Genome Editing: An Ethical Review Launch

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Following the publication of their interim report on the titled topic at the end of September, the Nuffield Council on Bioethics launched their review on Thursday 6th October 2016 at the Royal Geographical Society in London. I was very fortunate to be able to attend this fascinating launch and witness the questions, discussions and forthcoming plans the working group had/have to deliberate.

The launch kicked off with the Council's Director Hugh Whittall briefing us on how genome editing first came to the Council's attention in May 2014. He reminded the audience that a few months later they released a background paper which identified key developments, issues and questions relating to techniques of genome editing. And that this was followed by a workshop which focused on the vast impact genome was having, thus fast-tracking its presence on the council's agenda.

Hugh shared that over the past 18 months the council have looked at research in relation to several specific fields and with much of the groundwork already done, they hope to publish the full report in mid-late 2017. A report which I eagerly anticipate in relation to my own research interests, hence my attendance at the event.

As to form a common understanding in the room, genome editing was described as the deliberate alteration of DNA by breaking the double strands of the helix to introduce/replace a sequence of information via programmable proteins, aka cas-9. The rise of CRISPR (the genetic editing tool at the centre of the ongoing excitement), was repeatedly voiced to be the most cost efficient, time effective and easy to use editing tool to date.

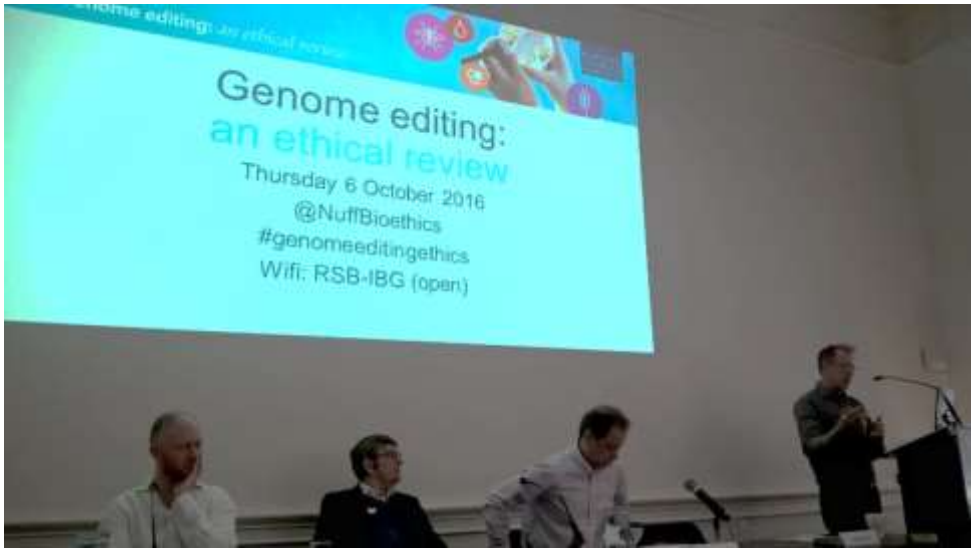
So far the biotechnology has been used for biomedicine and reproduction, as well as crops/farms and in industrial biotechnologies, such as third generation biofuels. It was reported that the overall utilisation of CRISPR-Cas9 is aimed at improving conditions involved in human existence. Thus, so far its main contribution to the field of human reproduction has centred on the prevention of disease.

The council claimed that extra moral contentions arise when its application to human genetic diseases are bought into question, largely because they recognise that the technology could interfere with human rights. Further to this, they continue to advocate that additional precaution must be taken as irreversible harm and possible negative effects have to be considered.

Whilst they concluded that CRISPR-Cas9 is possibly a transformative biotechnology that could alter expectations and ambitions of human control over biology, they believe that its growth is perhaps moving a little too quickly for robust critical thinking. This was perhaps most evident in their expressed uncertainty of how the working groups would progress forward in their limited time-frame and their reiterated pleas for ideas from the attending audience.

It was greatly articulated that there is a high level of concern on human genome editing in relation to reproduction and that should this come to light, changes in legislation will be required, hence the advance preparation. It is foreseeable that science could proceed in the same time frame it would take to change the Embryology Act, and that future application may extend beyond embryos to encompass germ cells.

Such possibilities are deemed to bring significant public interest, especially in the application of CRISPR-Cas9, rather than the technology behind it, simply because that is where the concern of its misuse potentially lies. However, as amusingly stated by panel member Professor Richard Ashcroft, *''the 'public interest' is often not actually what the public is interested in''*.



Following a 45-minute Q&A on livestock and other general uses, the latter half of the launch was specifically dedicated to addressing matters pertaining to human reproduction. There was significant discussion on how legislation is essentially CRISPR's biggest limitation and the panel highlighted that globally, albeit controversially, legislation is not enough to stop current practice, let along projected practice. As such, there was internal provocative debate on the need to speed up – slow down regulating the use of CRISPR technology.

Nonetheless, emphasis was placed on the need to work on human biological material rather than drawing upon parallels with animals, and eventually, fleeting recognition was given to the need for disabled people and their families/associates to be stakeholders in the ongoing ethical debate.

Interestingly a point was raised and ruminated upon that eugenics through genomic editing could lead to changing social attitudes, support and expressivist arguments surrounding disability, and that with this, societal acceptance, understanding and morals could also shift. This perhaps is something that will be explored more in my own forthcoming research and I eagerly await what the council will next report in relation to this.

During the event, I did express an active desire to be part of these discussions however a strong impression was imparted that the working group of five was not open to additional input. As such, if and how these considerations will ever come to light remain unclear, and indeed if anybody outside the working group, let alone the public will be consulted remains a mystery, which does present some concern.

However, moving forward, the working party for human reproduction proposed the following three terms of reference (paraphrased):

1. To examine ethical questions in relation to the attempted control of inherited characteristics in light of genome editing technologies
2. To review relevant institutional, national and international practices and provisions, and assess their suitability
3. To report on the above matters and make recommendations

In this context, it would be a considerable shame if the final report was void of public/patient and opinion. As such, I sincerely hope that the council manage to uphold their esteemed work within the time constraints they are presented with and find a way to ensure these somewhat crucial opinions are considered before publishing any future recommendations.

Regardless of what unfolds, I, undoubtedly like many others eagerly await to hear the conclusion of the Nuffield Council's ethical review on genome editing next year and cannot wait to read the final report.