Human genome editing: Where to draw the line?

Follow-up study to the
genetic technologies public dialogue

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This report is divided in to 5 main sections

Report structure

Human genome editing: Where to draw the line?

A summary findings report of a follow-up study to inform an international summit on genome editing taking place from 27-29 November 2018

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Human genome editing: Where to draw the line?

1. Introduction

This qualitative study was designed and delivered by Hopkins Van Mil (HVM), specialists in creating safe, independent and productive spaces for people to share their views. HVM facilitates engagement so that voices are heard, learning is shared and understanding achieved.

Purpose of this study

The Royal Society commissioned HVM to conduct follow-up qualitative research with a sample of participants from the genetic technologies public dialogue (HVM: 2018) to explore the reasoning behind the perceived acceptability of different human genome applications. The study aims were set by the Royal Society as being to explore the:

- Line between acceptable and unacceptable uses of these technologies
- Criteria used to distinguish between acceptable and unacceptable applications for genetic technologies
- Desired governance arrangements for human applications for genome editing
- Effect on attitudes depending on the permanence of changes made by the technologies.

The study used an iterative approach to capture reflections at an individual level through in-depth interviews, leading to community and society level discussions at a subsequent focus group

Methodology

What

- 10 in-depth telephone interviews
- A 90 minute focus group in London with the same interview cohort
- Group facilitated by an HVM Director and scribed/ transcribed by an HVM Researcher

When

- Telephone depth interviews were conducted in the week commencing 8 October 2018
- The focus group took place in London on 22 October 2018 from 6.30-8.00 pm

Who

- 9 participants had taken part in the genetic technologies public dialogue, 1 was unable to attend the dialogue but had been recruited for it and had received all the pre-participation materials
- Focus group attended by an observer from the Royal Society

How

- Participants were re-recruited via HVM's specialist fieldwork agency ensuring a broad demographic
- The interviews and focus group were delivered using a discussion guide and process plan signed off by the Royal Society Project Team.

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2. Criteria for acceptable and unacceptable uses

The majority of participants in the study were positive about the use of genome editing for health purposes. In all circumstances a **medical necessity** was the overriding principle for acceptance

Acceptable uses

Participants prioritised the treatment and prevention of **life-threatening diseases.** Although the majority said that they prefer somatic over germline applications, there was support for the latter for the **prevention of life-threatening** and **severely debilitating conditions.**

There was some support for applications which **improve the quality of life**, e.g. treatment of severe allergies and conditions which are potentially fatal and as a result require life-long dietary precaution.

Applications which have an enhancement effect were seen as acceptable as long as the **starting point for the treatment is a medical condition**.

Genome editing to enhance an individual's appearance was acceptable for participants in the study if the treatment is likely to lead to **significantly improved mental health** and **wellbeing.**

Criteria applied by participants

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Participants in the study were asked what uses of genome editing they felt were less acceptable for individuals as well as society. Unprompted **cosmetic use** was frequently mentioned

Unacceptable uses

There was consensus that genome editing for **cosmetic reasons** is unacceptable if paid for from the public purse, unless it's about treatment of impairments or disfigurations which severely affect an individual's mental health and wellbeing.

Participants had mixed views on the acceptability of genome editing to treat **non-life threatening conditions for which alternative solutions are available**, including dietary precaution.

Pro-active genome editing in embryos which results in **heritable changes** was unacceptable to a minority of participants with the **absence of large scale trials** being mentioned as the most important reason.

A clear no go area for a number of participants was enhancement of intelligence, as that is perceived to lead to **personality change.**

Criteria applied by participants

'I think using this for cosmetic reasons would be a misuse of the momentum that is clearly building up which should be focusing our resources on medical necessity.'

Use of public money to enhance physical appearance for non-medical reasons

Availability of alternative solutions

Conditions like coeliac disease and gluten intolerance, I think of them as an inconvenience. You might be a bit uncomfortable but if it's not life threatening then there are more important things.'

Trials of sufficient scale involving wide range of people

'When you're rolling it out on a large scale you need to be fully aware of the benefits and the draw backs and make that information available. Trials need to involve a wide range of people from all ages, cultures and backgrounds.'

Personality changes leading to wide-spread alteration in what it means to be human

'Where do you draw the line? I'd like a better memory; would that be acceptable? Yeah – I would go for that [jokingly]. But would I be the same person as I am? I might not be as nice, I might become really annoying. Personality change is a cut-off point..'

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3. Effect of heritability of the change on attitudes

As the study evolved it became clear that the main area for ambivalence is germline genome editing

Factors affecting participants' attitudes

Acceptability of genome editing is lower for applications which result in heritable changes to the human genome - unless it is with the purpose of **eliminating life-threatening conditions**.

The perceived **lack of clarity about the risks** of genome editing when changes are heritable impacted most on participants' views. Overall they felt more comfortable about somatic applications. When offered the proposition of the **reversibility of change** some participants felt more reassured.

For some, the inevitable lack of consent for future generations was an issue. However, overall the study demonstrated that members of the public **balance self-determination with the potential fatality of a condition** in favour of germline genome editing**.**

Germline applications become more acceptable if there is a reassurance that **tracking of several generations** will take place to monitor the occurrence of other changes over time.

Risk of fatality

'Something may have fatality attached to it. If we can eradicate a condition that will kill a child early then I find that more compelling than other things.'

'A genome could be edited so that a child didn't die. Of course they don't have the competencies to make that decision for themselves, but if it is objectively in their interest and medically necessary, that overrides a little bit of the self-determination and consent.'

Clarity on risks

'Germline applications only if we know how it works and are aware of what the risks are/ how we can mitigate them.'

'We have to be very, very cautious. This is tampering with nature at its most fundamental level. I'm not immovable though. If a case can be made that this can be done safely and without impinging on other people's wellbeing…'

Long term monitoring

'It would be in the interests of everyone if any tracking of this process is done in such a way as to make sure their rights and their privacy are at the forefront of everyone's minds.'

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4. Perceptions of terminology

To understand what in the public's mind constitutes a treatment, disorder and enhancement, participants in the telephone interviews were asked for their first reaction to the three terms

Although the use of the terminology is not always helpful in framing discussions on human genome editing[1], for members of the public the words 'treatment', 'disorder' and 'enhancement' are mentioned spontaneously and have very clear connotations.

For participants in this study 'treatment' is linked to a medical intervention aimed at improving a condition; 'disorder' to something that is not the norm, which raises questions around who decides what an anomaly is; and 'enhancement' to a non essential cosmetic modification. The latter raises concerns about the societal value attached to this type of application.

Treatment

- Fairly positive connotations for most participants
- Link to medicine
- Link to improving something

Treatment: 'Something to help someone get better.'

Treatment: 'It suggests a schedule/ plan to improve health, it feels closer to what I expect what I go to the doctor for.'

Disorder

- An anomaly
- Something that's not right/ has gone wrong
- Associations with the mind, i.e. cognitive/ behavioural challenges
- Who decides what's a disorder?

Disorder: 'Is it just someone else's view that someone has a disorder? You know, you might be altering that person to make them more like you.'

Enhancement

- More trivial than treatment
- Designer babies
- Cosmetic
- Modification with a societal value attached to it (what the norm should be)
- 'Improvement' for a small minority

Enhancement: 'The ability to improve a human being's condition. Enhance someone's wellbeing, lifestyle, physical appearance.'

Enhancement: 'One of those characteristic understandings of what it might be, like super humans, or Ken Doll type humans, or designer babies.'

[1]. Nuffield Council on Bioethics: July 2018

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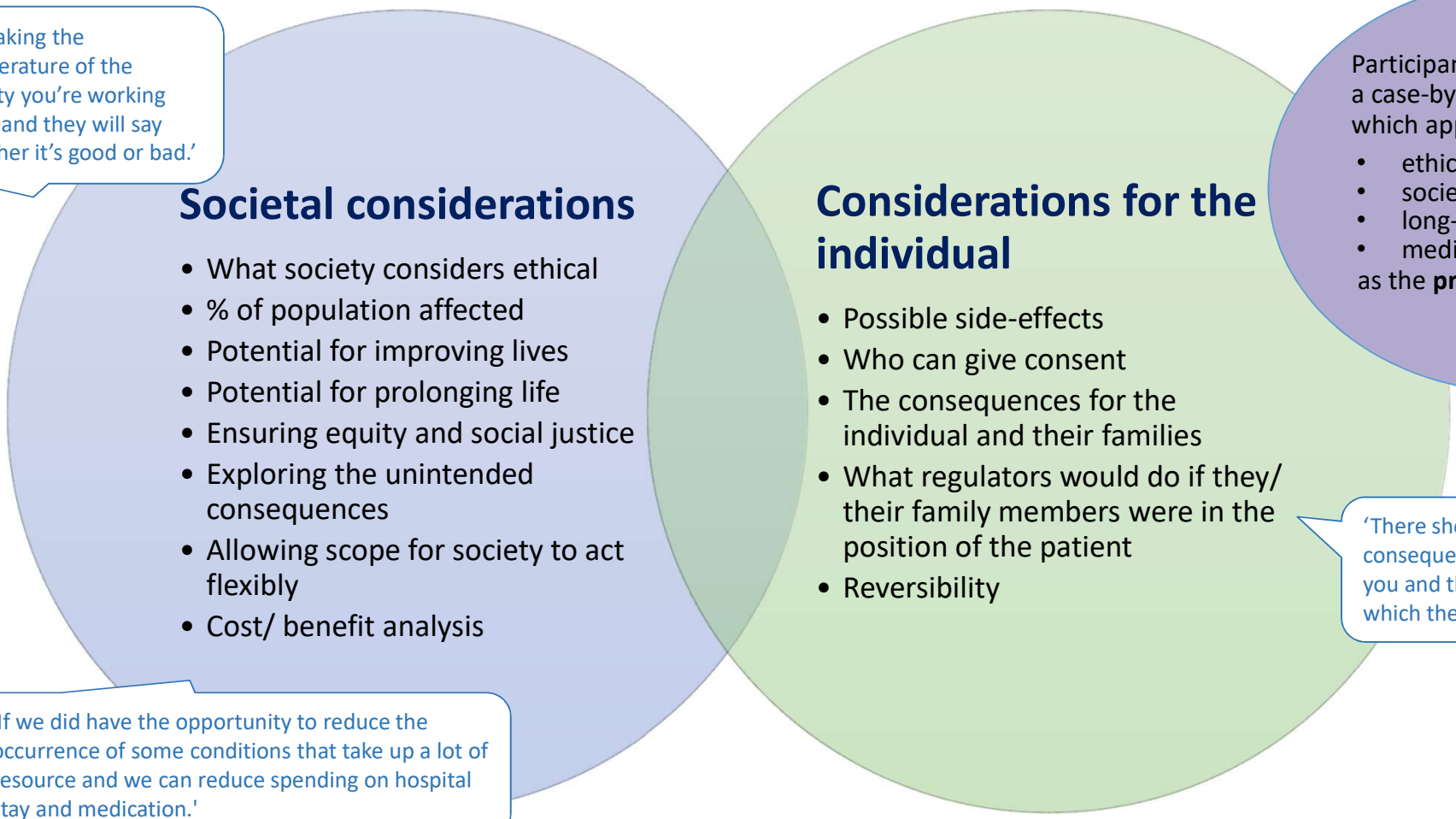
5. Desired governance arrangements

Participants reflected on the points the regulators of 2040 should take in to account to decide on the acceptability of a particular use of genome editing in humans



In the focus group participants were asked to consider the steps that would be required to ensure appropriate governance and regulation

Legislation voted on in parliament, informed by a democratic process, as the foundation for regulation.

A well-informed **multi-disciplinary panel** recruited from a diverse cross-section of society with key roles for scientists, ethicists, lawyers and the general public.

Ensure **funding** is available for effective research to be conducted on genome editing in humans. A recognition that this is likely to include **public** and **private** funders, both of which should have a seat at the table at the multi-disciplinary panel.

Ensure the panel can be informed by **new evidence** and **research** on new genetic technologies and the **long-term consequences** of their use, reacting flexibly to this information for the good of society.

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6. Summary of fundamental principles

The fundamental principles behind the acceptability and unacceptability of human genome editing as perceived by participants are summarised as follows:

Strong support for medical purposes, particularly life threatening diseases

Germline gene editing acceptable for prevention of life-threatening & severely debilitating conditions

Uses need to be regulated based on a legislative framework

Less support for cosmetic applications, unless the condition severely impacts a person's mental health

Enhancement as a consequence of treatment for a medical condition acceptable

Ensuring there is an ethical approach with embedded social justice measures

Preference for control and use by NHS to ensure equity of access

Image credits:
HVM genetic technologies public dialogue, Edinburgh

Participants drew a tentative line between acceptable and unacceptable uses of human genome editing – framed in part by the significance of the challenge and whether or not the public purse should be used:

When the purpose is seen as 'frivolous' and does not take the potential of genome editing seriously

Unacceptable — **Acceptable**

When the application will save a life and/ or provide substantial improvements to quality of life. And certainly when there is no other option.

'I wouldn't support NHS money going to somebody who wants their nose to be smaller or their eyes bigger. The priority for society should be the serious issues.'

'If it is life threatening then by all means use what you can use. More money should be put in things like that.'

In conducting this study HVM noted that:

'Our views are constantly changing. The more that is offered about genome editing, the more we will get used to it. We couldn't have imagined the Internet and the impact that would have on our lives. It's exciting.'

'We have to be very, very cautious. Our genetics is the make-up of our being. I'm not immovable though. If a case can be made that this can be done safely and without impinging on other people's wellbeing…'

'I don't know exactly what I think. It is very challenging and it raises huge questions. Science versus the way of the world.'

- There was a sense of hope amongst participants about the opportunities human genome editing offers
- Most participants felt developments are in line with societal evolution
- A small number of participants had more ambivalent views which they traced back to the complexity of the issue and their perception that the general public lack technical knowledge
- There was a view that acceptability will grow once successful applications are being reported more widely
- **And** society keeps talking about it.

'It does seem a little bit ridiculous to have this gem of potential, a game changer, and do nothing with it. If we can change life for the better, and do it well, it will be one of the most important things in history if it goes ahead.'

I'm really excited by it. It's natural for human beings to experiment, we've always done that. I think ultimately it's driven by a human desire to feel happy and to reduce suffering. Treating illnesses is really, really important, how far we go down the road of enhancement, I'm not sure.'

'If you know more people who are talking about this stuff and it becomes normalised then I think people will be not only accepting but will have a greater understanding.'

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HVM thanks all the participants in the depth interviews and focus group for their engagement in these discussions.

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