

A Review of Nuffield Council on Bioethics' report on Genome Editing and Human Reproduction: Social and Ethical Issues [Part 1]

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Background

Genome Editing initially came to the Nuffield Council on Bioethics' (NCOB) attention in 2012. Following their report on the [prevention of mitochondrial DNA disorders](#), the Council 'recognised the need for a broader *public discussion* of the ethics of different kinds of germline therapies (NCOB, 2015). As such, in 2014 the Council commissioned Dr Anthony Wrigley and Dr Ainsley J Newson to write a [background paper on key issues and questions relating to techniques of genome editing](#), and the resulting paper was published in February 2015. Genome editing techniques, namely CRISPR-Cas9, allow targeted edits to be made to DNA sequences.

A few months later on 10th April 2015, the Council announced they would be 'starting a new project exploring the ethical issues around genome editing techniques' (NCOB, 2015a). To assist the scope of this new project the Council asked others with an interest in the topic to submit up to 300 words in response to the question 'What are the most important challenges raised by genome editing that the Nuffield Council on Bioethics should address?'. Responses were discussed at a workshop with over 30 invited participants from a range of disciplines on 22nd April 2015. The workshop also included four presentations from prominent researchers working with genome editing techniques so participants were equipped with the most up-to-date information prior to their discussions (NCOB, 2015b). An overview of the meeting is available at the following [link](#).

The Council then established an interdisciplinary working group that included expertise in ethics, industry, law, philosophy, science and sociology. The working group invited further 'contributions from a wide range of people, including an open call for evidence that ran from November 2015 until February 2016' (NCOB, 2016). The working group considered the impact of advances in genome editing across several biological fields, one of which was human genome editing, and published an interim review entitled [Genome Editing: An Ethical Review](#) on 30th September 2016. The Council hosted a launch event for the review on 6th October 2016, greater details of which can be found in an earlier [blog post](#).

At the launch event the Council's Director, Hugh Whittall, announced a new working group specifically for human reproduction. The initial working group consisted of five academics, with a further two academics and a lawyer joining the working group as the group's inquiry developed. At the event Hugh also expressed that there was uncertainty about how the new working group would progress forward, in what was originally anticipated to be a limited time-frame, and invited ideas from the audience. As verified by *Figure 1.*, the Council claimed they would publish a report alongside another on livestock farming in 2017, more specifically, a published report on human reproduction was anticipated for July 2017.

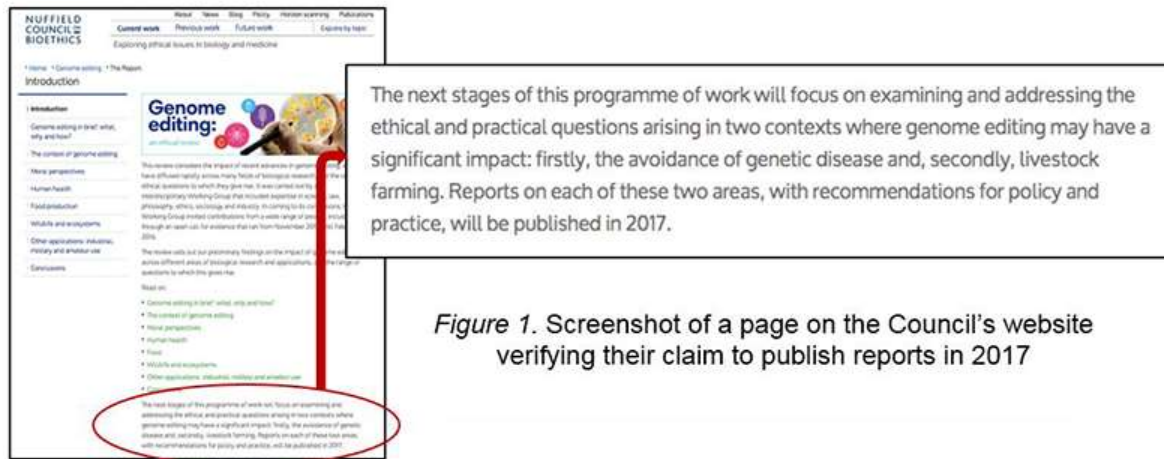


Figure 1. Screenshot of a page on the Council's website verifying their claim to publish reports in 2017

(<http://nuffieldbioethics.org/report/genome-editing-ethical-review/introduction>)

Representatives of the Council recognised that genome editing technology, namely CRISPR-Cas9's main contribution to the field of human reproduction centres on the prevention of disease. They claimed that the technology could interfere with human rights, perceivably, individuals with genetic disease(s) more prominently, and that irreversible harm and potential negative effects could be a possibility.

In this context, there was considerable discussion on public interests and public consultation being sought as part of the working group's inquiry at the launch event. The Chair of the new working group, Prof. Karen Yeung – a Professorial Fellow in Law, Ethics and Informatics at Birmingham Law School (University of Birmingham, 2018), repeatedly skirted offering clarity on whether public consultation would be conducted and skilfully deferred to the group's terms of reference instead.

The Report

The working group's terms of reference (NCOB, 2018a) have remained stagnant and in essence, have been fulfilled. However, I will return to the methodology employed to meet the three terms of reference later. The working group's terms of reference were:

1. To examine ethical questions relating to the attempted influence of inherited characteristics in humans, in the light of the likely impact of genome editing technologies.
2. To review relevant institutional, national and international policies and provisions, and to assess their suitability in the light of the ethical questions examined.
3. To report on these matters and to make recommendations relating to policy and practice

With the above terms of reference in mind, the working group's report consists of five chapters. Chapter 1 – 'The landscape', is a relatively well-balanced and engaging overview of many scientific aspects linked to heritable edits to the human genome. I personally felt this chapter was very well written and provided a good overview of genetic disorders and genetic testing. Readers exploring the ethics of human genome editing in relation to reproduction would benefit from the understanding which can be gained from this chapter. However, because of this strong start I had high expectations of the remaining chapters.

Chapter 2 – 'The horizon' proceeds to add great depth into the scientific minutiae of genome editing, and in my opinion deflects from the working group's terms of reference. I hold this view because whilst having an understanding of human genome editing is important, the level of detail in this chapter spans far beyond the basic knowledge needed to examine ethical questions relating to inherited characteristics, and is somewhat arbitrary to the overall report. However, if substantial explanation or clarity is needed on the technical process behind human genome editing, this chapter in the report is an excellent reference point.

Chapter 3- 'Ethical considerations' is essentially an extensive literature review on the ethical arguments surrounding 'heritable genome editing', which is a term the working group chose to adopt for the report. The chapter is scattered with a few select findings from their 'public' survey, and this is perhaps the downfall of the entire report. I had anticipated a greater level of findings from the council's own research to be reported and/or a sense of originality to stem from this chapter at the very least, most especially because of the detail in Chapter 2. Considering the focus of the entire report is supposed to be ethical questions, this chapter lacks depth and the expected rigorous examination of ethical considerations. This chapter is therefore quite underwhelming after waiting an extra twelve-months for the report to be published, and the content of the chapter could easily be gained elsewhere.

Chapter 4 – 'Governance', adopts a roundabout approach to reviewing legislation in the United Kingdom (UK) by drawing attention to European and International laws. The chapter notes that heritable genome editing interventions are currently prohibited in the UK, and as per the Council's previous work, continues to fixate on a 'broad and inclusive societal debate' being conducted before legislative changes are made. Once again, a lengthy literature review was not necessary for this conclusion to be written, and very few helpful recommendations are made in this chapter. Interestingly however, the Council does explicitly bypass willingness to self-foster the debate they continuously advocate for in this chapter and states that a new institution or commission should be made for such work.

Whilst some recognition is extended to 'ad hoc initiatives' from organisations such as the Progress Educational Trust and the Royal Society, the working group fail to acknowledge other, wider, proactive initiatives. Sciencewise, for example, 'was set up to deepen the dialogue between scientists, policy makers and the public', and in partnership with the National Co-ordination Centre for Public Engagement (NCCPE) and the Wellcome Genome Campus, have developed a new programme (NCCPE, 2018a). The new programme, titled the *Genome Editing Public Engagement Synergy* (GEPES) continues to pull together existing, ongoing, and forthcoming research outputs to coordinate a national approach to public engagement with genome editing (NCCPE, 2018b).

Finally, Chapter 5 – 'Conclusions and recommendations', offers a summary of the literature presented in the preceding 152 pages, most of which are not remarkable, and several of which are repetitive. Of the Council's fifteen recommendations, the very last may however encounter considerable controversy if the recommendation was to be actioned. Recommendation 15 states:

'We recommend that heritable genome editing interventions should be introduced only within the context of well-designed and supervised studies, reporting regularly to a national coordinating authority, and that the effect on individuals and society, including over generations, should be closely monitored as far as possible, compatibly with the privacy of the individuals concerned'

(NCOB, 2018b)

This recommendation could result in individuals who had their genome edited as part of their embryonic development could potentially be subjected to a lifetime of increased (and possibly unwanted) surveillance. In my opinion this recommendation would continuously draw attention to this aspect of an individual's life which could feasibly shadow their otherwise conventional life and personal development. Such attention could cause segregation / isolation that may not otherwise be encountered. The working group should have perhaps extended greater consideration to the implications of this recommendation before simply adding 'compatibility with the privacy of the individual concerned' to the end. Children often have very little say but can be impacted by their experiences and treatment for life.

The working group's methodology surrounding the construction of this report will be addressed in a later blog. The forthcoming blog will question the working group's exploration and data collection for this report, particularly because the Council's report offers recommendations at a national level.

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