these kinds of initiatives
12
13 are intended to ensure that academic research delivers excellence, relevance and value for
14
15 money as judged not just by their peers but different publics/stakeholders. This is one
16
17 understanding of ‘impactful’ research.
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25 Another perspective on impact can be found in the work of the Impact Ethics research team
26
27 based in Dalhousie University, Canada. Impact Ethics is described as
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32 using the tools of ethics to shock, press, crack, and chip society into a better place. It
33
34 is about outcomes and ordering the study of ethics around changing things for the
35
36 better.²
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42 This requires challenging the status quo of both health care and professional bioethics,
43
44 putting science to work for human good and making human institutions more accountable,
45
46 transparent and just. Bioethics is called upon to be ‘innovative, responsible and
47
48 accountable’, and Impact Ethics described as challenging individual professional bioethics
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59 ² Impact Ethics home page <https://impactethics.ca/about/> [Accessed 28 November 2018].
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3 academics to ‘re–examine their values and bias and to be transparent about goals, priorities
4
5 and conflicts of interest’.³
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10 These two accounts of impact and focussing research on what matters beyond academia are
11
12 not necessarily incompatible. Arguably both are intended to promote human good. The
13
14 latter, however, captures a sense that bioethics as a discipline⁴ has, and therefore that
15
16 academics working in bioethics have, a *particular* obligation to instigate change. This
17
18 suggests a potentially seamless relationship between bioethics as an academic subject and
19
20 activities that will bring about change. For some bioethics researchers, the shift to greater
21
22 stakeholder engagement and impact has merely required formalising, perfecting and
23
24 making explicit existing research practices. Indeed, the impact agenda in the UK may even
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32 ³ About Impact Ethics <https://www.dal.ca/sites/noveltechethics/about.html> [Accessed 28
33
34 November 2018].
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36
37 ⁴ I do not wish to get distracted here by what bioethics is and is not. I have written about
38
39 this elsewhere: “bioethics is a discipline in its own right: it is a community of scholars, with
40
41 its own journals, conferences, networks and ways of approaching and debating moral
42
43 problems and issues in the area of the life sciences. This community includes others from
44
45 disciplines such as medical law, medicine and sociology who contribute to this specific
46
47 community of practice. However, for it to be ethics, it has to keep as a central element the
48
49 elucidation of normative claims and corresponding analytical strategies.” (L. Frith & H.
50
51 Draper. 2017. Publishing Research in Empirical Bioethics: Quality, Disciplines and Expertise.
52
53 In *Empirical Bioethics: Theoretical and Practical Perspectives* J. Ives, M. Dunne & A. Cribb,
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55 eds. Cambridge : Cambridge University Press: 235–255 p.239.)
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3 be regarded as sanctioning activities (including activism) that had previously only been
4
5 perceived as at best borderline work– or discipline–related.
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10 But this is not a view of the relationship shared by all. Ideological objections have been
11
12 raised, not perhaps so much to the drive for research excellence, but to working so closely
13
14 with stakeholders. Distance, detachment and remaining dispassionate are valuable and, for
15
16 some, possibly even defining, dimensions of open–minded academic enterprise.
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23 Once a philosopher abandons her academic detachment and jumps headlong into a
24
25 particular case or controversy, she sacrifices the unique and valuable perspective of
26
27 one who seeks primarily to *understand* a problem, rather than to *fix* it.⁵
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32 David Benatar is also cautious about '[a]ctivism *in* (rather than as a *consequence of*) an
33
34 academic field',⁶ because activism rallies to a specific agenda that entails commitment to a
35
36 particular set of values and outcomes. Regardless of whether one agrees with Benatar that
37
38 '[t]he primary purpose of academic work is to enlighten', that prior commitment may
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49 ⁵ M.M. Dempsey, & M. Lister. 2016. Applied Political and Legal Philosophy. In K. Lippert-
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51 Rasmussen, K. Brownlee, & D. Coady, eds. *A Companion to Applied Philosophy*. New Jersey:
52
53 John Wiley & Sons, Inc.: 313–327 p.319.
54
55

56 ⁶ D. Benatar. Bioethics and Health and Human Rights: A Critical View. *Journal of Medical*
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58 *Ethics*. 2006; 32(1), 17–20, p.19.
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3 potentially hinder robust research is a fair concern.⁷ His distinction between activism ‘in’ or
4
5 ‘as a consequence of’ is also a useful for considering different ways in which activism and
6
7 research can interact.
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12 Against this back ground, this paper aims to describe the different ways in which bioethics
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14 academics may respond the calls for greater public engagement, *as academics*. I will sketch
15
16 a taxonomy of impact or engagement activities for academic bioethics that ranges from
17
18 little or no engagement beyond academia, as a matter of principle, to activities that can be
19
20 described as activism. In between these lies a range of activities that fall short of activism
21
22 and may be quite differently motivated – like impact activities in fulfilment of the UK REF
23
24 requirement. Creating a nuanced typology of differently intended and motivated bioethics
25
26 engagement might be useful for thinking about questions such as whether (or when)
27
28 academics working in the field ought to be prepared to engaged with, or be pro–active in
29
30 bringing about, that which their academic research suggests would improve the human
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32 condition, or human behaviours or institutions. What I am proposing is only a taxonomy; I
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34 am not supposing, for instance, that the closer an activity sits to activism the better it is.
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45 Next, I will establish how the terms ‘activism’ / ‘activist’ will be used in this paper from here
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47 on in.
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54 ⁷ Once people have firm beliefs these can be difficult to shake. See for example, J. Kaplan,
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56 S.I. Gimel & S. Harris. Neural Correlates of Maintaining One’s Political Beliefs in the Face of
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58 Counter-evidence. *Scientific Reports*. 2016; 6 (39589) doi: 10.1038/srep39589.
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3 2. ACTIVISM, EXTREME ACTIVISM AND (PURE) APPLIED ETHICS: OPPOSITE POLES ON A
4
5 CONTINUUM
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10 Dempsey and Lister⁸ describe three approaches – Standard Activist, Extreme Activist and
11
12 Conceptual Activist. Their distinctions are useful when thinking about how academic effort
13
14 might be focussed, but the terminology is misleading. For example, Dempsey and Lister say
15
16 that the Standard Activist ‘takes no direct causal role’ in bringing about change. Rather:
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22 [t]he philosopher presents an argument, directed primarily to other philosophers,
23
24 defending or critiquing some policy or set of policies. If policy makers happen to come
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26 across the argument, are persuaded by it, and then manage to secure the
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28 philosopher’s desired outcome, so much the better, from the philosopher’s point of
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30 view.⁹
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45 Whereas, ‘in extreme activism...the philosopher acts as an expert consultant and presents
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47 an argument direct to policy makers.’¹⁰
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53 When thinking about activism as ordinarily understood, these descriptions are overly
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55 passive and all-inclusive (in the case of standard activism), and overly tame (in the case of
56
57 extreme activism). Activism, as ordinarily understood, is far from passive. Activism requires
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54 ⁸ Dempsey and Lister, *op. cit.* note 5.

56 ⁹ Ibid: 314.

59 ¹⁰ Ibid: 315.

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3 vigorous, concerted effort; it is 'taking direct action'. As Benatar intimates, activism is
4
5 partisan, by which I mean that activism is 'prejudiced in favour of a particular cause' (the
6
7 Oxford English Dictionary definition of the adjective 'partisan'). Activism is political, usually
8
9 conducted publically and thereby, prior to the internet at least,¹¹ entails aligning oneself
10
11 personally, as an identifiable individual with a particular cause and its agenda for change.
12
13
14 Activists are motivated to effect social change by what they see as the strength of the cause
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16 (their partisan commitment) and this motivation, together with sustained and vigorous
17
18 personal effort, distinguishes activism from, for example, mere virtue signalling. Activism
19
20 tends to be associated with effort directed at bringing about a wholesale change. This is
21
22 reflects the view that many social problems are spawned by an endemic, underlying
23
24 injustice such as wealth, race, gender or even species inequalities. Against this backdrop,
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32 ¹¹ There is now considerable scope for activism in online spaces. Here it is much easier for
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34 individuals to operate using pseudonyms. In some cases, this may be an attempt to
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36 protecting or even hide one's identity. However, in other cases individuals might have a
37
38 distinct and important-to-them online identity, which may be as vulnerable to hostile
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40 criticism (for example, for inconsistency or for voicing views about which others disagree) as
41
42 are individuals who are not using pseudonyms. Thus, whilst it may be argued that being
43
44 identifiable is not a necessary criterion for activism, what does matter is that one is seen to
45
46 be presenting views one holds (or views that are held by the individual represented by the
47
48 pseudonym) rather than arguments that might be made in the abstract. The use of
49
50 pseudonyms and anonymity in activism is a moot point – see for instance T. Sorell. Human
51
52 Rights and Hacktivism: the cases of Wikileaks and Anonymous. *Journal of Human Rights*
53
54 *Practice* 2015; 7(3): 391–410.
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3 small changes in policy might be regarded as mere window dressing. As suggested by the
4
5 Dalhousie definition, however, big problems can be chipped away at. Small changes, for
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7 example in a local or national policy improving treatment delivery or how a new technology
8
9 is (or is not) incorporated into a care system, may fall short of addressing underlying
10
11 injustices but still make things somewhat better than they were. Given that this paper is
12
13 discussing activism and academic bioethics, for the purposes of this paper, whether or not
14
15 an activity will be regarded as activism will be measured by the persistence and vigour of
16
17 the individual's efforts to secure change in areas associated with their academic research,
18
19 rather than the scale of the issue being tackled or whether the intended results are
20
21 achieved.
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30 Contrary to Dempsey and Lister, in this paper *extreme* activism will be defined according to
31
32 the effort devoted or means used in activism. For instance, devoting most, if not all, of one's
33
34 time and resources to a cause (which is likely to be incompatible with academic duties). Or
35
36 resorting to non-peaceful, aggressive or potentially illegal, methods (such as arson, raids,
37
38 covert surveillance, 'outing' and so on). Or it may refer to sacrificing personal safety, such as
39
40 maintaining peaceful protest in the face of violent state response (as occurred on Ghandi's
41
42 Salt March, for instance, or lying in the path of a lorry transporting livestock for slaughter
43
44 abroad). Activities that Dempsey and Lister describe as extreme, such as presenting
45
46 arguments to policy-makers and acting as an ethics consultant *might* be forms of ordinary,
47
48 non-extreme activism, as we shall see.
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3 Thus, when thinking about bioethics, research and activism, we may be in fact be thinking of
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5 a range of different forms of engagement. Extreme activism, as defined above, lies at one
6
7 end of the spectrum, with pure philosophy (as we shall now see) marking the other end.
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10
11
12 Pure philosophy and applied ethics (according to Kasper Lippert-Rasmussen's¹²
13
14 characterisation of these) and 'standard activism' (according to Dempsey and Lister¹³) are
15
16 on the same spectrum as activism (as I define it), because both include some measure of
17
18 engagement. They are remote on the spectrum from activism because they are not
19
20 necessarily meant to bring about change in the world outside academia. Applied ethics is,
21
22 however, supposed to be of *relevance* to the world, in that it considers human behaviour
23
24 and suggests changes in it for the better: it is closer to activism than pure philosophy, but
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26 still remote from activism.
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35 Engagement in terms of publishing and exposing one's findings/arguments to the scrutiny of
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37 others (one's peers at the very least) is entirely compatible with bioethics. We might also
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39 suppose that *all* those who claim to be publishing *academic* research have an obligation to
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41 do so with honesty and integrity. At the very least, this means not plagiarising the work of
42
43 others, not falsifying data and fairly acknowledging the contributions others have made to
44
45 their work. As researchers, we should also acknowledge any limitations of our arguments,
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51 ¹² K. Lippert-Rasmussen. 2016. The Nature of Applied Philosophy. In K. Lippert-Rasmussen,
52
53 K. Brownlee, & D. Coady, eds. *A Companion to Applied Philosophy*. New Jersey: John Wiley &
54
55 Sons, Inc.: 3–47.
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59 ¹³ Dempsey and Lister *op. cit.* note 5.
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3 which includes acknowledging, for example, known counter–examples that may weaken
4
5 them. Some have gone further and suggested that we should also declare any potential
6
7 biases we may have in a process of reflexivity similar to that employed in the social
8
9 sciences.¹⁴ Even if one is not willing to go this far, some direct consideration of potential
10
11 non–specialist audiences may be prudent as well as helpful to those unfamiliar to the
12
13 conventions of philosophical writing. Whilst more theoretical applied ethics should have
14
15 relevance to the world outside academia, this relevance might not be immediately apparent
16
17 to non-philosophers. Thought experiments, for example, are not meant to be taken literally,
18
19 despite appearances to the contrary.¹⁵ Philosophers such as Jonathan Glover,¹⁶ who have
20
21 helped to popularise applied ethics by writing in plain English for non–specialists, should
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32 ¹⁴ J. Ives & M. Dunn. Who's arguing?: A Call for Reflexivity in Bioethics. *Bioethics* 2010; 24:
33
34 256–65.
35

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37 ¹⁵ A. Giubilini & F. Minerva. After Birth Abortion: Why Should the Baby Live? *Journal of*
38
39 *Medical Ethics*, 2012; 39; 261–263. This paper attracted considerable and sometimes very
40
41 hostile public attention (including death threats) and resulted in the authors publishing an
42
43 open letter ([http://blogs.bmj.com/medical-ethics/2012/03/02/an-open-letter-from-](http://blogs.bmj.com/medical-ethics/2012/03/02/an-open-letter-from-giubilini-and-minerva/)
44
45 [giubilini-and-minerva/](http://blogs.bmj.com/medical-ethics/2012/03/02/an-open-letter-from-giubilini-and-minerva/) [Accessed 5 March 2018]) explaining the nature and intended
46
47 audience of their paper.
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49

50
51 ¹⁶ For example, Glover's book *Causing death and saving lives*, which was published by
52
53 Penguin Books (a popular, non-academic publishing house) in 1977. More recently, TED
54
55 Talks and blogs have served a similar purpose. See also note 17 below re choosing to publish
56
57 in specialist non-bioethics journals (e.g. technology, scientific and medical journals).
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1
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3 also be regarded as engaging with the public as well as their peers, and have done so
4
5 without (necessarily) being activists.
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10 When thinking about the relationship between bioethics research and activism, however,
11
12 we perhaps also need to give some thought to whether those who are working at the non-
13
14 activism end of the spectrum are also supposed to feel personally bound by the force of
15
16 their own published arguments. For example, if an academic argues strongly against the
17
18 exploitation of animals in farming or about the unreasonable environmental costs of eating
19
20 meat, shouldn't we expect them to be personally committed to veganism? This may depend
21
22 on the nuances of the argument proposed, but let us confine ourselves here to the thought
23
24 that as bioethics researchers we should not be hypocrites: we should at least strive to adopt
25
26 the principles and practices we publically espouse. Insofar as our work overlaps with it, we
27
28 should at least take direct and sustained action to change/maintain (as appropriate) our
29
30 *own* behaviour even if we do not feel moved actively to influence that of others.
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40 In this section I have suggested that theoretical or pure applied ethics does have a place on
41
42 a taxonomy of engagement that places activism in general, and extreme activism in
43
44 particular, at the opposite end. I will now explore some forms of engagement that sit
45
46 between these two poles. On the whole, I have tried to work across from the more
47
48 theoretical end of the spectrum towards its activism end. The whole taxonomy is
49
50 represented in figure 1 in the conclusion to the paper.
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56 3. BEING CONSULTED VERSES BEING AN ETHICS CONSULTANT 57 58 59 60

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3 In their analysis, Dempsey and Lister run together (as examples of 'extreme activism' in their
4 account) giving evidence in court as an expert witness and working as a clinical ethics
5 consultant. In a more nuanced account, these may be regarded as quite distinct activities.
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10 Accepting an invitation to provide an expert opinion, based on one's academic publications,
11 for a public forum like a court, or in some policy arena, falls far short of activism as defined
12 above. But it is clearly engaging with a wider audience than one's fellow specialists.¹⁷
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17 Addressing a public forum as an *identifiable individual* meets one element of activism (as I
18 have defined it), and may leave one *personally* open to public scrutiny or criticism in return.
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22 Accepting an invitation is, however, too passive to count as activism: such invitations may
23 be issued only rarely or only rarely accepted. Similarly, accepting an invitation issued to
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29 _____
30 ¹⁷ It should also be noted that some bioethics researchers deliberately publish in places
31 where they are able to engage directly with practitioners who are not fellow bioethics
32 academics, for instance, in specialist engineering, science, technology or medical journals.
33
34 This is another way of popularising applied ethics research that goes a step further than the
35 plain English accounts mentioned in section 2. This might be regarded as becoming
36
37 embedded with the audiences one seeks to influence. It increases the chances of one's work
38 influencing practice, and therefore increases the prospects of some tangible impact. It is not
39
40 an entirely cost-free decision, however. Publishing in specialist technology journals may
41 mean that one's work is less well regarded by, e.g. more philosophical colleagues in the UK
42 making decisions about what to include in a philosophy REF return. It also means adapting
43
44 to different publishing norms. One of these may be much lower word limits (these can be as
45 low as 1,500 words in some medical journals). Another is a different view about the status
46
47 of conference papers; computer scientists and engineers regard some published conference
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3 speak for a position one's academic writing in any case supports, falls short of being
4
5 partisan. Moreover, agreeing to give expert evidence in the context of court proceedings in
6
7 a growing number of jurisdictions, requires one explicitly *not* to be partisan.¹⁸ For example,
8
9 section 35.3 of the UK Ministry of Justice *Civil Procedures Rules* states:
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14
15 (1) It is the duty of experts to *help the court* [my emphasis] on matters within their
16
17 expertise.
18

19
20 (2) This duty overrides any obligation to the person from whom experts have received
21
22 instructions or by whom they are paid.¹⁹
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28 These duties are echoed in Section 19.2 (1) (a) of the *Criminal Procedures Rules* which also
29
30 obliges experts to be 'objective and unbiased'.²⁰ The reasons for accepting an invitation to
31
32 provide an expert opinion may likewise not align with activism: one may accept solely or
33
34 primarily to enhance one's reputation or improve one's CV. Soliciting as many invitations as
35
36 possible to speak at such fora, or seeking a position on a committee *in order* to influence
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42 papers more highly than papers published in conventional journals, and rank conferences
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44 for impact and prestige in the same way that other disciplines rank journals.
45

46
47 ¹⁸ I am grateful to the anonymous reviewer for reminding me of this point.
48

49 ¹⁹ Ministry of Justice *Civil Procedures Rules* <https://www.justice.gov.uk/courts/procedure-rules/civil/rules/part35#IDASLIICC> [Accessed 27 November 2018].
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52
53 ²⁰ Ministry of Justice *Criminal Procedures Rules*
54
55 [https://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2015/crim-proc-rules-](https://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2015/crim-proc-rules-2015-part-19.pdf)
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57 [2015-part-19.pdf](https://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2015/crim-proc-rules-2015-part-19.pdf) [Accessed 27 November 2018].
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3 change in a particular direction, would take one nearer to activism, and this is something
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5 that being a published academic in bioethics may facilitate. But there are other activities
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7 that fall between these kinds of action and being an invited expert, and these include some
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9 types of work as an ethics consultant.
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15 There are different ways of working as an ethicist, or ethics consultant. This kind of work –
16
17 we might even call it practice – is unlikely to be a one-off. It is likely to be work that one has
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19 *actively sought*. It may be part of the job description of an academic post one has applied
20
21 for; or it may be an additional role that one's employer recognises as being in harmony with
22
23 one's substantive post; or one may undertake the additional duties in one's own time but
24
25 apply using one's academic role as collateral in one's application. These activities can greatly
26
27 improve one's understanding of the context in which practical ethical decision-making takes
28
29 place, thereby improving one's academic work. There is an established body of literature
30
31 exploring what it means, and does not mean, to be an ethics expert. This is suggestive of the
32
33 kind of interactions the authors argue ethicists should have in these roles. For example, as
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35 David Archard put it:
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45 His role should not be that of invoking his expertise to ensure that what is done
46
47 follows from his *own* [my emphasis] better moral judgement of what should be done.
48
49 Rather it ought to be that of advising and 'coaching' non-philosophers, ensuring that
50
51 they may come to see why better judgement is a better judgement.²¹
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56 ²¹ D. Archard. Why Moral Philosophers are not and should not be Moral Experts.' *Bioethics*
57
58 2011: 29(3); 119–127.
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6 This kind of model accords with seeing the primary goal of academic work being to
7
8 enlighten but adds an element of *facilitation* to the process. This is not something that
9
10 occurs in the abstract, but is rather aimed at problem-solving of an immediate practical or
11
12 policy kind. As Sherwin and Baylis²² imply, however, one can mediate or facilitate in a
13
14 manner that accords with a particular set of ideals (in their case feminist) without trying to
15
16 influence the actual decision that needs to be made. If one is active in bringing about
17
18 change in the *process* and *decision-making environment* rather than the *outcome*, one is
19
20 what they describe as a 'consultant-architect'. Moreover, Sherwin and Baylis envisage the
21
22 possibility of this form of engagement leading to outcomes in the form of patient choices
23
24 that are *contrary* to those the ethicist would like to see, but accepts nonetheless.
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32 [She] may deeply regret these decisions and work hard to make certain that the
33
34 patient understands the social implications of her choice: she may identify and bring
35
36 to the discussion alternative actions that might be acceptable to the patient. She
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38 would certainly try to the best of her ability to counter coercive forces ... Ultimately,
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40 however, in most cases, the clinical ethics consultant must accept the patient's
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42 informed decision.²³
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55 ²² S. Sherwin & F. Baylis. The Feminist Health Care Ethics Consultant as Architect and
56
57 Advocate. *Public Affairs Quarterly*. 2003: 17(2); 141-158.

58
59 ²³ Ibid : 153.
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2
3 As Sherwin and Baylis describe the feminist clinical ethics consultant–architect, she is very
4 active in the background ensuring to the best of her ability that power imbalances and
5 gender oppression do not impede decision–making. It is not necessarily the case that either
6 the academic invited to give evidence or the advising and coaching philosopher is *indifferent*
7 to these sorts of concerns. But it is also not necessary for their chosen role that they are
8 concerned about them, and what is more, actively working to address them. Thus, Sherwin
9 and Baylis’ model of ethics consultant as architect would seem to be nearer the activism
10 end of the spectrum than a facilitating mediator or philosopher–coach model is.
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25 Two further observations can be made about the ethics consultant–architect model. The
26 first is that the context in which the role is located by Sherwin and Baylis lends itself to not
27 interfering in a decision with which one disagrees. They are envisaging a clinical ethicist
28 bringing together various parties in a clinical setting, where the decision–maker is an adult
29 patient with capacity to make her own decision. This fact alone – in Western cultures at any
30 rate –favours accepting whatever decision is made by the patient. The outcome whatever it
31 is, provided the patient decides it, is in this respect an acceptable outcome, even if it is not
32 what the feminist ethics consultant hoped for. Improving the process and environment is
33 the object of the action Sherwin and Baylis describe, rather than what is decided (hence the
34 ‘architect’ component). There are, however, other situations where there is no single,
35 obvious ‘rightful’ authority. For example, when deciding where to locate consultant–led
36 maternity services, or whether to concentrate all intensive care beds in specialist urban
37 centres, or whether to legalise cannabis use. Confining oneself to being facilitator when one
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3 disagrees with the decision in these circumstances is clearly more difficult.²⁴ Here the ethics
4
5 consultant may be tempted to bring her the skills born of her academic expertise to bear to
6
7 persuade others to a different conclusion. Indeed, she may question the facilitator model
8
9 because, as Singer suggests:
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14
15 it would be surprising if moral philosophers were not, in general, better suited to
16
17 arrive at the right, or soundly based, conclusions than non-philosophers. Indeed, if
18
19 this were not the case, one would wonder whether moral philosophy was
20
21 worthwhile.²⁵
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28 Whether or not the ethics consultant is right to agree with Singer, if this is her view and she
29
30 acts on it, she will have moved a step closer to activism.
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34
35 The second observation to make about Sherwin and Baylis' feminist ethics consultant-
36
37 architect model is that its commitment to feminism is itself a commitment to a certain kind
38
39 of political engagement and action. The same could be said of utilitarianism. In determining
40
41 that morality requires the maximisation of benefit, utilitarianism not only chimes with non-
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47 ²⁴ Though arguably determining what weight should be given to the various stakeholders'
48
49 views might also be salient, and one's commitment to a particular theoretical method –
50
51 feminism or utilitarianism for example – might influence one's views about this. Moreover,
52
53 one might have a view and also be trying to ensure that the process by which the decision is
54
55 made is free from oppression and gender imbalance etc.
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59 ²⁵ P. Singer. Moral Experts. *Analysis* 1972: 32(4); 115–117.
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3 academic intuition in ways that have enabled it readily to colonise public policy (think about
4 the ready acceptance of cost–benefit analysis in healthcare), but it also provides a clear
5
6 recipe for living at a personal level. This is manifest in the movement for effective altruism,²⁶
7
8 which is actively promoted by high profile utilitarians and other academics. The request for
9
10 *public* pledging of a proportion of one’s income to causes identified by effective altruism
11
12 serves to identify contributors personally with the movement. In both feminism and
13
14 utilitarianism, some form of political action in one’s personal life seems to be necessitated
15
16 by the conclusions drawn from one’s academic work. This is one indication of the way in
17
18 which activism and academic research may go hand–in–hand.
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28 The more closely one’s work in bioethics brings one into contact with stakeholders, the
29
30 more likely one is to be drawn into actions to improve their circumstances, and the closer
31
32 one may move to activism in research. Here it is fruitful to consider again the range of
33
34 different action, circumstances and motivations in play.
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43 ²⁶ P. Singer. 2015 *The Most Good You Can Do: How Effective Altruism is Changing Ideas*
44
45 *about Living Ethically*. Yale University Press. Preface (ebook [http://0-](http://0-web.a.ebscohost.com.pugwash.lib.warwick.ac.uk/bsi/ebookviewer/ebook/bmxlYmtfXzk5MDg0MV9fQU41?sid=bf458fee-20b5-4f8d-8b23-4172bf6f19cd@sessionmgr4008&vid=0&format=EK&lpid=n6&rid=0)
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47 [web.a.ebscohost.com.pugwash.lib.warwick.ac.uk/bsi/ebookviewer/ebook/bmxlYmtfXzk5M](http://0-web.a.ebscohost.com.pugwash.lib.warwick.ac.uk/bsi/ebookviewer/ebook/bmxlYmtfXzk5MDg0MV9fQU41?sid=bf458fee-20b5-4f8d-8b23-4172bf6f19cd@sessionmgr4008&vid=0&format=EK&lpid=n6&rid=0)
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49 [Dg0MV9fQU41?sid=bf458fee-20b5-4f8d-8b23-](http://0-web.a.ebscohost.com.pugwash.lib.warwick.ac.uk/bsi/ebookviewer/ebook/bmxlYmtfXzk5MDg0MV9fQU41?sid=bf458fee-20b5-4f8d-8b23-4172bf6f19cd@sessionmgr4008&vid=0&format=EK&lpid=n6&rid=0)
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51 [4172bf6f19cd@sessionmgr4008&vid=0&format=EK&lpid=n6&rid=0](http://0-web.a.ebscohost.com.pugwash.lib.warwick.ac.uk/bsi/ebookviewer/ebook/bmxlYmtfXzk5MDg0MV9fQU41?sid=bf458fee-20b5-4f8d-8b23-4172bf6f19cd@sessionmgr4008&vid=0&format=EK&lpid=n6&rid=0)) ‘Living a minimally
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53 acceptable life involves using a substantial part of our spare resources to make the world a
54
55 better place. Living a fully ethical life means involves doing the most good we can’.
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5. ADVOCACY AND WHISTLE-BLOWING VERSES ACTIVISM

'Advocacy' and 'activism' are sometimes used interchangeably but this runs together two different types of action represented by the term 'advocate'. 'Advocate' can be defined as follows:

1. A person who publicly supports or recommends a particular cause or policy.
2. A person who puts a case on someone else's behalf.²⁷

In order to distinguish between 'activism' and 'advocacy', in this paper I will take 'advocate' to mean 'a person who puts a case on someone else's behalf', whilst accepting that advocacy as it is used elsewhere may have either or both meanings.

An essential element of advocacy in this sense is that the advocate speaks not as herself but as someone who is authorised by those for whom she advocates to voice and defend *their* views and claims, whether or not they accorded with her own views. Legal advocates – criminal barristers, for example – should represent clients to the best of their ability without regard for what they personally think about them or the crimes that may or may not have been committed. Nurses are likewise expected to be their patient's advocate, regardless of what they think about what the patient wants. The advocate is perceived to be better placed than those she represents – perhaps because of her skills, knowledge, confidence or position in a particular system – to ensure that their voices are amplified and not misunderstood. An essential component of advocacy is that it self-consciously represents

²⁷ Oxford English Dictionary. Available <https://en.oxforddictionaries.com/definition/advocate> [Accessed 27 November 2018].

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2
3 the views of others who have authorised the advocate to represent them. The advocate's
4 professional rather than personal persona is likely to be at the fore in these activities.
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8 Advocacy on this definition, is about helping individuals/groups of individuals to achieve
9 their objectives, rather bringing about changes that align to one's own beliefs.
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15 Advocacy becomes activism when the academic moves from helping individuals or groups
16 better to present their views, or to navigate systems, to aligning herself to their cause and
17 voicing her *own* views on the issue. One may be closer to activism than advocacy if one's
18 offer to speak for an individual or group is motivated by one's political beliefs that those
19 who are often silenced or ignored should be given help to amplify their voice. Skills that
20 academics develop in their professional lives may help them to be effective advocates in
21 areas otherwise unrelated to their work interests.
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35 Occasionally, bioethics academics are also engaged in (or support) whistle-blowing. This
36 may be related to advocacy; having helped individuals to navigate the systems for redress
37 within an organisation and failed to obtain a satisfactory response, the next step may be to
38 make the complaint or issue more public. Alternatively, work that is done as a consultant to
39 a specific committee (such as a research ethics review board or a clinical ethics committee)
40 may bring an academic into contact with systematic malpractice that she feels compelled to
41 expose (notwithstanding any explicit or implicit confidentiality agreement).
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54 Whistle-blowers take action to expose circumstances in the hope that others will be
55 thereby be forced to bring about change. Whistle-blowers are not necessarily personally
56 committed to taking things forward or being part of action for change – though blowing the
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3 whistle may be the first step on a path to more active involvement. Whistle-blowing is
4
5 different to, for example, covert surveillance with a view to exposing bad practice. Whistle-
6
7 blowers may have tried and failed to call attention to problems or failures using in-house
8
9 mechanisms before going public. Such pre-blowing the whistle activities may include
10
11 stealth activism (see below). Important to where this kind of engagement lies in my
12
13 typology, is that the whistle-blower addresses the public, as an identifiable individual,
14
15 acting on their personal judgement. Silence becomes unconscionable. Academics may rally
16
17 to the support of a whistle-blower by signing a petition. This too is a form of engagement,
18
19 though one often requiring little personal effort or cost in western democracies well served
20
21 by the internet. Here academic credentials may be used to lend force to the personal
22
23 judgement of the whistle-blower: '150 professors of bioethics support the action', as
24
25 opposed to '150 concerned members of the public support the action'. Those being asked to
26
27 sign petitions in support of whistle-blowers or other actions and causes may, therefore,
28
29 need to consider what their own views about moral expertise are before they sign as
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31 Professor J. Bloggs (or other academic role/indicator), rather than as plain J. Bloggs.
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42 6. STEALTH ACTIVISM VERSES THE RELUCTANT MINORITY MEMBER

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47 'Stealth activism' is sometimes used to describe the planting of subliminal messages that
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49 may be more arresting, and therefore more effective, than active confrontation. Some
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51 vegans use the term when, for instance, promoting vegan fast food outlets to counter the
52
53 view that, because vegan food is boring and tasteless, adopting a vegan diet is unduly
54
55 onerous. It has also been used to describe the placing of graphic stickers on apparently non-
56
57 meat-related food items to call attention to animal ingredients, or the placing of cuddly-toy
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3 cows, sheep and pigs etc. amongst the cuts on the meat aisle of supermarkets to remind
4
5 customers where meat comes from.²⁸
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10 It could also be used to distinguish between ways of being an activist that are more or less
11
12 strident. Alice Dreger, who describes herself as a historian of science, activist and bioethics
13
14 academic, describes the reactions of some intersex activists to her own brand of activism at
15
16 the time as follows:
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21
22 Bo and I were not, after all, with the extremists on the picket line outside ... I was an
23
24 especially easy target of the identity–card–carrying activists. I was not intersex, I was
25
26 not queer, I was not a clinician, so what was I doing there?... Some accused me of
27
28 being a kind of mole – of being ‘in bed with the doctors.’ When people put this charge
29
30 to my face, I asked whether they realised that being in bed with the doctors provided
31
32 a lot more opportunities to tickle their nuts, so to speak, than simply yelling at them
33
34 from outside the window. In fact, I admitted, I found the window–yellers useful,
35
36 precisely because they made us look sane and reasonable.²⁹
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45 Or ‘stealth activism’ might be used to describe deliberately working for change, quietly or
46
47 even covertly, from within the system. For example, putting oneself forward for committee
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51 _____
52 ²⁸ Tofu Temptress. Stealth Activism. 2017. Available [http://vegans.uk/cruelty-free-](http://vegans.uk/cruelty-free-living/stealth-activism/)
53 [living/stealth-activism/](http://vegans.uk/cruelty-free-living/stealth-activism/) [Accessed 28 November 2018].
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55

56 ²⁹ A. Dreger. 2015. *Galileo’s Middle Finger: Heretics, Activists and the Search for Justice in*
57 *Science*. Penguin: Chapter 1 (ebook no page numbers)
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2
3 roles in order to quietly steer discussion in a particular direction without overtly ‘playing the
4
5 ethics card’, or preferentially offering to mentor or supervise students from disadvantaged
6
7 backgrounds.³⁰
8
9

10
11
12 Here we might distinguish between messages that work through stealth, and using stealth
13
14 as the means of bringing about change. Leaving the supermarket’s own soft toys in the meat
15
16 aisle may mean that the toys have to be discounted for sale (thereby eroding the
17
18 supermarkets profit margins) but the use of such non-graphic messages to get consumers
19
20 to think differently about meat seems otherwise morally innocuous. Other kinds of
21
22 subliminal messages may be more controversial for reasons that are already widely
23
24 rehearsed in relation to nudging (coercion or manipulation, deception, lack of transparency,
25
26 undermining personal responsibility for decision-making etc.). Fitting in to be taken
27
28 seriously raises different issues that range from compromising personal integrity to subtle
29
30 forms of manipulation that play on existing prejudices of, for instance, what one should look
31
32 like and how one should behave if one expects to be taken seriously in particular social
33
34 groups.³¹ What is clear from Dreger’s book, however, is that she was not a *covert* activist
35
36 when it came to trying to change clinical practices and attitudes towards intersex babies and
37
38 children. She made frequent public statements about the kinds of changes she was seeking
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50
51 ³⁰ Thanks to Professor Wendy A. Rogers for these examples.

52
53 ³¹ Dreger *op. cit.* note 29, for example, describes recognising that she would need to change
54
55 her appearance (e.g. grow out her hair, and wear pantyhose and pumps) to be taken
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57 seriously.
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3 and why, and publically associated herself with the cause she supported. Activism that uses
4
5 stealth, such as working quietly from within without declaring one's agenda, might be
6
7 regarded as more suspect *because* it is covert and may therefore be regarded deceptive and
8
9 manipulative. Or, stealth activism in the case of quiet preferential personal mentoring and
10
11 supervision decisions, may be criticised for being both covert *and* preferential because the
12
13 lack of transparency means that the preferential treatment is not open to scrutiny or
14
15 challenge.
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22
23 There are other ways of employing stealth in activism as an academic. When working in
24
25 areas that are highly controversial, or which are already subject to hostile activism activities,
26
27 one may choose to work with practitioners in the field to bring about change incrementally
28
29 from within. One might do this by genuinely engaging with the obstacles to change that
30
31 practitioners themselves face, that they may be somewhat powerless to change on a
32
33 whole-scale basis, and by accepting that the practitioners themselves may also be people of
34
35 good will. For example, working with military doctors who are caught between being a
36
37 soldier working within the chain of command on the one hand, and being a doctor working
38
39 within the constraints of professional ethics and regulation on the other. Building
40
41 constructive relationships of trust and confidence can be the sugar that helps the medicine
42
43 go down. This kind of stealth activism means foregoing opportunities to be shrill or 'right
44
45 on'; it involves being patient with underlying flaws and necessitates playing the long game
46
47 of waiting until such time that fundamental or systemic criticisms will not be dismissed out
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49 of hand.
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3 The covert nature of stealth activism means that one is not personally and publically
4 associated with a movement for change. This lack of public exposure may make it attractive
5 to those who value their own private lives and feel uncomfortable when their professional
6 and private worlds collide. Not everyone is willing to expose themselves (or their families
7 and friends) to violent, verbal attacks and indiscriminate public broadcasting of aspects of
8 their private lives (past and present). For those with thicker skins, financial and other types
9 of security, or greater confidence (or combinations of all of these) this unwillingness may be
10 viewed as cowardice. Activists, especially those with vested-interests, may rightly feel that
11 they have not the time or patience to 'play nice' with academics who either blunder naively
12 into their orbits³² or who are trying to achieve change by means of stealth. Some kinds of

28
29 ³² As academics generally publish under their own names, they may be unwittingly
30 catapulted into public controversy (see note 15) and in this respect the line between their
31 public and private life is already blurred. Some academics have attracted extremely hostile
32 reactions to their published views, including death threats and sustained efforts to have
33 them removed from post. Dreger (*op. cit.* note 29) documents some of these. There are
34 concerns that these sorts of reactions constitute intimidation and may suppress the
35 expression or exploration of some controversial topics. In response consideration is being
36 given to founding an academic journal (which will be rigorously peer-reviewed) that gives
37 academics the option of publishing controversial pieces under a pseudonym (J. McMahan, F.
38 Minerva & P. Singer. 2018 Setting the Record Straight on the Journal of Controversial Ideas.
39 *The Guardian* 18 November. Available
40 [https://www.theguardian.com/world/2018/nov/18/setting-the-record-straight-on-the-](https://www.theguardian.com/world/2018/nov/18/setting-the-record-straight-on-the-journal-of-controversial-ideas)
41 [journal-of-controversial-ideas](https://www.theguardian.com/world/2018/nov/18/setting-the-record-straight-on-the-journal-of-controversial-ideas) [Accessed 28 November 2018].

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2
3 activism are, however, a deterrent to other forms of engagement or activism. Indeed,
4
5 silencing any kind of opposition may be precisely their point. We may, therefore, need to
6
7 differentiate between would-be activists who work for change quietly and more
8
9 anonymously to avoid unwanted aggressive attention, and activists who would in principle
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11 be willing to be publically identified but who judge stealth to be the most effective means to
12
13 achieve change.
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21 Activism by stealth may fail to meet all of the components of activism given that activism as
22
23 defined in this paper requires one to publically align one's own views with a particular
24
25 movement or call for change. Working behind the scenes seems to be the antithesis of
26
27 activism in this respect. It may, however, nonetheless have the components of being
28
29 motivated by partisan commitment and conducted with persistent, vigorous effort.
30
31 Recognising activism by stealth as a separate category distinguishes on this typology
32
33 between those who actively seek appointments to committees and policy-forming groups
34
35 overtly intending to make change (as described above and in contrast to those who merely
36
37 accept invitations to give evidence in such fora) and those who may be equally active in
38
39 seeking appointment as a vehicle for change by stealth.
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47 7. VESTED-INTEREST ACTIVISM, RELUCTANT ACTIVISM AND IMPACT ENGAGEMENT

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52 It is not uncommon for bioethics academics to write on areas where they have a vested-
53
54 interest or to reflect on the ethical dimensions of personal experience.³³ Others, who may
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59 ³³ For example, T. Shakespeare. 2006. *Disability Rights and Wrongs*. Oxon, Routledge.
60

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2
3 or may not self-identify as working in bioethics, have been motivated to become activists
4
5 for causes because of their personal experiences and publish in journals selected to
6
7 influence bioethics debate.³⁴
8
9

10
11
12 Not all activists have a vested-interest in the causes they join and some bioethics academics
13
14 are activists in areas completely unrelated to their areas of research interest – indeed they
15
16 may have been activists quite independently of, and prior to embarking on, their current
17
18 career path. In other words, even where they use their professional skills in their activism
19
20 they do so as concerned citizens who happen to have those skills. So, for example, an
21
22 academic best known for her work on reproductive ethics might be an activist for the
23
24 preservation and promotion of bees. Likewise, some academics are committed trade
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26 unionists but whilst they may be activists at work, their activism relates to their position qua
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28 employee rather than qua *bioethics* academic.
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37 Vested-interest activists on the other hand, engage in bioethics research as part of their
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39 activism. Vested-interest activism can lead academics to research areas in which they are
40
41 already activists, whether or not they are personally affected by the issues they choose to
42
43 campaign on. This distinguishes them in this typology from those who do not conduct
44
45 professional research in the areas in which they are activists. So, the bee-loving bioethics
46
47 academic only becomes a vested-interest activist on this definition when she switches her
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54 ³⁴ For example, C. Kitinger & J. Kitinger. Withdrawing Artificial Nutrition and Hydration
55
56 from Minimally Conscious and Vegetative Patients: Family Perspectives. *Journal of Medical*
57
58 *Ethics*. 2015: 41; 157–160.
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3 professional research attention from reproductive ethics to the ethics of bee preservation
4
5 and promotion.
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10 Vested-interest activism of this kind comes with benefits and draw-backs. Having shared
11
12 experience and being active in a particular cause can open doors to being able to conduct
13
14 research with participants who might otherwise be suspicious or hostile. This can greatly
15
16 enhance the quality of the resulting research. One might also have the benefit of speaking
17
18 with a different sort of authority: the authority of one who has 'been there' and to whose
19
20 experience-informed views some weight needs to be given.³⁵ One may also be open (rightly
21
22 or wrongly) to criticisms of the kind described at the front of this paper; namely one's
23
24 academic research may be regarded as less than open-minded. Indeed, anyone who is an
25
26 identifiable activist and who is publishing in the same area might be open (again, rightly or
27
28 wrongly) to the reaction of 'you would say that wouldn't you'. This reaction might be
29
30 sufficient for some academics to avoid activism: they may feel that their research will have
31
32 more traction if they are not personally linked to the causes that might useful employ their
33
34 findings or arguments. Undoubtedly, though, vested-interests have produced excellent
35
36 research in bioethics and those with vested-interests working in bioethics have been
37
38 effective champions for change.
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51 ³⁵ Whilst personal experience gives weight, it might not be decisive: the experience of
52
53 others might be different and even similar or shared experiences can result in people
54
55 holding contrary views. Experience should not be denied, but neither should it function as a
56
57 trump card in academic debate.
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1
2
3 Vested-interest activism is differently motivated to what for the purposes of this paper I
4 describe as 'reluctant action' by minorities. In many organisations, academia included,
5
6 describe as 'reluctant action' by minorities. In many organisations, academia included,
7
8 obvious or self-declared members of minority groups may find themselves drawn into
9
10 supporting others belonging to the same groups, or being asked to be (sometimes token)
11
12 members of institutional committees. 'Reluctant' here is being contrasted with 'vested-
13
14 interest' because action in this area may not be something that the academic concerned
15
16 considers a priority in either her professional or personal life. This may be a for a variety
17
18 reasons: just not being interested in action of this kind, or objections to tokenism, or
19
20 resentment at being saddled with additional responsibilities (seemingly *just because* one is a
21
22 member of a minority group), which may not receive much in the way of institutional
23
24 recognition when it comes to promotion or securing tenure. Those acting reluctantly may be
25
26 nonetheless very effective and persistent agents for change, conscientiously devoting time
27
28 and energy to the task, thereby moving closer to activism. Others may feel that they ought
29
30 to offer a helping hand, particularly to junior faculty, or to act in solidarity with colleagues,
31
32 just because they have experienced similar difficulties; but may not do so openly or
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34 consistently. Some may feel that they need to describe or speak out about their difficulties
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36 either to call attention to them or to bolster their own support mechanisms. Here
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38 engagement has nothing to do with one's research interests even if the actions take place in
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40 the work environment.
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52 Both vested-interest activism and reluctant activism contrast with engagement designed to
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54 meet institutional targets and preoccupations such as the UK REF. Here, research for
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56 activism – such as that conducted by vested-interest researchers – contrasts with actively
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58 engaging with stakeholders for research purposes. In the latter case, the researcher forges
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3 relationships with, for example, specific patient groups or NGOs and activists representing
4 their interests, in order to improve the quality of her research, the outcome of which may or
5 may not align with the stakeholders' interests as they perceive them.³⁶ This paper started
6 with the observation that research in the UK is being shaped by what has been dubbed the
7 'impact agenda' and the related PPI agenda. Undoubtedly academics of all kinds are working
8 more closely with stakeholders and in ways that gives more weight to the latter's interests
9 as they define them. The motivations for doing so may, however, be mixed – both at the
10 level of populations and individuals. Engaging with stakeholders as a means of further one's
11 own research career and reputation falls short of activism where *self-interest* rather than
12 *the good of others* is the primary motivation. Engaging directly with stakeholders and taking

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30 ³⁶ There are some grey lines here. Research findings may add evidence that can be used to
31 effect change for the better. However, the results may disappoint collaborators hoping for
32 change if the evidence produced points in a different direction. Unlike research for activism,
33 the researcher is not partisan; she will start from a position of equipoise and will judge the
34 research to be successful if it is methodologically robust, whatever the results are. In this
35 respect, the good towards which the research is aimed is better understanding. This does
36 not imply that research for activism will necessarily produce biased research results, but the
37 research effort will be focussed on producing evidence for a particular kind of change.
38 Results that do not support this change might be regarded as disappointing in this context.
39 Dreger (see note 29) recalls stating quite explicitly that she was willing to accept reliable
40 evidence, whatever it shows, in her own activism for intersex children, and is critical of
41 activists who reject out of hand results that do not conform to their view of how the world
42 is/should be.
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3 one's research questions and findings directly to them is, nonetheless, likely to be beneficial
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5 to all parties. Good quality evidence can be vital in determining what practices and policies
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7 ought to be. At the same time, being very active in ensuring that the results of one's
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9 research are implemented *because* this is required for REF or *because* one is bowing to
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11 pressures from one's employing institution to raise its research profile, lacks the quality of
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13 being partisan that is required for activism.
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20 8. ACKNOWLEDGING GROSS WRONG-DOING AND ETHICAL VIOLATIONS

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25 Wendy Rogers has written about her reaction to being confronted with evidence of the
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27 systematic murder for their organs of Falun Gong practitioners in China:
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32 I felt fairly stunned after the film [Hard to Believe³⁷]: if I was an 'expert' in the ethics of
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34 organ donation, why didn't I know about this?³⁸
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40 The scale of this atrocity is difficult to calculate, and should not be confused with the
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42 controversial removal of organs from Chinese prisoners immediately following their
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44 execution for capital offences. Ethan Gutmann estimated a range of between 9,000 and
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54 ³⁷ K. Stone. (2015). *Hard to Believe*. Swoop Films. Retrieved on 8 Feb 2018, from
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56 <http://www.hardtobelievmovie.com/> (reference as originally cited in Roger's paper)
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59 ³⁸ W.A. Rogers. Bioethics and Activism: a Natural Fit? *Bioethics* (forthcoming)
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3 120,000 murders of Falun Gong for their organs between 2000-2008³⁹. In an update to their
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5 combined work in this area, Gutmann, David Mattas and David Kilgour concluded that their
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7 'original estimates were far too low'.⁴⁰
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13 There is general, international support for the dead donor rule⁴¹. Technical disagreements
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15 over what it means to be dead for the purposes of organ removal abound, however.⁴² There
16
17 are also disagreements about whether, and if so under what circumstances, convicted
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19 prisoners sentenced to death may be considered suitable donors in countries that use the
20
21 death penalty.⁴³ Some prohibitions, however, seem so axiomatic that they do not warrant
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23 careful exposition in academic journals: not murdering people for their organs is one such.
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25 The bioethics academic is not able to respond to such atrocities by publishing a tightly
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27 argued paper enlightening the reader about the wrongness of the policy because academic
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34 ³⁹ E. Gutmann. 2014. *The Slaughter: Mass Killings, Organ Harvesting, and China's Secret*
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36 *Solution to Its Dissident Problem*. New York, Prometheus Books
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40 ⁴⁰ D. Kilgour, D. Mattias & E. Guthmann. *Bloody Harvest/The Slaughter: an Update* April 30,
41
42 2017: 13. Available <https://endtransplantabuse.org/an-update/> [accessed 3 April 2018].
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46 ⁴¹ This stipulates that donors must be dead before vital organs are removed for
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48 transplantation (and that the removal of organs should not contribute to, or hasten, death).
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50 Some countries permit living donation of a single kidney or liver or lung lobe.

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52 ⁴² See for instance, M. Nair-Collins & F.G. Miller. Do the 'Brain Dead' Merely Appear to be
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54 Alive? *Journal of Medical Ethics* 2017: 43; 747-753.

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56 ⁴³ See for instance, A. Caplan. The Use of Prisoners as Sources of Organs: an Ethically
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58 Dubious Practice. *American Journal of Bioethics*. 2011: 10; 1-5.
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3 journals expect original contributions not statements of the obvious. In the case of China
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5 and the Falun Gong (and other prisoners of conscience, and including, more recently,
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7 concerns that the Uyghur community is next to be targeted), what is required is carefully
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9 documented evidence that the practice is continuing.⁴⁴ But ensuring that the evidence is
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11 taken seriously by everyone involved in transplant (including potential recipients traveling
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13 for organs) requires persistent, informed and articulate persuasion outside academia:
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16 activism, in other words.
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23 What I am interested to try to capture here is a particular spur for bioethics academics to
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25 engage in activism: the ‘why did I not know about this?’ reaction to being unexpectedly
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27 confronted by systematic and colossal wrong-doing in one’s own area of research expertise.
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29 It is a kind of professional shame that mirrors the personal horror, and demands action.
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35 Recent revelations of sexual exploitation in the aid community might prove to be another
36
37 such example. Sexual exploitation and harassment is currently receiving much attention and
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39 its endemic proportions are being exposed, including, at the time of writing (April 2018),
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41 within aid organisations.⁴⁵ Academics working in disaster bioethics are familiar with the
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49 ⁴⁴ For example, W.A. Rogers, T. Trey, Fiatarone Singh, M. et al. Smoke and Mirrors:
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51 Unanswered Questions and Misleading Statements Obscure the Truth about Organ Sources
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53 in China. *Journal of Medical Ethics*. 2016: 42; 552–553.
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57 ⁴⁵ J. Gillespie, C. Wheeler, I. Ramzan & R. Kerbaj. 2018. Oxfam among Charities Reeling as
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59 120 Workers Accused of Sexual Abuse in Last Year Alone. *The Sunday Times* 11 February.
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3 particular dangers for women and girls in the aftermath of conflict and disaster; also with
4
5 the practical and ethical difficulties responders and agencies face in ensuring that effective
6
7 healthcare is delivered, by competent practitioners without eroding and undermining local
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9 services. These are the serious but 'bread and butter' issues tackled in the literature. But
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11 claims that aid workers themselves are known to be engaging in predatory sexual activities
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13 targeting the vulnerable population they are meant to serve, is also stunning. Worse is the
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15 suggestion that, along with all of the other compromises for the greater good seen in
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17 disaster responses, the:
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25 Sexual exploitation and abuse of women and girls has been ignored; it's been known
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27 about and ignored for seven years. ... Somewhere there has been a decision made that
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29 it is OK for women's bodies to continue to be used, abused and violated, in order for
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31 aid to be delivered for a larger group of people.⁴⁶
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36 Where this example differs from that of systematic killing for organs in China is that it does
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38 invite a careful ethical exposition of the apparently accepted trade-off between protecting
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40 women from sexual violation and ensuring the aid supply chain for the greater good. Like
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42 the carefully compiled evidence of transplant activity in China, an academic contribution of
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44 this kind would bolster activism activities. It is fair to presume that all academics working in
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46 bioethics think that their chosen area is important to some extent. Many of us may,
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48 however, have fallen into these areas through a combination of fortune and circumstance
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55 Available [https://www.thetimes.co.uk/article/charities-reel-as-120-workers-accused-
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59 ofsexual-abuse-in-last-year-alone-tcqcm8zb2](https://www.thetimes.co.uk/article/charities-reel-as-120-workers-accused-
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57 ofsexual-abuse-in-last-year-alone-tcqcm8zb2) [Accessed 28 November 2018]
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⁴⁶ Danielle Spencer, speaking on Today programme, BBC Radio 4. 27 February 2018

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3 rather than as a result of a considered judgement about where our talents could make the
4
5 *most* impact. Perhaps more consideration should be given to the targeting of talents, as
6
7 suggested by the Dalhousie Impact Ethics team. Either way, when ethical violations are
8
9 uncovered in one's area of expertise, there is surely a professional obligation to respond to
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11 these even if this does not translate into an obligation to follow—though with the activism
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13 activities that will translate the carefully crafted philosophical arguments into social change.
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20 9. CONCLUSION

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25 There are a variety of ways in which academics working in bioethics can be involved in
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27 engagement activities that fall short of activism, and others that can be described as
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29 activism. I have offered a taxonomy of activities that range from the publication of more
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31 theoretical applied ethics to extreme activism, and which excludes some activities such as
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33 those unrelated to one's professional research (for instance, union activities). This can be
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35 presented in the following way:
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40 <insert figure 1 here>

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45 There are reasons why public engagement of all kinds can be regarded as 'part of the job',
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47 fruitful for academic research and rewarding in terms of contributing to beneficial (from the
48
49 point of view of the academic concerned) changes in human behaviour, processes,
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51 institutions or environments (or combinations of all of these). There are also reasons to be
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53 sceptical about research that seems to be partisan. There are personal and professional
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55 risks, as well as rewards, to activism.
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3 My original intention had been to write a piece for this special collection on whether
4 bioethics academics ought to be involved in activism. It became apparent, however, that
5 this depended on how activism in bioethics was to be defined. I have offered a definition of
6 activism that distinguishes it from other forms of public engagement that academics might
7 increasingly be involved in, which included being partisan, and being *personally* and publicly
8 involved in activities aimed at bringing about change. As activism engages individuals
9 personally (as well as or even instead of) professionally, the degree to which a bioethics
10 academic ought to be an *activist* in areas in which she publishes is probably going to be a
11 personal decision, as well as one that depends on the kinds of research she does. Activism is
12 time-consuming and the desire to strike a balance between work and non-work activities a
13 legitimate one. Being an activist in areas unrelated to one's work interests is one way of
14 striking this balance. Recognising the demands of time and energy in one's non-work life is
15 also a legitimate reason for resisting activism of any kind.

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38 The degree to which one should be aiming to maximise the impact of one's research, and
39 active in achieving this aim, is a different question but with its own normative elements.

40 Drivers such as the REF, contractual agreements made with funders and employers'
41 expectations are likely to be influential. There are good moral as well as prudential reasons
42 for ensuring that research is excellent, relevant and effective.

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52 Since activism by definition requires personal effort and resources, it may be incompatible
53 with academic employment to be an extreme activist where 'extreme' refers to time rather
54 than methods. It may also seem incompatible with ideals of academia for academics to use
55 falsehood and *ad hominem* attacks in their activism.

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6 Impact Ethics as described by the Dalhousie team serves as a reminder that we are to some
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8 extent free to consider what our research priorities ought to be. Evidence of horrific,
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10 systematic and wholesale wrong-doing ought, however, to provoke *some* response from
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12 the academic bioethics community already working in those areas.
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For Peer Review

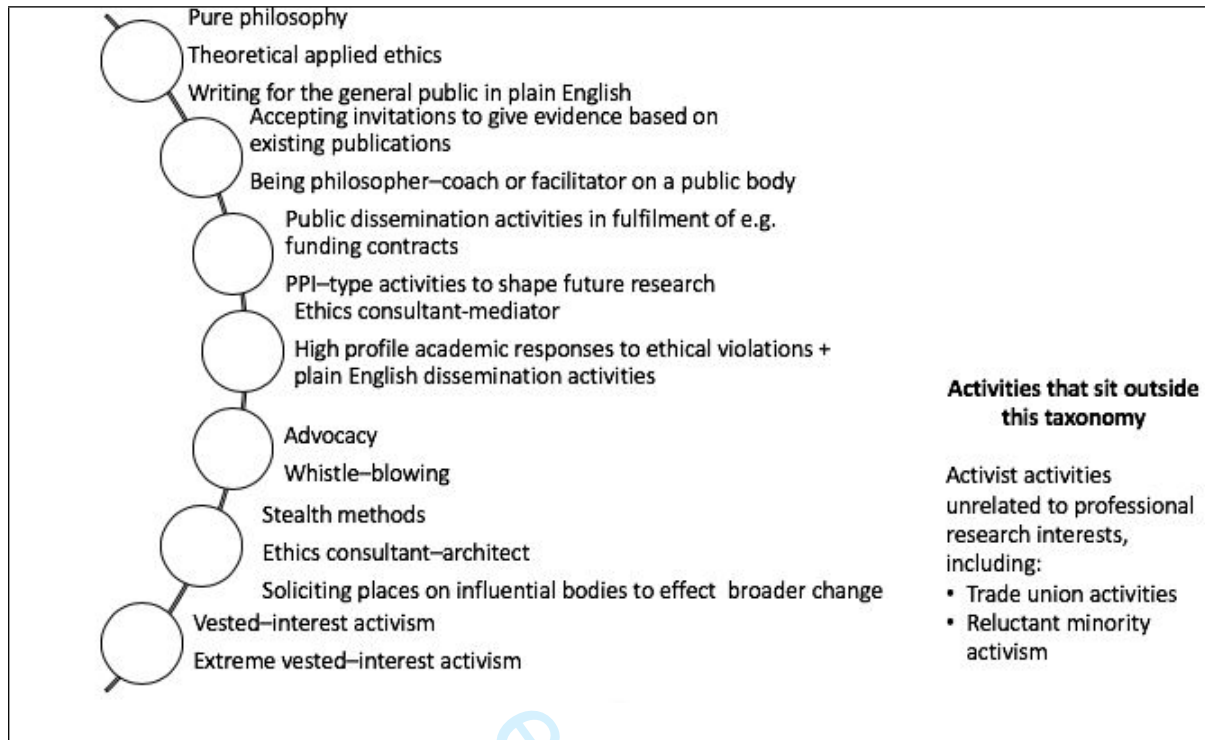
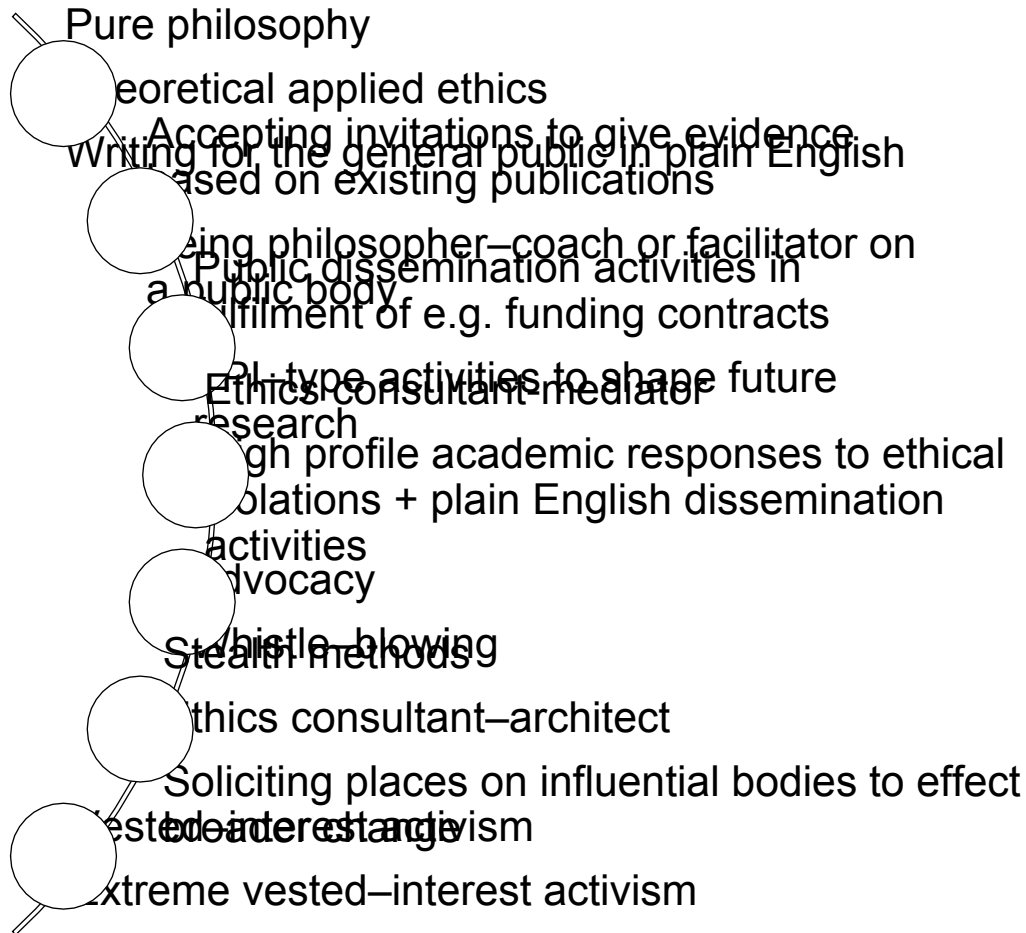


Figure 1 Taxonomy of activities from 'pure' philosophy to extreme vested interest activism.



Activities that sit outside this taxonomy

Activist activities unrelated to professional research interests, including:

- Trade union activities
- Reluctant minority activism