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SPONSORED SYMPOSIUM: NUFFIELD COUNCIL ON BIOETHICS: ARE WE MAKING PROGRESS IN BIOETHICS?

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INTRODUCTION to Q1 and Q2:

1. It turns out to be very hard to separate these two questions, especially when you have only 5 minutes on each. But we'll all try.
2. Obvious starting point for both questions is: what do we mean by 'progress' and what do we mean by 'bioethics'?
3. I'll speak from a predominantly UK perspective and set the bookends of my review with reference to my own career, i.e. roughly 1979-2016. This isn't just my ego (!) as those dates more or less coincide with:
 - a. the birth of the first IVF-conceived baby in 1978 and the beginnings of the *open* debates over embryology and human fertilisation, eventually introducing the 14-day limit on embryo experimentation....
 - b. and come up to date with current discussions on the 14-day rule, an issue that the Nuffield Council recently announced it will be looking into.
4. What has happened to, and in, bioethics over that time period?
5. And is that progress or not? Does a return to a consideration of the 14 day rule, for example, illustrate that we're going round in ever-decreasing circles or that we're actually making progress?

I'll read my piece to ensure that I keep to time.....

QUESTION 1: HAS BIOETHICS CONTRIBUTED TO PROGRESS?

1. It is annoyingly difficult to address this question without reference to Stephen Pinker's (2015) admonition for 'bioethics to get out of the way' as it is impeding progress in science and preventing cures for millions of people.
2. The question, 'Has bioethics contributed to progress?' invites a review of the past (possibly with lessons for the future)
 - a. but clearly we're not talking about a linear progression from morally bad science to ethically good science;
 - b. nor can we really talk about 'science' as though it were an undifferentiated, homogenised set of practices and institutions. Nonetheless...!
3. And other ways of asking the question about whether bioethics has contributed to progress would be to ask:
 - a. in my main substantive field, for example, would the science of reproduction be different without bioethics?

- b. and has bioethics been a sufficiently critical friend to science or has it simply been an ethical fig leaf, protecting science from scrutiny but letting down society?
4. **In terms of reproduction**, certainly in the UK and probably globally, given that it functions as a key reference point, the practice, regulation and clinical implementation of research would be very different without the work of the Warnock Committee (1982-1984) and the subsequent establishment of the Human Fertilisation and Embryology Authority (HFE Act 1990).
 - a. Their report is a mixed bag, without doubt, but in slowing down the science of embryology while at the same time developing assistance for those with sub-fertility problems, and in regularising practices that had been going on largely unchecked (such as donor insemination) then I think that, on the whole, the Warnock Report made improvements.
5. The Warnock Report certainly qualifies as an example of 'getting in the way of science and medicine' and with producing better outcomes as a consequence.
6. And that is what I think bioethics' biggest contribution has been to science. As Richard **Ashcroft (2015)** argues, it is the *job* of bioethics to get in the way and ask questions about the conduct and implementation of science.
 - a. And if 'science' finds those questions awkward, then it's probably all the better for that science.
 - b. It's too easy, though ultimately unhelpful, to turn those who are asking the questions into the problem, and attacking *them*, thereby avoiding answering the questions.
 - c. Instead the questions need to be answered. If they can be answered easily, then fine; if they can't be answered and, as a result, progress in science (as defined by Pinker) is impeded, that suggests that some aspects of that scientific endeavour require further thought.
7. **In terms of contemporary bioethics** I think:
 - a. one example of where bioethics has perhaps failed to ask sufficiently searching questions, in the UK, and therefore hasn't made the contributions to science or society that it might have done, is the field of mitochondrial therapies. (Come to our Symposium after the coffee break to hear more!).
 - b. On the other hand, and more positively, an example from my own involvement, where I think bioethics made a good contribution, particularly in the early stages of the work, is through the Interim Advisory Group (Ethics and Governance) of UKBiobank and their/our (!) Ethics and Governance Framework (not least through the processes where that advisory group was initially set up) (see Laurie, Hunt and Richards (2009) on the contributions of the EGC)
8. **In summary:** There is an expression in English about opening a can of worms, as a warning about the consequences of asking too many awkward questions. Jack Stilgoe wrote a very nice blog about a meeting here in Edinburgh, on making science more open to public scrutiny, titled, 'Can open. Worms everywhere'. I think that's been the main contribution that bioethics has made to the progress of science so far, insisting that the can is opened – and actually revealing not just worms but also sometimes butterflies.
9. As Stilgoe argues, 'In this area, questions are more important than answers, especially if we think that we are in a period where...there is an opportunity to reshape the scientific enterprise.'

10. Another English expression is, 'Don't let the cat out of the bag', referring to a warning (we have a lot of warnings about secrecy in English!) not to reveal secrets because again of the possible consequences; however, I think the *ongoing* contribution of bioethics to progress in the life sciences is not just to open that bag, but to let the cat roam as freely as it likes!

Thank you.

QUESTION 2: HAS BIOETHICS ITSELF PROGRESSED?

1. Just as Pinker can be accused of presenting a Whig history of science and medicine, suggesting a smooth linear progression from less good science to better science, we should be wary of suggesting such a development in ethics or bioethics.
2. In some ways we wouldn't expect ethics to have 'progressed' in terms of answering the big questions.
3. However I'm not as pessimistic as Julian Savulescu (JME, 2015) where he suggests that 'both bioethics and medical ethics together have, in many ways, failed as fields'
4. And the reason why I am less pessimistic is precisely because I share the view that bioethics is primarily a *field of study* rather than a single strand discipline.
5. So, once again, this second question pushes us to consider what is bioethics?
 - a. Savulescu (2015) argues, 'Ethics is concerned with norms and values. Its subject matter is the way the world ought to be or should be. It is about good and bad, right and wrong.'
 - b. In contrast, Richard Ashcroft suggests, '...bioethics is precisely a way of telling stories about new technologies and exploring them and seeing what we make of them.' (2015 blog).
 - c. As a sociologist who (i) first, works on the 'sociology of bioethics', and (ii) second, who conducts research on areas of social life that involve what have been described as ethically challenging issues, and (iii) third, who contributes to various ethics and bioethics advisory bodies, I am somewhere between these two definitions.
 - d. For example, I am not sure if the Warnock Committee was a case study in bioethics, as we currently understand it; if anything, I think it is a case study in the pre-'bioethics turn' in the late twentieth century. (One thought is what would the Warnock Committee look like now if set up to conduct a government inquiry?)
6. I think the 'bioethics turn' has broadly taken three forms:
 - a. **First, bioethics as a disciplinary/intellectual pursuit:** where we might argue about the theoretical rigour, or possibly theoretical rigidity, of whatever we decide to call, or refuse to call, 'bioethics';
 - b. **Second, bioethics in its institutional forms:** ranging across ethics research committees to the expansion of bioethics activities through specialist organisations and funders;
 - c. **Third, bioethics as praxis:** that is, a recognition that we all, as ordinary citizens but also as clinicians, ethics consultants, scientists, lawyers, academics, make and act on ethical decisions about our bodies and our health at numerous points in our everyday working and personal lives.

7. I think that a consideration of these various forms leads to further observations:
 - a. In terms of the **first** of these forms (bioethics as a disciplinary pursuit), such work has progressed in interesting ways, and is useful for clarity (or one might say, 'for conceptual hygiene') but has also led to redundant disciplinary turf wars;
 - b. In terms of the **third** of these forms (bioethics as praxis), this has developed strongly through collaborations between ethicists and e.g. Sociology and there is still much more to be considered. Such examinations legitimately include the practices of bioethicists of course;
 - c. The **middle** form (bioethics in its institutional forms) is, I think, the most interesting because it shows both the most progress but also illustrates potentially the most stultifying aspects of bioethics, at the same time.
 - i. I think that the concerns that colleagues like Pinker are actually expressing relate to institutional reviews of scientific research. Pinker doesn't actually suggest that such reviews should be eliminated but rather should be more constructive and efficient; however, I suspect that, in the UK context at least, there is a mistaken conflation here between, on the one hand, research ethics committees (which I have found possibly too accepting of many scientific proposals but also, more positively, increasingly helpful and efficient) and, on the other hand, the Research and Development arm of the National Health Service which is increasingly unclear, inefficient and stultifying.
 - ii. However, there is also another more positive aspect of the institutionalisation of bioethics in the UK in the late 20th-early 21st century and that is the support given to bioethics from the Wellcome Trust and the systematic reviews of new developments in the life and clinical sciences conducted by the Nuffield Council on Bioethics, as well as the establishment of the IAB itself in 1992..
 - iii. I would say that, of course, being funded by the WT and being a member of the NCoB, speaking at the IAB – but that can actually be taken as evidence of the effectiveness of these institutional forms in supporting inter-disciplinary work addressing ethically challenging issues.
8. **And that takes me back to the Warnock Committee:** when I interviewed Mary Warnock for my PhD in the late 1980s, she said a weakness in the Committee was its lack of social science (Sociology and Anthropology). I was a mere PhD student so she didn't have to curry favour with me!
9. **So, in Conclusion:** Julian Savulescu's diagnosis for making progress in bioethics and medical ethics is 'better philosophy'. Alongside that (since who wouldn't argue for better scholarship?) I would add better inter-disciplinary collaboration.
10. In contrast to Julian, I think *the expansion of bioethics as a field of study*, drawing in a number of disciplinary contributions, underpinned by institutional support, *is a sign of progress*.
 - a. Charis Thompson (2015) says something similar; if efforts are made 'to bring the diverse strands of understanding together...we might end up with better science and better ethics.' (2015:415)

Thank you.

As presented on 15/6/16

References:

Ashcroft, R. (2015) 'On not "getting out of the way": a reflection on Steven Pinker's critique of bioethics' (Velim blog; August 11th, 2015)

Haimes, E. (2002; 2006; 2007) What can Sociology contribute to the study of ethics? Theoretical, empirical and substantive considerations. *Bioethics*, 16 (2):89-113 (*reprinted* in Rehmann-Sutter, C., Duwell, M. & Mieth, D. eds (2006) *Bioethics in Cultural Contexts*, Springer-Verlag, Amsterdam: pp277-298); also reprinted in Chadwick, R. et al eds (2007) *The Bioethics Reader: Editors' Choice*)

Laurie, Hunt and Richards (2009) UK biobank ethics and governance council: An exercise in added value, in J Kaye & M Stranger (eds) *Principles and Practice in Biobank Governance*. Ashgate Publishing Ltd., pp. 229-242.

Savulescu, J. (2015) Bioethics: why philosophy is essential for progress. *Journal of Medical Ethics*, 41:28-33

Stilgoe, J. (22/11/11) 'Can open. Worms everywhere.' Blog.
<http://jackstilgoe.wordpress.com/2011/11/22/can-open-worms-everywhere> (last accessed Dec 6th, 2011)

Thompson, C. (2015) Move beyond differences. *Nature*, v522:415, June 25th, 2015